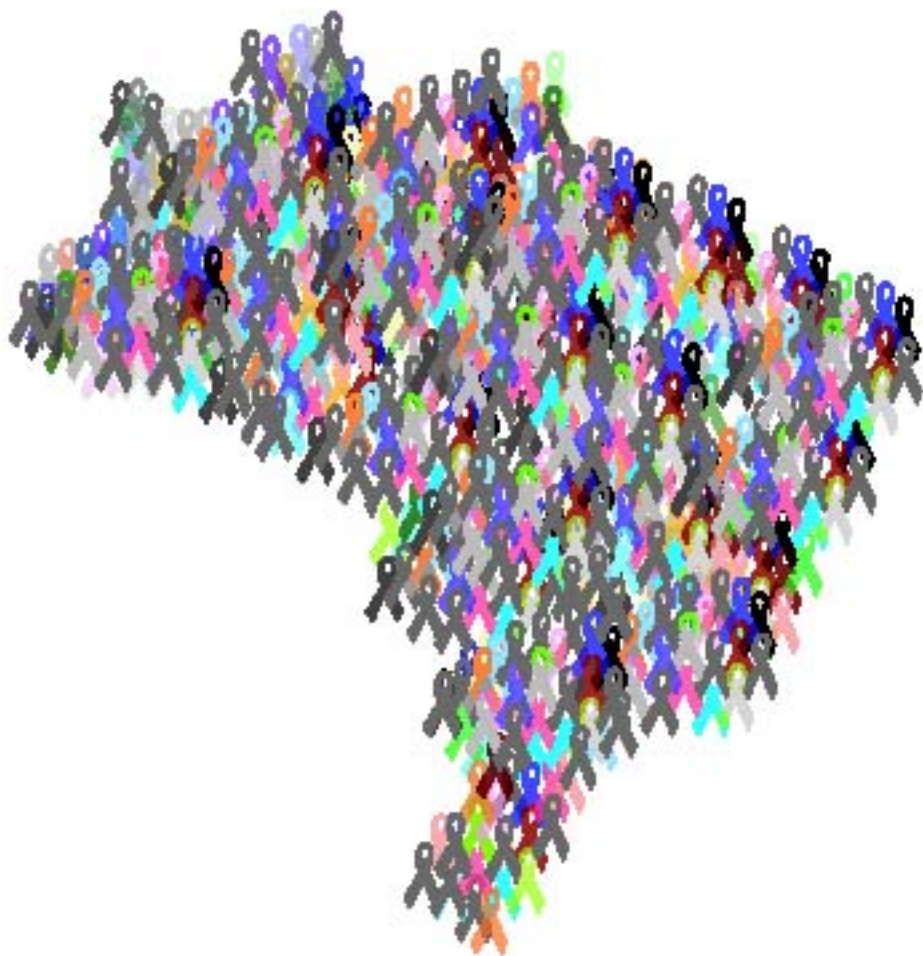


RESPONSES TO AIDS CHALLENGES IN BRAZIL:

LIMITS AND POSSIBILITIES

Mary Garcia Castro • Lorena Bernadete da Silva



Ministério
da Saúde



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**RESPONSES TO AIDS
CHALLENGES IN BRAZIL:
LIMITS AND POSSIBILITIES**

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FOREWORD

*Richard Parker**

Along the last two decades, no other country in the world has developed a more effective and comprehensive response to the HIV/AIDS epidemic than Brazil. The Brazilian response – including not only the outstanding work of the National Aids and STD Program of the Brazilian Ministry of Health's, but also several initiatives of civil society and other governmental spheres, such as the Judiciary and the Legislative Powers — is now worldwide acknowledged, not only for its success, but for courage and commitment in fighting the epidemic.

Typically, the National AIDS Program deserves more attention in the media and international news concerning the Brazilian response to HIV and AIDS. However, anyone deeply engaged in the collective project of building this response clearly knows that the Program is, itself, a result and a reflection of the much broader mobilization by the Brazilian society in response to the epidemic. In this regard, it seems that no other set of social actors has played a more relevant role than the non-governmental organization sector. It was in this sector, during the mid-1980's, when the country was amidst a process of re-democratization after two decades of military dictatorship, that it took the very first steps towards building the ethical and political principles that, ultimately, would serve as guidelines not only for the NGOs, but also to the government and to the civil society in general. Nowadays, these principles are powerful features of the Brazilian response to AIDS.

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It was here, in this sector, in the voices and lives of its early leaders, that principles such as solidarity, diversity, rights, and citizenship started being mutually articulated, as the cornerstones to the civil society mobilization towards facing the epidemic. And it was also here that, over the last two decades, the most important components of the political sustainability aimed at expanding and ensuring this response, which became an actual social movement over time, have been built and reaffirmed. This has converted the Brazilian response to Aids into this broadly acknowledge experience as it is today.

The publication of the book, ***Responses to AIDS challenge in Brazil: limits and possibilities*** marks an especially important moment in the history. While the Brazilian response to the epidemic has been widely recognized for its quality, one serious limitation has been our collective inability to adequately document the components and process through which this response has been elaborated, in ways that would allow for other countries and societies to fully learn from the lessons that this wealthy Brazilian experience has to provide. Because of the complexity and the diversity of this sector, additionally to the lack of proper records of its history and experience, our broader understanding of its accomplishments has been limited – limiting, in turn, our overall understanding of the Brazilian response to AIDS. ***Responses to AIDS challenge in Brazil: limits and possibilities*** is the new study published by UNESCO, based on extensive research among NGOs leaders, participants and collaborators from multiple centers throughout the country. It documents the several challenges that the NGOs sector has confronted (and still confronts), its major achievements, and the core role that it plays, together with the various initiatives of the Brazilian government in the control of the HIV and AIDS epidemic in Brazil.

The importance of this accomplishment cannot be stated strongly enough. Only the record of this experience should allow for the understanding about components and replicating its effectiveness, both in Brazil and in other countries. Thanks to this

important research, we now understand much more about what has been accomplished in Brazil than we used to do. We now rely on a detailed report that serves as a witness to the impressive struggle to which the Brazilian civil society has engaged towards facing the global tragedy that is the AIDS epidemic. ***Responses to AIDS challenge in Brazil: limits and possibilities*** thus stands for one of the most important documents registering the dimensions of this experience – a living register of the principles that grounded this movement, and of the struggles that it has been built around.

PRESENTATION

UNESCO and the National Program on STD/AIDS, of the Brazilian Ministry of Health, once again establish a partnership to carry out an activity, which records and cooperates towards implementing one of the most successful Brazilian public policies in health, worldwide acknowledged: those oriented to the fight against AIDS.

This publication, basically addressed to tackle the dynamics of those agencies participating in AIDS-related governance in Brazil, lists and itemizes practices and representations of collective civil society units, at different territories. Furthermore, it records contemporaneous debates, assessments, criticisms and suggestions, aiming at adjusting the path.

Hence, this publication is not limited to recording well-deserved social memories about that collective, resting on glories, neither to cooperate with international partnerships like South-South, disclosing knowledge and know-how of Brazilian agencies. It goes beyond by tackling challenges to be faced in current stage of fight against this epidemic, and in consolidating Governmental action, at national and local level, since here decentralization is part of perspectives perceived for this stage. Moreover, it calls attention to the relevance of continuous surveillance, mobilization of resources and wills towards preventing setbacks in this fight, taking into consideration its current diversification in relation to target-audience, as evidenced by increased cases among women and youngsters, poor and inland population.

In the words of several leaders of AIDS-related Non-Governmental Organizations, and managers of state and municipal STD and AIDS secretariats, there is also the warning tone signaled by the Program, i.e., how the efficiency of AIDS fight system depends on the quality of the Brazilian public health system, concerning social justice rates. No program against AIDS can be successful – or remain successful – without

investments in services quality and on health professionals as a whole. The spread of AIDS among poor and rural populations discloses another evil side of this epidemic: Although it victimizes all, it is spreading among those who most need State social welfare, low-cost drugs, and high-quality health services.

However, as UNESCO underlines in several documents, in times of globalization AIDS also becomes a trans-national issue, demanding cooperation from international community. It can no longer be restricted to local or national actions, regardless their importance. Brazilian case is an example of this perspective, since it happens within global and local context. Brazilian Government performance is outstanding in the international forum. It has called different countries and multinational corporations to undertake responsibility, besides debating drugs patents, and assistance, treatment and prevention dependence on free trade. Furthermore, World Bank loans were mobilized at those forums, however maintaining national identity to formulate proper Program to address the epidemic.

UNESCO respects this autonomy, through symmetrical and cooperative partnership, whereby it emphasizes and provides tools entailed by education, science, culture and communication in AIDS-related matters. Therefore, it induces the creation of anti-stigma culture, free of intolerance and capable of shifting behaviors through youth-focused education. For instance, other partnerships with the National Program on STD and AIDS have resulted in publications on “Violences in Schools”, Drugs at School¹ and Youth and Sexuality². UNESCO also cooperates with a basic element of National Program to the epidemics, i.e., assessment of projects and actions, and

¹ ABRAMOVAY, M.; CASTRO, M. G. *Drogas nas escolas*. Brasília: UNESCO, National Coordination on DST/AIDS, Ministry of Health, State Secretariat on Human Rights, Ministry of Justice, CNPQ, Ayrton Senna Institute, UNAIDS, World Bank, USAID, Ford Foundation, CONSED, UNDIME, 2002. 448p.

² ABRAMOVAY, M.; CASTRO, M. G.; SILVA, L. B. *Juventudes e sexualidade*. Brasília: UNESCO, Ministry of Education, National Coordination on DST/AIDS, Ministry of Health, Special Secretariat on Policies for Women, Ayrton Senna Institute, 2004. 428p.

communication of successful practices in education for AIDS. This cooperation is evidenced in publications like “Assessment of STD/AIDS preventive actions and undue use of drugs in fundamental and high-schools at Brazilian capital cities”, besides the recently started survey on the program of preservative distribution in schools. Moreover, UNESCO jointly with the National Program on STD and AIDS, focused its strategy on strengthening education and health workers, non-governmental organizations and social communication professionals in facing challenges posed by epidemics; disseminating excellence legislative practices and public policies, thus contributing towards the movement against discrimination and stigmas of people directly or indirectly living with HIV/AIDS; and stimulating preventive messages among opinion-builders, such as parliamentarians, journalists and young entrepreneurs.

It is worth noticing that this publication is a contribution to social memory, especially on the importance of civil society, political will of the Brazilian government and international cooperation for fighting AIDS. Brazil succeeded in maximizing this triad – under coordination of the National Program on STD and AIDS – in times of democratization and affirmation of social movements for human rights to identity, like that of homosexual individuals.

Moreover, this publication is a contribution to other countries, assisting them in building networks to exchange experience, where Brazilian experience could be adjusted to different realities.

Nevertheless, it is also a call about current challenges so that, rather than winning more battles, Brazil succeeds in finally winning this war against that pandemic. For that, it should rely on several agencies and constant awareness within the framework of an active citizenry.

Jorge Werthein
Director of UNESCO in Brazil

Pedro Chequer
National Program
on STD/AIDS Coordinator

RESUMO

Este livro apresenta um estudo baseado nas percepções de dirigentes de organizações não-governamentais, coordenadores de programas dessas ONG, dirigentes de redes/articulações e gestores das coordenações estaduais e municipais de DST e Aids relacionadas a questões e desafios envolvidos na resposta brasileira à epidemia da Aids. A pesquisa foi realizada a partir de dados levantados em todo o país (*survey*), e em seis estados para um estudo mais aprofundado, utilizando técnicas qualitativas. Os estados participantes do estudo em profundidade são: Bahia, Distrito Federal, Rio de Janeiro, Rio Grande do Sul, Pará e São Paulo.

No trabalho, são discutidos diversos aspectos relativos à governabilidade estruturada para fazer frente, no Brasil, à pandemia da Aids, tais como a atuação do Programa Brasileiro de DST e Aids do Governo, o lugar de agências internacionais, destacando-se o papel da UNESCO, e o perfil, práticas e imaginário das ONG e gestores do estado em nível local.

Mas o foco nuclear do estudo são as experiências da sociedade civil e suas perspectivas no campo das respostas à epidemia, assim como as ações institucionais locais na percepção dos gestores estaduais e municipais de DST/Aids.

O trabalho realça as estratégias utilizadas nas ações implementadas por diferentes entidades da sociedade civil organizada para o trabalho com DST/HIV/Aids; as influências dessas na elaboração e execução de políticas públicas para o enfrentamento da epidemia, em níveis nacional, estadual e municipal; a interlocução e relações construídas com o governo, organismos internacionais e outros segmentos dos movimentos sociais, para fazer frente à aids; e, estratégias para a captação de recursos e possibilidades de sustentabilidade política, técnica e financeira das ONG/Aids, os financiamentos e o controle social para a construção das respostas ao desafio da Aids no Brasil.

A partir do registro de vozes dos atores/agências mencionados, o estudo alinha recomendações para políticas públicas, considerando desafios futuros a serem enfrentados, tanto no campo internacional quanto no nacional.

Os resultados deste estudo indicam que a busca de soluções para as diversas questões que envolvem a epidemia da Aids deve se basear na cooperação contínua entre as diferentes esferas de governo e as organizações que conformam os vários movimentos de luta contra a Aids.

O Brasil vem-se destacando internacionalmente no controle e combate da pandemia, sendo que a memória social sobre a governabilidade em relação a essa luta e a franca discussão sobre desafios a serem enfrentados para que se continue o curso de um sistema bem-sucedido sem soluções de continuidade, como aqui se documenta, se constitui em material importante não somente em nível nacional como para outros países.

INTRODUCTION

Brazil has played an outstanding role at international level, concerning public policies to manage the AIDS pandemic. Several dimensions and indicators base such acknowledgement. Several achievements are worth of notice: the free distribution of anti-AIDS drugs; the posture for international social responsibility concerning patents, aiming at cheaper medications and local production; investments in educational campaigns; developments concerning access to diagnosis, treatment and prevention; surveillance and focus on contamination rates in groups traditionally known as of *added risk* like, for example, men who have sex with men, injection drug users and sex professionals; supply of HIV tests in the pre-natal and services to seropositive pregnant women; cultural projects against stigmas in relation to groups with AIDS; investment in education and with youth groups, particularly concerning sexuality, gender and provision of preservatives; assemblage of an institutional system on shared social responsibility and partnerships in several activities, where international agencies, states and the civil society are major players. These are some of the efficient strategies acknowledged in international forums.

The World Bank (2004) recently disclosed the assessment of AIDS I and AIDS II loan projects – 1993 to June 2003 – mainly focusing on activities on epidemiological surveillance, monitoring and assessment and, through more restrict criteria, the extension, scope and costs of the components of the system assembled by the National STD and AIDS Programme of the Brazilian Government. This assessment trends to highlight also the positive results and *substantial* efficacy and potentials of the system, although it points out that some areas related to these activities demand for higher investments. Furthermore, they warn on the importance of diversifying the target-audiences, considering as current challenges – like author players

also stress – the feminization, ruralization or interiorization, the impoverishment of AIDS, besides its spread among the youth. They also call attention for the challenge posed by the current stage of the system decentralization, where states and municipalities are expected to have greater participation. The Government investments, upon cooperation by the international agencies and the mobilization and services of the civil society organization, are responsible for expressive changes in the rates of reported AIDS cases.

An intervention on the sustainable prevention was expanded to all regions in the country, and shall have contributed towards reducing and refraining the epidemic. This is reflected in the low prevalence rate of 0.65% among adults of 15 to 49 years old in 2000, and the continuous concentration of the epidemic among the high risk population.

...

In 2003, about 140,000 patients with AIDS were reported to be in active treatment under the Brazilian programme and, additionally, 196,000 asymptomatic positive cases would be monitored, but not yet under treatment. (The World Bank 2004:IX and X)

In 1995, the mortality assigned to AIDS in Brazil reached 12/100.000 – prior to the highly intensive antiretroviral therapy. In 2000, this mortality rate is 6.3/100 000. In March 2002, 237,588 cases of AIDS were reported (in the World Bank, op.cit.). According to the Ministry of Health, “the incidence of AIDS is stable, about 25,000 new cases a year... among pregnant women, the HIV infection stabilization can [also] be observed (March 1997 -1.2%....October 1999 -0.8%)” (cit in The World Bank, op. cit.).

The cost of investments in STD/AIDS in 1997 was about 295 million dollars by the Brazilian government, additionally to 44.6 million dollars, corresponding to the World Bank participation. In 2001, the Brazilian government commits an investment of 543.2 million dollars, while the Bank financing amounted to 51.7 million (data from the World Bank, 2004).

If the dimensions and indicators, as the aforementioned, ground the importance of the Brazilian response to the AIDS pandemic, the processes of institutionalism and assemblage of the singular

governance based on partnerships and shared social responsibility require for more practical references; mainly, appealing to the voice of a player that encouraged the public policies in the field of AIDS, and that is specially relevant to the daily modeling, or daily fight at local level, with several target-audiences and who, sometimes, belong to these audiences: the civil society organizations – which usually match being social movement, associations, networks, non-governmental organizations (NGOs) and being para-governmental, like its participation and the dialogue they hold with the state apparatus.

This is one aspect of this publication: to contribute towards social memory, by identifying the profile, practices, critical imaginary and the recommendations by members of many of such civil society organizations, which also represent the matching of valuable processes to the Brazilian history: the democratization based on mobilization and social control, and the activism of groups oriented to building identities, like the homosexual groups.

The flow and interactivity between the political sphere and the civil society in Brazil are shaped in a singular way – characteristic to their consolidation time, i.e., in the 1980's – concerning public policies. In this sense, despite the relatively comprehensive literature, based on studies of case on specific experiences of the NGOs and social movements, most produced by the organizations, there was a need for more systematic and comprehensive records at national level. Therefore, this publication matches a comprehensive profile of the universe of such organizations, to more vertical presentations, recording the experiences according to statements by activists and local managers in the state and municipal levels. The civil society resources (human and institutional) to fight the AIDS are presented in detail, and the systematization of innovations, methodological practices and conceptual frameworks are developed, incorporating the wealth of a fragmented field, which provides singular cultural and social capital.

The analytical chapters on and with civil society organizations and local management – at state and municipal level – are preceded by

texts more oriented to present other basic players that make up the tripod of Brazilian response to AIDS – civil society, government and international community. Therefore, the initial chapter, after providing explanations about the work methodology, presents some features of the National STD and AIDS Programme history. The next chapter concerns the international agencies and the Brazilian system in the fight against AIDS, with special reference to UNESCO.

The survey was based on data collected countrywide and in six states for a deeper studies. The collection employed qualitative techniques. The states that have participated in the in-depth survey are: Bahia, the Federal District, Rio de Janeiro, Rio Grande do Sul, Pará and São Paulo.

The work discusses several aspects concerning structured governance to face AIDS challenges in Brazil, such as the work developed by the Governmental Brazilian STD and AIDS Programme, the role played by the international agencies, where UNESCO is outstanding, and the profile, practices and imaginary of the NGOs and state managers, at local level.

However, the core focus of this study is placed on the civil society experiences and their perspectives in the field of responses to the epidemic, as well as the actions developed by local institutions, in the view of state and municipal STD/AIDS managers.

The work emphasizes the strategies employed to the actions implemented by different entities of the organized civil society in the work on STD/HIV/AIDS; their influence on the outlining and execution of public policies to fight the epidemic at national, state and municipal level; the dialogue and relationships established with the government, international organizations and other segments of social movements, to fight AIDS; and strategies to raise resources and possibilities of political, technical and financial sustainability to NGOs/AIDS, financing and social control to build responses to the challenge of AIDS in Brazil.

Based on the recorded ideas of the players / agencies mentioned, the study aligns recommendations for public policies, considering the future challenges to be faced, both at international and national level.

The findings in this study point out that the search for solutions to several issues involving the AIDS epidemic should be grounded on continuous cooperation between the different governmental spheres and the organizations that make up the different movements of fight against AIDS.

The social memory on governance in relation to the fight against AIDS, additionally to the open discussion on the issue of the civil society organizations' sustainability – financial, technical and political –, besides other challenges that should be faced to keep on the successful way, with no instability. What is documented here is an important material not only in terms of lessons and records of the Brazilian social memory. In fact, this work records active citizenship, matching histories, diagnosis on practices, criticisms and proposals. But is is also a reference study to the international cooperation with other countries.

I. METHODOLOGY

I. INTRODUCTION

I.1 CORE ISSUES AND GENERAL SCOPE

The general purpose of this survey is to register the roles carried out by different participants in the Brazilian response to the AIDS challenge. Such participants include the state – at both the local and national levels, and international agencies as UNESCO, in particular. Above all, the survey intends to assess the impact of actions performed by civil society entities engaged in AIDS-related actions, mainly those supported by UNESCO and UNODC.

This survey is a joint work by UNESCO/Ministry of Health – National Program on STD and AIDS. It is worth mentioning that in 1986, when it was established, and in 1998, the Program National underwent deep reformulations that changed even its name. For the purposes of this study, the Program is sometimes referred to as National Program on STD and AIDS, as it used to be called at the time of field work in late 2003 and early 2004.

The work is guided by an exploratory-comprehensive perspective that matches quantitative techniques (surveys) to qualitative ones (interviews) on how non-governmental organizations (NGOs), and those associated with government entities (OSC – Civil Society Organizations) cooperate towards public policies, services in different fields, and advocacy of AIDS-related rights.

This research strives to respond some core issues that define NGOs measures. Among them, are outstanding the Brazilian experiences in relation to NGOs participation in implementing the epidemics control

policy; the diversity of civil society working on varied responses and concepts regarding the AIDS phenomenon, focusing on practices developed in states and municipalities; potential sustainability generated by several entities; impact of NGOs-measures over STD/HIV/AIDS preventive behaviors, processes of support to individuals living with HIV/AIDS; relationships among entities concerning knowledge and practice, solidarity and competition, national and international forums and networks; role played by NGOs in influencing current trends of juvenilization, feminization, interiorization and impoverishment that characterize the epidemic.

The study is guided by the following objectives:

- To disseminate experiences in the field of AIDS-oriented experiences in Brazil, and that are replicable in other countries;
- To analyze the perception of different participants on AIDS – NGOs and government;
- To record the background, scope, and effects over different target audiences brought about by entities working with AIDS. Furthermore, the study should analyze the obstacles to sustainability and recommendations on public policies;
- To identify governmental and non-governmental responses, and outline the typology on likely ways to face challenges posed by AIDS;
- To analyze several relationship grids built to fight AIDS, e.g., with other organizations, in addition to relationships with government and international technical cooperation.

1.2 DATA COLLECTION PLAN

This survey is comprised of several different activities, as follows:

- Carrying out a survey that is both Internet-based and on-site, to describe typology of civil society organizations (non-governmental, mixed and community-based), according to target-audience and working area;

- Holding interviews with NGOs leaders, program coordinators in those NGOs, and leaders of networks/articulations in six different sites;
- Holding institutional interviews with managers of state and municipal STD and AIDS coordination units, about links with civil society and decision-making and the policy-implementation processes;

The qualitative survey encompassed 576 NGOs³, out of which 328 have answered the questionnaire – incorporating but not limited to UNESCO – and UNODC-related NGOs. On the other hand, the quantitative survey was under-taken in six Brazilian states (São Paulo, Rio de Janeiro, Rio Grande do Sul, Federal District, Bahia and Pará), by six different teams of different institutions – universities and/or NGOs – and that were coordinated by the UNESCO team.

The work is also focused on selected organizations working with AIDS-related topics in similar ways, i.e., where AIDS is their core topic. It is a comprehensive work, comprising broad territorial extension and a diversity of working areas and target-audiences.

UNESCO, jointly with the National Program on STD and AIDS (NP STD and AIDS) of the Brazilian Ministry of Health, started this study in May 2003. The research took place at two levels: First, with data surveyed countrywide and, secondly, through direct survey in five states – Bahia, Rio de Janeiro, Rio Grande do Sul, Pará and São Paulo – and in the Federal District, focusing on seventy NGOs. Surveyed areas rely on civil society entities dealing with AIDS.

Ninety six institutional interviews were held with NGOs leaders, program coordinators of those NGOs, leaders of networks and articulations, in addition to managers of state and municipal secretariats of STD and AIDS.

³ “The Ministry of Health has partnership with over sixty civil society organizations for fighting AIDS. These are entities that perform retail actions in controlling epidemics, by providing assistance, establishing support groups to seropositive individuals, fighting for their rights, enhancing their self-esteem and vindicating power. They are core partners to decentralize the program” (José Serra, Minister of Health by that time, IN Noticias UNESCO, May – September 2001, n 16: p 11).

1.3 DETAILS OF THE QUANTITATIVE SURVEY

1.3.1 Sampling Outlining

The Project Monitoring System (*Sistema de Monitoramento de Projetos - SIMOP*) database of the National Program on STD and AIDS – Ministry of Health, was employed to select the survey sampling and to build NGOs registry. The selection criteria for NGOs were: a) to have projects supported by UNESCO or UNODC; and, b) to have an ongoing Project within the scope of AIDS II. Questionnaires were forwarded – whether electronically or by mail - based on NGOs records of the National Program on STD and AIDS Unit on Civil Society and Human Rights, made up by approximately 576 NGOs.

Then, 576 questionnaires were sent and 328 answered. Thirty-two questionnaires were returned due to changes of or unknown addresses. Additional 213 questionnaires were not answered because the NGOs no longer existed, which points out sustainability issues in the NGOs field.

Answered questionnaires (328) totalize about 57% of total questionnaires submitted. Chart 1.1 briefly discloses the reach of the quantitative survey per State.

CHART 1.1 – Number of questionnaires sent, received, returned and not answered, according to Brazilian States, 2003

State	Questionnaires sent	Questionnaires received	Questionnaires returned	With no answer (I)	Ratio of non-received questionnaire in relation to questionnaires sent (%)
TOTAL	576	328	32	213	56.9
Acre	5	1	2	2	20.0
Alagoas	3	0	0	0	0.0
Amapá	4	0	3	1	0.0
Amazonas	8	4	0	4	50.0
Bahia	31	22	1	8	70.9
Ceará	41	22	0	19	53.6
Federal District	18	10	0	8	55.5
Espírito Santo	10	3	3	4	30.0
Goiás	15	7	4	4	46.6

CHART 1.1 – (continuing)

State	Questionnaires sent	Questionnaires received	Questionnaires returned	With no answer (1)	Ratio of non-received questionnaire in relation to questionnaires sent (%)
Maranhão	7	2	0	5	28.6
Mato Grosso	12	7	1	4	58.3
Mato Grosso do Sul	23	8	2	13	34.8
Minas Gerais	19	11	0	8	58.0
Pará	15	12	0	3	80.0
Paraíba	12	6	1	5	50.0
Paraná	29	17	3	9	58.6
Pernambuco	19	9	1	9	47.4
Piauí	6	1	2	3	16.6
Rio de Janeiro	92	52	2	38	56.5
Rio Grande do Norte	4	0	1	3	0.0
Rio Grande do Sul	33	21	2	10	63.6
Rondônia	7	2	2	3	28.6
Roraima	1	1	0	0	100.0
Santa Catarina	26	16	1	9	61.5
São Paulo	128	91	0	37	71.1
Sergipe	7	3	1	3	42.8
Tocantins	1	0	0	1	0.0

Source: UNESCO. Research on the Response to the AIDS Challenges in Brazil: limits and possibilities, 2003. (Survey on Responses to AIDS Challenges in Brazil: limits and possibilities).

(1) Includes 170 NGOs that did not answer: 34 could not be reached (wrong number, or no reply to phone calls, could not be found); two NGOs (AVE/SP and O CORSA/SP) no longer exist; one NGO (AMA/SP) does not work throughout the whole year, only during Gay Parade; one NGO (Associação Liberdade e Vida/SP) would only participate upon written request; one NGO (AIRVO/SP) refused to answer by phone, only by fax; two NGOs (PROSAM/SP and Network de Informação Um Outro Olhar/SP) refused to answer, claiming they were very busy; one NGO (Sindicato Trabalhadores Metalúrgicos de Taubaté/SP) refused to attend the researcher; one NGO (COLIBRI/SP) claimed they no longer work with prison population.

1.4 DETAILS OF THE COMPREHENSIVE SURVEY

Some NGOs have been selected to be analyzed in terms of practices and representation of people working in the NGOs. The selection took into consideration diversified knowledge about them, whether by local teams that assisted in field research, whether by

technicians of the National Program on STD and AIDS, or even by UNESCO staff members who have direct contact with several NGOs in the field. The selection was also based on information provided by the *Sistema de Monitoramento de Projetos – SIMOP* and took the following criteria into consideration: Level of interlocution with the State; works held in terms of the proposal and monitoring of public policies; degree of insertion into the debate on public policies; level of explicit negotiation with government programs; implementation of advocacy measures; measures for the promotion of favorable environments; strategy for building up public opinion; degree of insertion into the sustainability debate; strategic position concerning decision-making in “the world of AIDS”; works in the field of human rights and citizenship; background, history, social visibility and production in the field of AIDS; and, link to some social control sphere.

According to aforementioned criteria and procedures to select a NGOs, following is the composition of the experiences analyzed (Chart 1.2):

CHART 1.2 – Number of NGOs surveyed – stage of intensification – by selected regional unit, 2003

REGIONAL UNITS	# OF NGOs SURVEYED
Bahia	9
Distrito Federal	8
Pará	6
Rio de Janeiro (1)	16
Rio Grande do Sul	9
São Paulo (1)	22
Total	70

Source: UNESCO. *Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003.

(1) Total Number of NGOs and Networks

The selection was based on the most recent data available, i.e., of 2002. Field survey was carried out in May, June and July of 2003. Initially, it was estimated to take two months (May and June). Given several events held at that time and that counted on the participation of NGOs (ERONG, ENONG, EDUCAIDS, Gay Parade, among others), the deadline was extended to 31 July.

1.4.1 Components

The survey used several techniques of semi-structured individual interviews (with leaders and coordinators of NGOs programs, leaders of network/articulation and managers of state and municipal STD and AIDS secretariats) and on-site observations. Details of how each technique was employed in this survey are as follows:

Individual Interviews

The interviews were applied to 79 leaders and coordinators of NGOs programs, 5 leaders of Networks / Articulation and 12 managers of state and municipal STD and AIDS coordination units, and also to one technician of social coordination. Thus, 96 individual interviews were carried out in the 6 regional units surveyed (Chart 1.3).

It is worth noticing that content and duration of interviews varied according to the category of the interviewee. On average, interviews lasted one hour and a half.

Therefore, the research has about 144 hours of individual interviews to be analyzed. Chart 1.3 itemizes the number of each tool by state and time spent. In its turn, Chart 1.4 provides further details on the most usual kinds of tools.

CHART 1.3 – Number of interviews. 2003

Interviews	Quantity	Number of Hours
Interviews with NGO leaders and program coordinators	79	118,5
Interviews with Network / Articulation leader	5	7,5
Interviews with state and municipal STD and AIDS managers (1)	12	18
Total	96	144

Source: UNESCO. *Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003.

(1) Includes one technician of Bahia State Coordination on STD/AIDS.

CHART 1.4 – Number and kind of qualitative tools used, by selected regional units, 2003

Regional Units	Individual interviews with NGO leaders (1)	Individual interviews with managers	Interviews with Network / Articulation Leaders
Bahia	9	3	0
Distrito Federal	8	1	0
Rio Grande do Sul	19	2	0
Rio de Janeiro	13	2	3
Pará	11	2	0
São Paulo	19	2	2
Total	79	12	5

Source: UNESCO. *Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003.

(1) Includes NGOs Program Coordinators.

NGOs Selection Criteria

NGOs selected to participate in the qualitative survey have also answered questionnaires similar to those applied in the quantitative survey.

The following NGOs, State and Municipal coordination units on STD and AIDS, and Networks/Articulations make up the scope of the survey (Chart 1.5):

CHART 1.5 – Roster of NGOs, networks and state and municipal coordination on STD and AIDS surveyed – intensification stage – by selected regional unit, 2003

NGOs / Networks / Municipal and State Coordination on STD and AIDS, by state					
RJ	PA	BA	RS	SP	DF
CEDUS	GAPA/PA	ABAREDA	GAPA	ECOS	ARCO-ÍRIS
APADA/Niterói	Associação Livre dos Pescadores Artesanais do Cajueiro	APROSBA	NU ANCES	MAPA	ARCA
Grupo Arco -Íris	Associação de Moradores Brasil Novo	Associação de Moradores Unidos de Cosme de Farias	NEP	AVAIDS	CFEMEA

CHART 1.5 – (continuation)

NGOs / Networks / Municipal and State Coordination on STD and AIDS, by state					
RJ	PA	BA	RS	SP	DF
PELA VIDDA/Niterói	SESMA (Coordenação municipal)	CECUP	IGUALDADE	CONVIVER É VIVER	GAPA
Associação de Mulheres do Morro dos Telégrafos	MOPROM	GAPA	MARIA MULHER	GTPOS	ANDI
IBISS	GEMPAC	GLB	VHIVA MAIS	SOC.AMIGOS VILA MARA	GRUPO ESTRUTURAÇÃO
ABIA	MHB	Grupo Gay da Bahia	Municipal STD and AIDS Coordination	FÓRUM DE ONGS/AIDS	INSTITUTO ATITUDE
GESTAR	SESPA (State Coordination)	Grupo Gay de Camaçari	THEMIS	PELA VIDDA	INSTITUTO DIVERSIDA DE BRASIL
PELA VIDDA/RJ	Movimento das Mulheres do Campo e da Cidadania do estado do Pará	Grupo Palavra de Mulher	State STD and AIDS Coordination	APTA	STD and AIDS Bureau of the Federal District' s Secretariat of Health
PIM	PARAVIDDA	Municipal STD and AIDS Coordination	CEAMEM	ABORDA	
CHARLATH'S		State STD and AIDS Coordination	MMRD	GIV	
Casa da Mulher Trabalhadora				GAVI	
DA VIDA (Network)				ALIVI	
Associação Carioca de Redução de Danos				GAPA	
Grupo Fio da Alma				FALA PRETA	
Rede Nacional de Pessoas Vivendo com Hiv/AIDS				ANIMA	
Municipal STD and AIDS Coordination				ASSOC. FIQUE VIVO	
State STD and AIDS Coordination				ORION	
				Centro de Conviver é de Lei	
				Coletivo Feminista Lésbica	
				Municipal STD and AIDS Coordination	
				State STD and AIDS Coordination	

Source: UNESCO. *Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003.

Dimensions surveyed in the comprehensive stage

The following dimensions were surveyed throughout the survey's comprehensive stage: methods and strategies used in measures implemented by different organized civil society entities, towards the work pertaining to STD/HIV/AIDS; strategies adopted to relate with target-population served by ONG/AIDS; influences of civil society in the elaboration and execution of public policies towards fighting the epidemics at the national, state and municipal levels; interlocution with other segments of social movements; and strategies towards the intake of resources as well as the political, technical and financial sustainability of NGOs/AIDS.

2. THE BRAZILIAN STD AND HIV/AIDS PROGRAMME: SOME THOUGHTS ABOUT ITS WORK⁴

2.1 AIDS INSTITUTIONAL DEVELOPMENT

Grounded on the relationships between society and the states, this chapter approaches the dynamics set between the Brazilian government – through the National STD/AIDS Programme, and the civil society through its organized groups aimed at building a national response to the AIDS epidemics. This text places such response development as an ongoing process within the context of collective health, and achievements by the Movement of Sanitation Reform in Brazil, characterized by wealth social participation. Some approaches assist in understanding the path followed by the formulation and implementation of HIV/AIDS-oriented public policies, within the Brazilian national scenario. This is a process that is permanently being internationalized and in tension and includes participants from different spheres of society: governmental, non-governmental organizations, universities, organizations of classes, people living with HIV/AIDS and international cooperation agencies. These participants and their unique views share the responsibility of building up a Brazilian policy on the HIV/AIDS epidemics.

Some researchers (PARKER, 1997; GALVÃO, 2002 and OLIVEIRA-CRUZ, 2004) are increasingly focusing on talking about

⁴ Original text prepared by Pamela Díaz Bermúdez – Professor at the Collective Health Department, Health Science School, University of Brasilia. This version is part of a thesis from the author named “Política e narrativa sobre a aids: um contraponto Brasil-França”. University of Brasilia, 2005.

a health institution that, along the last few decades, has pursued not only the control of the HIV/AIDS epidemics, but also the leading principles on universalization, integralization, and decentralization – which govern the Brazilian Unified Health System⁵ to be incorporated into several service modalities. The so-called AIDS “institutional responses” appeared worldwide as increased consciousness upon the magnitude of the HIV/AIDS epidemics, not only in Latin America, but also in Europe and the United States. In this sense, is clear that the contribution of policies to fight this new disease and thus strengthen health care systems, and building new health care modalities, are also influencing international debate on health issue.

It is worth bearing in mind that, when AIDS emerges as a challenge for sciences and the formulation of public policies, new events in the global-political arena contributed towards the rethinking of the health model in force. Focus was mainly placed on efforts to build global health policies that were impregnated by the globalization process and that, years later, would bring new order to the world. In anyway, the spirit that guided those proposals was the vocation towards reducing huge differences of health access among countries, building new financing tools and strengthening the role played by the State as major health care service provider. In spite of ambiguities brought about by its operationalization, as health starts being faced as a right, the world became closer to outlining a new paradigm, a new philosophy in health. This is the context wherein arise proposals on Primary Care and Health for All Program in 2000, acknowledged in the renowned Declaration of Alma-Ata, in 1978; Health Promotion approach, which appears structured, one decade later, during the First International Conference on Health Promotion, in 1986, consubstantiate the so-called Ottawa Letter. This important text synthesized the new contents and opened ways to launch tools

⁵ It would be wise to recall at SUS starts to be formally institutionalized in 1988, when HIV/AIDS epidemic was fully installed in Brazil. However, the first responses to AIDS, as further discussed herein, resulted from a concept impregnated by new values and strategies of the new public health, as a claim of social movements fro health field organization.

for operationalizing this new concept within the scope of health services. It focused mainly on access to health, social balance and individual autonomy. It gave birth to innovative notions, such as healthy environments, and brought about a new way of facing the individual-collective relationship within institutional spaces, providing flexibility to classic oppositions as State/society, public/private and local/global. The paradigm was further enhanced by the development of other conferences, and their respective final documents, such as the Declaration of Adelaide (1980), Sundsvall (1991) and, for Latin America, the 1992 Declaration of Santa Fé de Bogotá, to mention only the major conceptual platforms that have promoted democratization in health systems.

These processes have reinvigorated the pursuit for new definitions and political strategies for health, which is historically marked by disease-oriented focus and biological determinations of the phenomenon of getting sick. Within this new concept, sectoral public policies were developed, providing not only a new paradigm that included social determinants in the health-disease process, but under the light of State role, an articulation with other fields such as education, economics and social security, which also allowed for new ways of management. On the other hand, this new focus on health was also aimed at improving and expanding mechanisms of social participation in different governmental levels, which will be particularly relevant to the control of the HIV/AIDS pandemics. In the light of epistemology, the paradigm of health promotion develops on proposals about the role played by individual and collective subjects. Campos (2004:746) suggests understanding the agent “in the potentiality of creating their own lives, aiming at producing increased autonomy coefficients throughout the health care process”. Despite the new proposals, the paradigm of health promotion is inserted into several semantic fields, and that is the reason for the existence of countless possibilities to understand it. Castiel (2004:617) points out the plurality of theoretical grounds where the concept circulates, which also fosters the reconsideration of the meaning of what should a “good society” and even human condition be.

So, this national and international arena, marked by several trends in economic changes and social fights, characterized by tension of values and views among the possibilities of thinking a new world, especially for the health sector, is the environment where the Brazilian STD/AIDS Programme comes about, as well as the role it has played over the last two decades, as a consequence of the first HIV/AIDS cases reported in Brazil.

Therefore, this chapter approaches some analyses produced regarding the Brazilian STD/AIDS Programme, focusing on its work with NGOs – the core topic here – aiming at providing to the reader a general panorama of the work developed by the Program, which is internationally acknowledged as reference in response to the HIV/AIDS epidemics in Brazil (UNAIDS, 2004; OLIVEIRA-CRUZ, 2004).

The notion of non-governmental organizations is a concept that became routine in the national scenario– NGOs is used under several lights. Countless definitions try to give sense to this new sort of social organization, which was started during the 1970's, and that followed the path of social movements of that time. They started new ways for building citizenship and civil society participation in power, while reviewed how politics should be done, and the role played by “minority” groups as regards social acknowledgement of their rights – especially those of women, some ethnical groups, homosexuals and poor populations. Thus, ecologists, human rights advocates, community leaderships and other collective participants reached the status of new social agents. They then started articulating one to another, and established non-governmental organizations as a way to express those new political powers, and thus seek for innovative ways to make politics, whether in advocacy or the provision of services, and many other fields of work.

In a reflection that may be brought into this context, Castells (2000) uses the concept of social network to define ways of structuring and social organization of social groups. The networks serve as means to establish connection among different players, promote State actions and build up new interlocutions. The broad

range of modalities provided to NGOs allows thinking about the diversity they undertake in the systemic configuration endowed to new political participants in contemporaneous society.

According to Fernandez, (1988) *apud* Galvão (2000), the author claims that participants making up NGOs result from crossing **three** sources: universities, churches, left parties and/or organizations of political activism.

The concept developed by Landim (1993) follows the same line. The author points out that NGOs are a confluence of entities of different nature – from religious beliefs as catholic or protestant – passing through political trends as Marxism and others, up to people who used to consider themselves as political activists or professionals, and had accrued some work experience in the international field.

If the general definition of the concept of NGOs varies so greatly, the same happens when it is applied to the field of AIDS. A bibliographic review of this literature discloses the lack of consensus concerning the identity of NGOs in relation to works on AIDS. In opposition, one can observe a heterogeneous and controversial myriad of connotations assigned to those kinds of social expressions. In the words of Villela (1999:180), for example, they are considered as organizations that were especially created to bring an organized response by civil society to HIV epidemics. This response comprises diversified organizations in terms of political and religious membership, size, activities developed, kinds and ways of structuring and work.

However, as further disclosed herein, data obtained through the survey point out that many NGOs that are part of the universe of organizations working in the field of AIDS, are not necessarily exclusively devoted to AIDS, nor were they created for that purpose. In this sense, it is worth providing flexibility to Villela's definition, and establishing that the working field within fight against AIDS has been broadly and diversely set countrywide, and varies from organizations assembled to fight AIDS, to other nature organizations that have incorporated AIDS-related activities into their work agenda.

According to Galvão (2000:39) the field of AIDS brings about several different players and works, and thus hinders homogenizing

the expression “NGO”. On the other hand, the author proposes using “non-governmental responses” or “responses by civil society” to this set of political actions in the fight against AIDS held out of State sphere, whether voluntary or remunerated. In this fragmented concept of the term ‘NGO’, both at theoretical and operational levels, Câmara (1999:84) suggests that within the AIDS context, organized group against AIDS build a new sort of associative scenario. The author also states that such organized groups must bear the fight against prejudice, besides meeting the new necessities brought by people living with HIV/AIDS. Still according to the author, these groups try to respond to the crisis of social interactions, generated when people discover they are living with AIDS.

This survey effectively discloses the difficulty in ranking this sophisticated and diverse set of assistance and support measures, political claims, education and capacity building and social promotion, in addition to other manifestations observed within the scope surveyed herein. Therefore, the panorama provided by empirical data restates the need for placing attention on what anthropology refers as self-designation or self-reference. It means that agents’ identity – whether individuals or collective – is directly related to how the group members perceive and call themselves, and how they are recognized. Thus, the survey universe provides a broad range of organizations and institutions that call themselves NGOs, even upon the huge plurality in their concepts, views on epidemics, duties, internal organization, demands management, audience or target-populations, in addition the kind of impact produced over their respective fields of work.

It would be necessary to take into consideration such panorama, characterized by sophisticated differences and conflicts, in order to understand the experiences reported herein, and polyphonic sayings of participants who were directly interviewed. They have disclosed diversity in their self-perception and, simultaneously, in how they face other organizations working in this field. Then, while they clearly define their political identity of complaint against State institutions, sometimes they seem to be less challenged by State

powers, and some are community movements. Some NGOs even carry out care-based actions, or even those of mutual assistance, which are not necessarily politicized.

Nevertheless, it should be taken into consideration that Brazilian civil society response to AIDS is not limited to actions performed by non-governmental organizations. Union trades, universities, philanthropic entities and other organizational modalities have also developed relevant actions, as disclosed herein. These actions should be incorporated to the reflection on the complex grid, which is commonly referred to as national response to AIDS. It means that actions on HIV/AIDS have reached civil society in its several layers, rather than only those NGOs set for this purpose. Such dynamics imply that classic spheres, such as trade unions and other non-party associative ways – other than NGOs – have also changed to match classic topics related to the class, such as the fight for rights in the field of political economics, working conditions and incorporation of those claims into the fight for rights to citizenship.

This sort of approach poses the need of thinking about the facts that make up the responses being provided to the AIDS epidemics, in the light of the diverse historical realities wherein they were developed. The time/space relation and broader referential that inspire social action should be taken into consideration in order to understand the processes where social practices happen. In this light, works developed by authors such as Foucault (1986) and Elias (1990), about institutions in Europe, milestones for an important tradition in re-interpreting institutions and public policies in contemporaneous states help understanding Brazilian context dynamics.

As acknowledged by several authors, health and disease phenomena have always been, somehow, processes involving a combination of elements ranging from strictly clinical and biological aspects to the interaction of social players from different social contexts. The so-called “medical policy”, in middle 19th Century in Germany, besides other European models developed in England and France, for instance, are paradigmatic experiences of a medical view. Besides biological components of the human body, those views tried

to identify social factors implicit in populations' health status. As Duchet (1980) recalls, the political project of state building, and social replication by means of laws and institutions that succeed in granting ascending movement to humanity, were privileged at that time in political thinking and action. It resulted from idealism and establishment of utopias feasible to improving civil society. On the other hand, this process was also strongly marked not only for acknowledging "men's" rights, but also for recognizing new prisms of individual social control, and the achievement of what Rosen (1994) calls "awakening of public consciousness".

In a scenario very far and different from those European events, in times when capitalism was the major way of society organization, some moral and social ideas prevail or are redesigned, upon the possibility of building new social agents within the scope of the Brazilian Unified Health System – SUS, more specifically with the advent of AIDS, which would become the 20th Century epidemics.

Historically, one of the major focuses in sociology has been placed on reviewing institutions, mainly concerning the role played by State. This has specially flourished in the health field, when collective health started being outlined in Brazil, as a specific field of knowledge due to its object and how it was managed. By the beginning of the 1970's, State role in controlling population health and organizing its institutions towards the new practices proposed, was object of important academic production. These works have launched a new epistemological domain, increasingly expanding simultaneously to the construction of new relationships between civil society and the State. Among these studies, the following are highlighted: Coutinho, 1980; Arouca, 1975; Fleury, 1995; Luz, 1991; Escorel, 1987; Damaso, 1995 and Canesqui 1994, among others. All those works – in their own fashion and under different theoretical lights – tried to provide responses to the kind of health system needed, based on the state-of-the-arts notion of health of the time, mainly after the 1978 Conference of Alma Ata. These works also intended to attain the paradigms resulting from the concept of primary health care, set forth in the Letter of Ottawa, published in 1986, as previously mentioned.

2.2. HEALTH, A NEW ACHIEVEMENT

The first issue to have in mind, for the purposes of this work, is that such new concepts emerge late in the 1970's to the end of the 1980's, when Brazil is undergoing a re-democratization process, which will bring new order and features to political actions at all levels. In this scenario, health is understood as a concrete product of social relations and is, therefore, under a field of tension among several powers, not exempt from values, as it so happens in any process of social nature. On the other hand, civil society movements, already active in greater or lesser degrees of organization and presence, occupy important rooms in the political plan, and start proposing solutions for the gigantic social debt that Brazil then recognized it had to settle.

As Fleury (1995:31) underlines, thinking democracy in Brazil, or the re-democratization process in the Latin America, actually meant the spoiling of bureaucratic-authoritarian regimens, with different projects from several sectors. State reformulation could no longer be postponed; it could not remain exclusive business of the bourgeoisie, but instead should become an arena of political fights filled with contradictions (FLEURY, 1995:31). That is the ground for the dispute of major ideas that have prevailed in the Brazilian health policy panorama throughout the last twenty-five years, and that have deeply influenced the Brazilian response to HIV/AIDS.

Fleury reports that the Brazilian hospital-doctor and health services structure used to be guided by an expanding technological basis. The health system, even precariously, served most urban and rural populations. However, prevailing logics was that of health as an industry rather than as social good or universal value. And that is exactly the difference of the paradigm that was built within the scope of Brazilian society's contradictions of that time.

In the field of health, this process meant not only an important social movement, known as Sanitary Reform. It has also deeply penetrated in health and university-level institutions, mainly medical and nursing schools. Therefore, the sanitary reform project, as

Canesqui (1994) points out, had three senses: be a new concept in health care organization; formulate a cognitive Project in the Universities aiming at producing professionals capable of meeting new demands posed; and, finally, have impacts over the formulation of public policies on health and education. It was the only way for a new concept of health to actually be legitimate and, therefore, replicated in institutions and cultural scopes in general. That was the time when, as Rosen (1994) says, the “sanitary consciousness” arose within the Brazilian society, leading to shifts of power within the State institutions. Three decades later, new studies in the field of collective health and its emergence in the Brazilian reality evidence the dimensions of this phenomenon. According to Campos *et al* (2004:746) health promotion would be a theoretical-practical-political field, which jointly with concepts and definitions of the Sanitary Reform Movement, arises as a policy that should pass through the set of measures and projects in health, at all levels of managerial complexity and health system focus.

Under this light, the article by Araújo (1999:83) on the impact of HIV/AIDS policies, underlines the view of major ideals to which that policy adhered. According to the author, the policy recovers universal principles formally stated in the Brazilian constitution. In other terms, the author adds, Brazilian government response has always tried to match public health approaches and respect to citizenry rights (including the access to health goods and services).

Yet in theoretical grounds, it is worth mentioning that in the 1970’s and 80’s many works based on sociology and anthropology analyzed institutions under different views. The influence of studies over Goffman (1989) total institutions, for example, was relevant to disclose that institutions were merely the reflex of society itself. Civil society is the arena where complex social processes, tensions among groups, ideological memberships take place, in the sense of values to be preserved, which are endowed with macro expression when placed in the broader scope of civil society.

Analyzed under this light, the institutions are *locus* of social practices, forging individuals capable of setting affinities and

developing potentialities, besides representing room for socialization and conflicts. Anthropology-oriented studies are devoted to analyzing institutions in the light of their identities. Which values, peculiarities and social representations are entwined in daily life and allow for talking about a given institutional culture. These analyses evidenced how institutional facts are produced and reproduced, how specific knowledge, duties, customs and inscriptions are constituted and give sense to social practices performed within the institutions' scope. The role played by institutional leaderships is similarly important. Through its personal styles of tackling a political agenda, they impose some work procedures, priority settings and differentiated focus – and this can also be observed in National STD/AIDS Programme. Taking these characteristics into consideration, Goffman's (1989) notion of institution was useful in analyzing the Brazilian STD/AIDS Programme. It assisted in explaining how the program specificity is characterized, its sustainability under the light of its ideas, how its principles are operated, and which social order it expresses.

On the other hand, which principles organize practices in these institutions; which hierarchic levels are established in terms of field of knowledge and action; which classification principles surround the organization in terms of biological and cultural reality? These are some relevant issues that review what the Brazilian STD/AIDS Programme has pointed out. They succeed in expressing the sophisticated relationships between biological and social dimension of a disease, especially metaphorically.

These questions are the background to this chapter, and intend to reach a reflection that allows for evidencing that institutions are basically composed of individuals and groups. These individuals and groups are immersed in social dynamics, subject to advocacy – whether explicit or not – involved in fights for power, characteristic to the institutional sphere. On the other hand, institutions like the National STD/AIDS Programme may be faced as mirrors to civil society. They display traces that can be found in social life, somehow similar to what the French Sociologist, Marcel Mauss, called a total

social fact, because they may express a myriad of interests, demands, values, techniques and practices in social life.

Proceeding on the functional analysis of institutions, sociological studies allow for an understanding of institutions as a sort of social organization, where activities are performed, hierarchies are established, power relations are produced and collective identities are built. Among the attributes of these institutions, Goffman (1989) identifies some that may or may not exist in all institutions. For example, the consciousness that individuals desire to reach a social status there, or even a system of rules and clearly stated final objectives, besides adhesion to a political or programmatic platform of such institution.

When Brazilian STD/AIDS Programme clearly defined its role and what it calls “adoption of a consensual ethical referential” (Ministry of Health, 2000), it succeeded in bringing together a broad range of sectors, thus allowing for building up a public policy on HIV/AIDS control. Despite some minor variations, along the last few years the AIDS Program objectives have been: reduce the incidence of HIV/AIDS and other STD infections; expand the access to diagnosis, treatment and care; promote respect to human rights of people living with HIV/AIDS, and strengthen those institutions in charge of controlling the epidemics in Brazil.

2.3 BUILDING A NATIONAL RESPONSE TO THE HIV/AIDS EPIDEMICS

One major feature of Brazilian STD/AIDS Programme is the continuous incorporation of social segments, typically external to State duties. Nevertheless, due to AIDS epidemiological features and the kind of response gradually built, those sectors became part of the national response strategy, and now are representative in the Program organizational structure. Often, one can find players from different fields of work – including several levels of Government – participating in the Program scope.

The Program is staffed with members of social movements, municipal and state technicians, NGOs members, advocates of the AIDS cause and people living with HIV/AIDS. This may be understood as one of the managerial strategies built to national response, which is also unique to Brazilian experience.

Through NGOs/AIDS pro-active technicians, for example, but also of other sectors such as universities, health services or international organizations, class associations, organizations of vulnerable populations, etc., the Program found a way to incorporate the know how of people directly involved or affected by this epidemics into its practice. That also allowed for establishing communication channels legitimate to the target-population of its main actions⁶.

As Galvão points out, the responses by civil society organizations were prepared based on a broad range of actions, among which are outstanding projects, assistance, legal assistance, surveys and systematization of information, besides counseling to carriers and their family members. Along time, these modalities became baseline actions to the Brazilian policy on HIV/AIDS control. They result from efforts of major organizations, such as GAPA (*Group of Support to AIDS Carriers*) – the first ONG/AIDS in Brazil – PELA VIDDA, GIV and others.

As epidemics developed in Brazil, a Program on AIDS at the federal level could no longer be postponed. Within this context, it is worth referring to several factors that allowed articulating a national level policy. Some states, particularly São Paulo and Rio de Janeiro, had already succeeded in formulating a process of quick response at the state level – an important reference to the implementation of state and municipal actions countrywide. On the other hand, the World Program on AIDS of the World Health Organization and Pan-American Health Organization – WHO/PAHO – have fomented

⁶ The National Commission on AIDS, consultative body to the Brazilian Program of AIDS, is an institutional space of convergence to sectors representative of civil society, non-governmental organizations, people living HIV/AIDS, academic sectors and others that express the polyphony of voices present in the national response to AIDS, while simultaneously exercising mechanisms of social control over national policy on HIV/AIDS control.

the establishment of national programs on AIDS in developing countries, as a way to favor programmatic actions for a public health issue that is hardly acknowledged. Thus, under the dogged and brave coordination of Lair Guerra de Macedo Rodrigues⁷ - an icon who gathered her vocation and technical skills to national experiences in her work leading the Division of Sanitary Dermatology of the Ministry of Health, and within the international scope of the Centers for Disease Control – CDC, the Brazilian policy on AIDS starts to be structured at the federal level, leading to the emergence of the Brazilian STD/AIDS Programme. The remarkable contributions of Lair Guerra and her team became a core milestone in AIDS Program development. The quality and engagement that have marked her leadership remain an important legacy to the Program's organizational identity. Pedro Chequer, Euclides Castilho and Luiz Loures, among others, were part of this pioneer team.

The National STD/AIDS Programme was officially established in 1987. By that time, the epidemics dynamics, besides the organization of its control, had allowed for the accumulation of some experiences that were expandable to Brazil as a whole. Therefore, in 1986, a policy on HIV/AIDS started to be structured at the national level, although still precariously. According to Pedro Chequer, in an interview to the Inter-American Development Bank (IADB) Newsletter of 18 November 2004, there are references to those memorable moments of historical recovery of the Program in the voices of main players, and in the process of formulating a national policy on HIV/AIDS. These voices allow for perceiving the dimension of the political project that AIDS had brought about in Brazil. According to Chequer, Brazil adopted crucial measures when the epidemics extension was still unknown. In 1986, the Federal Government decided to build an AIDS division with its own structure and, then, established a national

⁷ Lair Guerra de Macedo, Biologist, held long-lasting career in Brazilian public health. She idealized the National Program on STD and AIDS, and was its first coordinator. She had to leave public life and her office after a work accident in Recife, which caused irreversible sequels to her.

commission composed of those Ministries with closer relations to the issue, NGOs, universities, researchers, academics and experts in several social areas.

NGOs play an outstanding role in this construction process. According to Teixeira (22/03/2004), NGOs stood for the first step towards creating programs and organizing the Brazilian response, which allows for assessing the extraordinary dimension of NGOs in the Brazilian response to AIDS. On the other hand, it is worth mentioning that NGOs' experiences in AIDS allowed other diseases to benefit from experienced social movements all over the country.

In light of the institution analyzed hereby, it would be crucial to acknowledge health policy at that time in order to chronologically place the emergence of the first measure of the fight against the epidemics, and the kind of response then outlined. Leaders who headed the first fights believed and were engaged in what in Brazil is commonly referred to as collective health; while in Latin America and Europe it is better known as public health⁸.

First of all, as Fleury (1995) points out, public policies play core role not only as leaders to social behaviors, but mainly because they express power and class relationships of several political and social powers. It is a decisive point in the developments that Sanitary Reform underwent, which should cause direct impact over further actions on AIDS epidemics control. Surely, economic aspects are also deemed fundamental when trying to analyze the relationship between health and civil society, in a social structure like that for Brazil, basically based on capitalism and where market power is hegemonic.

⁸ Like Lair Guerra de Macedo Rodrigues, who headed the Program from 1987 to 1996, with a break during Collor government, and Pedro Chequer, who is part of the Program technical staff since it was established, and headed it from 1996 to 2000, retaking the office in August 2004. Paulo Roberto Teixeira was also part of the National Program, heading it from 2000 to 2002, and Alexandre Grangeiro headed it from 2002 to 2004, after holding other technical offices.

Opening frontiers and expanding views on a world that is not restricted to national spaces, provided health with a geo-political view that, for AIDS, became crucial because of its gigantic epidemiological expansion. Therefore, as Câmara (1999: 88) states, AIDS arises as a global issue, “where perspectives on what is relevant at the international scope vary from country to country”.

What is now the so-called Brazilian STD/AIDS Programme, bound to the Surveillance Secretariat of the Ministry of Health, has a long and fragmented history. This history has not yet been integrally recorded or systematized by several studies on AIDS policy in Brazil. It lives and is rebuilt in the memory of those who engaged in developing a national response to the epidemics. Despite the countless sources on the organization of an initial response to AIDS, several social players have built it in their daily fight, mainly characterized by courage, desire for innovation, new understanding on public health and engagement with the highest ideals that have inspired the fight against dictatorship and of the re-democratization of Brazil. One could say, as pointed out by Fassin (2001), that a sort of “state of mind,” required for sensitivity towards demands and translate them into actions, is a structuring piece of public health. Along the years, this vocation became a crucial component in the Brazilian response to AIDS.

Within this set of efforts developed, the role that São Paulo and Rio de Janeiro State Secretariats played is outstanding in the formulation of AIDS-oriented actions at the state level. These Secretariats undertook one of the first attempts to provide a response to this rare public health phenomenon, focused on some specific social groups, with similar symptomatology. It announced the rising in Brazilian territory of a new pathology, which had recently been identified by biomedical sciences as Acquired Immunodeficiency Syndrome – AIDS. In Brazil, the disease is also AIDS, according to the original acronym in English, and its meaning is associated to the presence of the Human Immunodeficiency Virus - HIV in the body. In Brazil the term is also used according to the original acronym in English.

In a chronology prepared by Galvão (2000), those are the years of “awareness of the problem” and first institutional responses. That was also when NGOs started acting, engaged in a work of response to HIV/AIDS or, in a broader sense, responses by organized civil society. For example, in the State of São Paulo, where the first cases of HIV/AIDS in Brazil were manifested, there was a significant organization of homosexual groups, which allowed them to activate a reasonable movement claiming for responses. This appeal by organized social groups found in the State health institutions the required permeability to treat the new disease and start outlining a plan with financial and human resources made available. Teixeira (Folha de São Paulo, 22 March 2004), when referring to that period, recalls that for a given time the epidemics seemed to be invincible, and hospital lacked beds, patients used to die in ambulances and at emergency rooms. However, he adds, the Brazilian society found a way to solve or minimize all problems: more and more NGOs, care shelters, new service units, more hospital beds, more drugs, public opinion – mainly journalists – restlessly claiming for solutions from authorities. Still according to Teixeira, Brazilians have collectively built an unprecedented process of social participation.

AIDS history in Brazil is marked by an intensive relationship between government and civil society, in formulating and implementing policies to face this disease, which has strong social expansion. Nevertheless, such relationships were not free of contradictions. On the contrary, sources in literature clearly reflect its tensioned start, evidencing a gap left by the State, negligence by public sector in relation to that new disease that, for its dynamic and comprehensive spread, required financial resources and skilled health professionals, besides a health system capable of providing care to patients. Civil society organizations that emerged simultaneously to the intensification of the epidemics, claimed health institutions – at the three government levels – to adopt concrete actions and cease Public Power omission in face of HIV/AIDS threat to increasingly broader population segments (CÂMARA & LIMA, R.M. 1999; VILLELA, 1999; GALVÃO, 1997 and 2000).

Later, along twenty years of epidemics, the relationships between the State and organized civil society – especially NGOs – have ranged from processes of harmonious cooperation and tune, to strong antagonist positions. However, involved sectors have usually acknowledged the need for articulation between State and civil society towards formulating efficient policies to control the epidemic. In anyway, the pressure by NGOs has been crucial to provide continuity to AIDS-oriented public policies.

2.4 FOR GLOBAL CITIZENSHIP FOR LIFE

In fact, since its early stages the “Brazilian AIDS” – as some authors define it (DANIEL: 1989 GALVÃO: 2000) – did not remain in its social and political dimensions, restricted exclusively to Brazilian space. Global interlocutions were rapidly built. Activists, scientists, people living with HIV/AIDS were the backstage for interlocation on a disease always understood under the tension between endogenous and exogenous. On the other hand, under a non-governmental perspective, the speech of renowned individuals, such as Herbert Daniel and his claim to solidarity as a core ingredient in the fight against AIDS and prejudice, is another characteristic element of the so-called Brazilian response. Actions undertaken by Herbert Daniel and Hebert de Sousa – Betinho – founder of IBASE and ABIA, played core role not only in tightening articulations between civil society and government, but mainly for spreading over – or “contaminating” – expanded social spaces, which also included international forums.

Betinho’s contribution is outstanding in building awareness on AIDS meaning in Brazil. He decided to face the problem in a political way, talking about it to the whole country for two years through radio and TV stations, newspapers and seminars (IBASE statement www.ibase.org.br). On the other hand, Betinho encouraged NGOs in Brazil. His experience during exile allowed him to think about new modalities of political participation, aiming at building new democratic ways. The Institute of Studies on Religion – ISER and

the Brazilian Institute of Social and Economic Analyses – IBASE became important places for civil society organizations, and the fight against AIDS epidemics.

The principles of integrality, universalization, equity and decentralization that govern the Brazilian Unified Health System – SUS have in the field of AIDS a fertile soil for implementation. For example, still in 1988 the National Program started – within the scope of SUS – to distribute drugs to fight opportunistic infections. In 1991, when anti-retroviral therapy appeared, the Government also formulated actions oriented to grant drugs to all patients. Under the light of programmatic implementation efficacy, one could say that actions developed by the Program have strengthened mechanisms that allow for incorporating sanitary demands, specifically those resulting from HIV/AIDS epidemics, into the health system scenario and, in a broader sense, to the social protection system in force in Brazil. In other words, demands posed by AIDS control led to improving the health system. AIDS was an important opportunity for enhancing and advancing a political process that was previously built as a possibility of social participation and innovation. In this regard, changes are permanent. For example, Pedro Chequer – director of National STD/AIDS Programme – in an interview to *Boletim Em Questão N° 11* of 3 December 2004 explains a measure that allows for incorporating new AIDS-related procedures into SUS. These are repairing surgeries for adverse effects of anti-retroviral therapies in some patients, known as lipodystrophy, which worsen their quality of life. This is an old claim of non-governmental organizations, and organizations of support to HIV carriers. Therefore, these new actions are an important achievement in what Brazil may do concerning epidemics control and improvement of SUS scope. According to Chequer, there are eight interventions, all of which aesthetic and repairing plastic surgeries, of small- and medium-size: abdomen and neck fat liposuction, breast reduction, gynecomasty, graft and gluteus reconstructive surgery, besides face filling with fat and polymethyl. As set forth in the Ministerial Order that authorizes the inclusion of such procedures in the SUS table,

in 60 days protocols for referral to surgery and mandatory forms, to be attached to patients' records, would have been prepared.

However, the major jump is in 1996, after the International Conference on AIDS, held in Vancouver. The Conference was the stage for launching the triple antiretroviral therapy. The results of this therapy were a milestone in natural and social history of the disease, providing patients with longer outlives and improving their quality of life. Supported by Law 7.505, the so-called Law Sarney, of 13 November 1996, the distribution of antiretroviral drugs for patients with AIDS becomes mandatory and free in all health services, and is extended to HIV positive individuals with therapeutic indication. It was a baseline strategy in fighting the disease, as can be observed along this chapter, as it is one of the pillars of the Brazilian policy, acknowledged worldwide. However, it is worth noticing that when Brazilian government adopted this policy, it was subject to severe criticisms by some branches of the scientific community, and the World Bank was clearly against it. The scientific community believed there were no technical-operational conditions for implementing it. The World Bank believed it would be an economic disaster. The history of these years of fight against the epidemics clearly proved that scientific community and the World Bank were wrong in their analysis. Nowadays, through the System on control of drugs logistics – SICLOM and the SISCEL – System on control of laboratorial assays, antiretroviral drugs are provided for about 120 thousand patients, besides allowing monitoring viral load assays and lymphocyte counts of patients under antiretroviral therapy. Under the same light, it is worth mentioning the role played by the Renageno – Project on National Network for Genotypic Assay to HIV-1. Renageno laboratories monitor patients with HIV resistance to the antiviral drug(s) they are currently taking, aiming at identifying any mutations in the virus that are associated to HIV resistance to antiviral drugs. The identification of viruses existing in Brazil provides a more accurate view on the epidemics manifestation, besides the need for drugs combination and dosages, in addition to the adherence of patients to antiretroviral therapies.

Over the last few years, Brazil has reported – among outputs generated by its integrated policy on AIDS – a 50% reduction in mortality from HIV/AIDS, reduction in morbidity, besides reduced hospital costs and costs for producing antiretroviral drugs. Nevertheless, the relationship between civil society organizations and the National STD/AIDS Programme could not be understood out of the broader macro panorama of new relationships between democracy and civil society, imposed by modern states and the increasing autonomy of the Brazilian civil society. According to Fleury (1995), the concept of citizenship synthesizes notions of equality, individuality and representation, as expressed within the scope of new institutions.

The concept of citizenship does not have one single definition in scientific literature, as previously discussed in relation to NGOs. Rather, there is a broad collection of concepts that incorporate dialectical relationships in different plans, such as the field of individual and collective rights, legal plan, human rights, civil rights, new collective subjects and a core concern, i.e., incorporation of excluded populations or, as Castells (2000) prefers, those under social process of becoming disaggregated from those rights formally granted by Brazilian constitution.

Although citizenship is privileged in the legislative plan, as the mirror of democratic processes generated by societies, it is in the *locus* of social practice that it should actually be effective. It is in daily human interaction, in the fight for power rooms, in access to available goods and services, that the concept of citizenship is ruled and understood as the co-existence of individuals and groups. This is also the arena where political representation is faced as part of tensions and contradictions characteristic to developing democracies. Therefore, the emergence of new players, notably the members of organized civil society, who will fight for their place in the Program, would be playing one of the most relevant roles in democratic exercise, i.e., the representation and possibility of becoming a legitimate voice of their interests. As Carlos Coutinho (1980) argues, the discussion about policies implies in discussing representation of interests, and how such interests are represented, their players and rationale.

Within this macro context wherein fight against AIDS was inserted, it would be worth recalling that Brazil was undergoing deep economic restructuring and social transformation processes. The feminist movement in the 1970's was crucial not only to opening the debate on the role played by women in production, but also – as Diniz & Villela (1999:125) recall – to debate the right of women to control their fertility. These discussions had direct impact on the formulation of new health policies to women, incorporated into the *Programa de Atenção Integrada à Saúde da Mulher*⁹ – PAISM, resulting from the debate on gender issues and criticisms to the biologicist view about women and their reproduction. Gender unbalances and the need of viewing women in all their dimensions officially became part of the public health policies agenda, and now hold expressive room in the speeches about the AIDS phenomenon.

Focused on a broad and dynamic view on citizenship exercise, within the AIDS scope, another topic is exactly how and who represents the interests. Within a scene played by such different players, AIDS activism is considered to have brought to the Brazilian political scenario relevant experiences in the field of political representation of players. NGOs and other civil society sectors became, in their power of expression, interlocutors and representatives of interests of populations more strongly affected by the epidemics.

2.5 CONSTRUCTION OF SUBJECTS

As previously mentioned, the past twenty-four years of history, since the appearance of the first cases of AIDS in Brazil, points out that it was the homosexual population who was the first affected; nevertheless, this population was also the first to have voice in health institutions in order to claim attention to such “rare evil,” that was

⁹ Program of Integrated Care to Women's Health.

spreading all over the world among these groups. It provided AIDS with one of its peculiarities. The participants, who in this case were the ill people, became chief players in finding representation channels in the State scope. This happened in São Paulo, as well as in other urban centers worldwide, as described by Dennis Altman in his book *Comunidade e Solidariedade* (1995). A fact somehow unheard in public health history, the legitimating of groups of people affected by the epidemics culminates in a meeting held in Paris, in 1994, where participants signed a declaration recognizing the need for “greater involvement of people living with HIV/AIDS” in national and international policies. Since then, the process has been expanding, to a higher or lower complexity and depending on the place, it may be understood as a universal feature of AIDS.

AIDS experience as a phenomenon that cannot be transferred, provides hegemonic weight to this policy that, through practice, was endowed the statute of principle. If representation issue goes through legitimacy, as relevant here, it became decisive in voices that now call themselves as people living with HIV/AIDS. Hebert Daniel (1989) says that they were looking for room not only to be included in health policies, but also to fight the so-called “third epidemics”. This concept involves the entire process of social discrimination and several ways of stigmatization, whether veiled or not, that came about simultaneously to manifestations of the first cases of the disease, no longer jeopardizing individual’s biologic level, but instead the moral dimension of affected subjects.

Among the objectives of the Brazilian policy on the fight against HIV/AIDS, there is the respect to human rights, by assisting and fomenting Governmental and Non-Governmental spheres in initiatives towards granting rights, fighting recurring behaviors of prejudice and discrimination of people living with HIV/AIDS (Ministry of Health, 1999:17).

In this light, the Brazilian response continued putting into practice the theoretical paradigm developed by Jonathan Mann (1993), concerning collective vulnerability. This term is used to denominate macro-social processes that influence the capacity of national

response of several countries in face of the epidemics. For Mann, HIV/AIDS should be ruled as a health condition, and society should develop a broader understanding of the need to avoid discrimination against people infected by HIV (MANN 1993: 287).

On the other hand, through their speech and practice, the NGOs have allowed for building sensitiveness in actions by the state. Moreover, the concern in fighting prejudice and several ways of discrimination against people affected by the epidemics permeated Governmental spheres, and became a core component of public policies. The denouncement, for instance, of “civil death” to which activists such as Hebert Daniel (1989) used to refer, led to strong fights against it by several kinds of representation. First of all, by small groups of affected people followed by Non-Governmental organizations, which thus increased and became stronger as epidemics spread all over the country. Now, the fight to abolish prejudice against people living with HIV/AIDS remains the cornerstone of Non-Governmental Organizations and was incorporated into public policies issued by the State.

Within the historic panorama that this article tries to depict, GAPA/SP is outstanding both for the expression of its work and for its capacity of response. GAPA was established in 1985 (GALVÃO 1997) as a group aimed at advocating respect to HIV/AIDS carriers and developing activities for infected individuals. Later, and focused mainly on defining programmatic actions and following-up on public policies, ABIA was created. It is an NGOs that produces and disseminates knowledge on HIV/AIDS – the only of this kind in Brazil – with great capacity of articulation in the international arena with non-governmental organizations, international organizations and academic and religious sectors. The Group PELA VIDDA, in Rio de Janeiro, is a key-organization that, in principle, fights against the so-called civil death. According to its founder, Herbert Daniel, civil death is the most serious problems that affect HIV/AIDS carriers. The *Grupo de Incentivo à Vida – GIV* is a support group to seropositive individuals, sprung in São Paulo in the mid 1990’s and plays a core role in

articulating practices and speeches of people living with HIV/AIDS. Additionally to these groups, there are organizations of sex professionals, travesties, damage reducers, and shelters for low-income people, community-based associations, among others. Altogether, they make up the broad range of responses by organized civil society to the AIDS epidemics. This book strives to depict their strongest expression.

The background of this activism may be synthesized in what authors like Richard Parker (1994) have referred to as “solidarity building”. HIV/AIDS seems to be invincible if solidarity does not become a conscious part of daily behaviors in relation to the epidemics and affected people. The author perceives it under a social perspective. In this sense, solidarity is not granted; rather it results from a joint effort of collectivities that believe in human vulnerability to that infection, besides the need for setting mechanisms of tolerance to differences among individuals and social groups. Then, Parker introduces solidarity as a socialization process required to structure the national response to the epidemics, and a social construction process subject to valuations.

These deep learning processes in formulating and employing a public policy on HIV/AIDS allowed for a shift in the nature of State relationships. Now, these relationships are permeated by new voices and new actors, capable of influencing the destiny of public policies with their plural and collective interests – a remarkable feature of current complex societies and their new ways of expression in the social-political arena. As warned by a member of GIV, in São Paulo, the fight against AIDS is alert to any fight for democracy promoted by the Brazilian people, in an effort for articulating particular and more universal fights. It can be understood as the incorporation of an expanded concept of citizenship, and clearly of a broader concept of the health-disease process. The latter, as previously mentioned, sprung amidst of the sanitation movement, where popular participation struggled to become a structural part of new relationships with the state and where, finally, the basis for reinvigorating public spaces and renewing State institutions were settled.

2.6 EXPLORING AND FACING THE INTERNATIONAL FIELD

The range of interlocutors between the National Program on STD HIV and AIDS and its partnerships expanded. Brazilian policy on AIDS innovates in the formulation of agreements and principles of autonomy and respect that guide its relationships. By the end of the 1990's, local international organizations, urged by the National Program, became an articulated group with room for discussing the epidemics path and improving technical cooperation. By that time, within the framework of principles such as horizontality, where double way transmission of experience is favored, rather than just receiving outsider experiences, emerge the first relationships of external cooperation created by the Program. It is worth having in mind that it was not limited to bi-lateral relationships between Brazil and international organizations with offices in Brazil, such as UNESCO, UNICEF and UNODC among others. In fact, it tried to create new modalities of technical cooperation among similar countries in Latin America, aiming at optimizing the impact of policies on the fight against HIV/AIDS in the region, besides acknowledging cultural diversity and economic and political differences among the countries. Two forums following this line of work are worth mentioning: the Theme Group and the Horizontal Technical Cooperation Group – HTCG. The first is a sphere of coordination among several organizations part of UNAIDS, jointly with the Brazilian Cooperation Agency – ABC, and that are aimed at coordinating the contributions of such agencies to the process of international responses to the epidemics. The second modality comprises several national programs on AIDS in the region, intending to improve managerial capacity and exchange of experiences towards providing sustainability to programs in Latin America.

The early expressions of what would then become the HTCG happened in Montevideo, in a meeting convened by the Brazilian Program in 1994. Among participants let us highlight Pedro Chequer, Júlio Barrios and Mauro Figueiredo, from Brazil; Laura Astarloa, from Argentina; Raquel Child and Luis Toro, from Chile; Patrícia Uribe,

from Mexico, just to mention some names that provided decisive contributions to the establishment of partnerships among Argentina, Chile, Brazil, Colombia, Cuba, Ecuador, Honduras, Paraguay, Venezuela and PAHO and UNAIDS observers. Formally established in May 1996, during a meeting held in Rio de Janeiro, and structured with a technical secretariat and four focal points, HTCG engaged in discussing policies and projects on integration, development of planning and assessment methodologies, human resources training and joint actions for the purchase of drugs, policies on national production and quality control of patents. One of the major duties of the Group, which increasingly developed in the policy of external cooperation of the National Program to other regions in the world, was the streamlined action towards purchasing antiretroviral drugs, aimed at reducing their costs. Within the scope of HTCG several forums were held, both in Brazil and in other countries in the area, where all sectors involved in the respective national responses – i.e., governmental organizations, civil society organizations, academies, people living with HIV/AIDS, among others (Díaz Bermudez, 1999).

Although uncompleted and requiring permanent improvement, these processes have the merit of introducing new management fashions, agreed to among different players and within the field of bilateral cooperation. Secondly, the need for establishing new terms for interlocution among such different groups, with different paths and occupying public space in different ways in their respective national contexts. The third dimension that should be taken into consideration is that such processes are outlining the Brazilian insertion into globalization trends that emerged in early 1990's, besides a particular contribution of health policies in the region.

The National Program has set other actions in international field, and some should be recorded as they seeded a highly sophisticated process of innovation in external cooperation modalities. For example, in the scope of Portuguese-speaking African countries, known as PALOP and extended to other African countries, the execution of projects that allow for technological transfer among nations and

strengthen a consensual agenda. This had impacts beyond African and Latin American frontiers. Therefore, it promoted the definition of policies at the international level, expanding the traditional interlocution processes.

Several forums held by the World Trade Organization – WTO should be inserted in this path. Among them, the 2002 Doha Meeting was a milestone and led Brazil to advocate for its policy on the fight against HIV/AIDS, and its own capacity of producing antiretroviral drugs, in the perspective of setting health as a human right, in opposition to a basically profit-oriented view of the market and major industries worldwide. According to Teixeira, in an interview to *Folha de São Paulo* newspaper in March 2004, when countries were negotiating mechanisms for reducing drug prices worldwide, the Brazilian role in the fight for access to treatment may be synthesized as a shift from mere consumer to a strategist and negotiator. Still according to Teixeira, Brazil has adopted all possibilities of negotiation, from production of generic drugs to threats to breach of patents.

AIDS brought the field of public health to the debate at the international trade sphere, and was supported by the mobilization of civil society powers. For Galvão (2004), these strategies are inserted into the so-called “trans-national activism”, in the perspective of bringing the AIDS debate into the sphere of world security, besides acknowledging that epidemics has allowed – through the invention of new technological processes – for an international market that transacts huge amounts of money.

Once again, Brazilian leadership played a core role in approving the UN Resolution that defines health as human right and acknowledges the need for access to medications within the scope of pandemics such as HIV/AIDS. The document was issued during the 57th Session of the UN Commission on Human Rights, held in Geneva, in April 2001, as an advance in including AIDS-related issues in its interface with other dimensions of social and political life.

Since the pioneer experiences in the field of international cooperation, which started being organized under the leadership of Pedro Chequer in 1996, being more intensively and systematically

consolidated as of 2000, under the leadership of Paulo Teixeira, and remained during Alexandre Grangeiro's management, the National STD/AIDS Programme is developing a new stage in the international field. This new stage is characterized by an intensive openness to other countries, and places Brazil in the leadership in formulating policies and strategies on control of the epidemics at global level. As pointed out by Chequer (2004), the National STD/AIDS Programme is an exportable Brazilian product, the dimension of which may be perceived in the multi-faceted international agenda that it successfully established.

For the comprehensiveness and relevance of new international strategies of cooperation among countries, it would be worth mentioning the International Cooperation Program for Actions on Control and Prevention against HIV for Developing Countries – PCI, created by the National Program in 2002. This project aims at promoting Brazilian support to developing countries, mainly in the framework of South-South cooperation, which includes countries members of the Portuguese-Speaking Countries Community (CPLP) and Latin America and the Caribbean, towards supplying generic antiretroviral drugs produced in Brazil and, thus, contribute to set the required infrastructure of assistance to HIV carriers in those countries. Currently, the program provides treatment to about one hundred individuals in twelve countries: El Salvador, Bolivia, Paraguay, Dominican Republic, Colombia, São Tomé e Príncipe, Burkina Faso, Cape Verde, Angola, Namibia, Mozambique and Burundi. The project is executed in partnership with national institutions, such as the Brazilian Cooperation Agency – ABC, of the Ministry of Foreign Affairs – MRE, and international agencies as the Ford Foundation, Pan-American Health Organization – PAHO, Department for International Development – DFID, of Great Britain, and the German Cooperation Agency – GTZ. Under implementation, the International Cooperation Program started its II Stage at the end of 2004, and foresees the expansion of capacity and coverage of CPI I. In principle, the Program intended to provide support to one hundred individuals, but now expects to expand its services to four

hundred people and, in some instances, universal coverage. According to an official document by the Ministry of Health (October 2004), one of the purposes of this initiative is “to promote free access to first-line antiretroviral drugs to 100% of patients with therapeutic need.” On the other hand, it also intends to provide support to training health professionals in technical fields that countries consider priority. The program shall rely on a system of monitoring and assessment for executing the cooperation project. The program’s geographic reaching has also been expanded, and now includes the Guinea-Bissau and East Timor. This new stage of the cooperation process is also supported by the recently-established International Center of Technical Cooperation in HIV/AIDS, a joint initiative of the Brazilian Government and UNAIDS.

In another front of the international arena, in July 2004, the 15th International Conference on AIDS was held in Bangkok. It represented room for convergence among governments, non-governmental organizations, international organizations, and people living with HIV/AIDS, scientists, activists and advocates, for discussing the epidemics’ status worldwide. Under the light of international policies on AIDS and the need for new ways of articulation among global partners, Brazil suggested integrating, jointly with China, Russia, Thailand, Ukraine and Nigeria, a network of technology transfer to fight the disease. The first technology would refer to access to drugs, followed by preventive devices such as condoms, pharmaceutical inputs and vaccinations, considered as concrete measures to fight the emergence of new processes of social exclusion brought about by HIV/AIDS pandemics. The said social exclusion is characterized by social differentiation and unbalanced access to health services and consumption of several modalities of health care.

According to the National Program report, the strategy is justified because economics globalization and the need for projection require for developing horizontal programs of research and knowledge exchange, besides technical cooperation. That is why Brazil is so deeply engaged in joining nations around priority and consensual

objectives, where public health in social welfare is a priority (Ministry of Health, 2000).

This unprecedented position held by Brazil, towards balancing strategies on prevention and treatment, for a long time refused by international agencies and the World Bank in principle, years later was acknowledged in the implementation of the joint initiative by WHO and UNAIDS, named three by five, launched in March 2004. This policy intends to provide treatment and care to three million patients living in developing countries, mainly in Africa and Latin America, for the next two years. Currently, it is the major international effort towards controlling the pandemics. Out of the forty million individuals infected with HIV/AIDS worldwide, only seven percent have access to treatment. This figure clearly points out the crucial need for responses that allow for universal access to diagnosis and treatment.

2.7 STRENGTHENING MANAGERIAL CAPACITY

Decentralization – one of the principles that govern the Brazilian Unified Health System – is mainly focused on delimiting the competencies for managing public business at three governmental spheres. Traditionally centralized at the federal sphere, the transfer of budgetary resources does not merely imply funds transfers. In fact, it means a new concept of State organizational culture, which takes on new distribution of power mechanisms and agreement processes between, on one hand, governmental participants and, on the other hand, intensification of institutional mechanisms on social control exercised by interlocutors. In what concerns actions of fight against AIDS, decentralization became a decisive tool in the planning, management and assessment processes. With some degree of flexibility in the use of resources, the decentralization of strategic actions on epidemics control in the National Program allowed for the implementation of new management mechanisms among several government levels and their partners. Furthermore, it generated different experiences among States and municipalities. According to

Galvão (2002), one lesson that epidemics control in Brazil learned was the development of management processes, and its impact on health systems. Nevertheless, as previously mentioned, it should be understood in the light of conditions previous to the establishment of the health system itself, which had already settled the grounds for starting a process of democratization of access to health to Brazilian population as a whole, despite challenges brought by such political decision. In this sense, one could say that AIDS epidemics became an opportunity to the leverage and strengthening of the Brazilian Unified Health System principles: universal access to drugs, advocacy of people living with HIV/AIDS and respect to human rights are core contributions to strengthen SUS. The creation of special care services was another decisive initiative. Such special care services comprise Specialized Care Service, Day Hospitals, Centers of Assays and Counseling, Therapeutic Home Care and Drug Distribution Units, which carry out a set of measures such as blood and blood products control, lymphocytes counting assets (CD4), HIV serology assets and viral load assets, among others.

As broadly known, from 1993 to 2004, the Brazilian STD/AIDS Programme relied on three successive loans from the World Bank. The Project AIDS I reached the total of 160 million dollars by the World Bank and 90 million dollars as counterpart contribution of the National Treasury, totaling resources amounting to about 250 million dollars. These loans are also elements of identity to official programmatic action in the fight against AIDS in Brazil, and have allowed for visible advances in management policies, governance and accountability of public business. The second loan refers to the period of 1998 to 2002, and totaled 165 million dollars by the World Bank and 135 million as national counterpart, amounting to 300 million dollars.

The resources of Project AIDS I and Project AIDS II, with their several components, among which we highlight prevention, epidemiological surveillance and institutional development, accounted for the incorporation of new management modalities; have

allowed for new ways of financing; provided agility to the health system and allowed for universalization and decentralization processes within SUS, thus generating an intensive process of institutional development.

Besides investing in a process of internal reorganization and elaboration of strategic plans, the Program also made heavy investments in qualifying staff at the three levels of government, sectors of civil society and health professionals who worked directly in HIV/AIDS control actions, care services and laboratories countrywide. Furthermore, it tried new ways of assessing and monitoring AIDS policies, besides mechanisms that could gradually allow for using assessment as a managerial resource.

Although it had been inserted in the agenda since the first loan, and despite being a programmatic element to actions developed by the National Program, assessment was emphasized only in the last stage of Project AIDS II and in the elaboration and implementation of Project AIDS III – in an amount of US\$ 100 million as national counterpart and US\$ 100 million granted by the World Bank. Assessment shifted from merely a component of management and planning, to a direction in human resource qualification.

As an innovative experience within the health system, the National Program financed projects by organized civil society in the fields of assistance, prevention and human rights, oriented to groups affected by the epidemics. Resources were transferred to executors through public procurement processes or as agreements.

By allowing for building technical staff of excellence that, according to Pedro Chequer (2004) produced “technical grounds” and became one of the “major factors of success”, the National STD/AIDS Programme developed great expertise. Such expertise characterized the Program as an institution, and allowed it to replicate a given way of making its interventions and a given organizational culture, despite eventual changes in its leadership and in face of the myriad of different political and religious positions that characterize the AIDS field. Still according to Chequer (2004), Brazil committed large resources in training specialized staff.

Currently, he says, the Brazilian health system relies on the best human resources, all diagnosis centers are automated and patients are assisted in a place nearby their home.

Additionally to the renowned areas of prevention and assistance, other aspects of the work, such as planning and assessment, epidemiological surveillance, administration and finances, articulation with civil society and human rights, communication, research and scientific and technological development, external cooperation and capacity-building to human resources and executing technical staff, are some of the components mutually articulated to define major strategies of fight against the epidemics, and towards the Program identity as an institution.

Along these years of fight against AIDS, changes in government, changes of ministers and maintenance of high-level and technical staff of AIDS Program were not uncommon. Probably, this capacity of maintaining its managerial staff, in conjunction with other factors such as social participation, dialogue with society, definition of objectives and goals allowed for implementing AIDS policy and expanding its reaching. Let us highlight the fact that this does not mean that the process was exempt of contradictions and conflicts.

Concerning resources management, AIDS Program pursued equilibrium among its different strategies. Another feature of the Brazilian response to AIDS is the simultaneous action between strategies of prevention and assistance. If there are technical and human resources for obtaining treatment and medications, laboratory capacity and other capacities that allow for better monitoring and improving living conditions of people infected with and affected by HIV/AIDS, why shouldn't they be made available in a health system ruled by principles of universalization and integrality of actions?

The false prevention/assistance dichotomy that generated passionate global debates when antiretroviral therapies emerged, and still remains a polemic topic nowadays, was successfully equated in Brazil. Do prevent, but also treat. The major axes of the Brazilian policy on HIV/AIDS were established since its start, and are

maintained and readjusted on a regular basis, as drug production conditions change, discoveries on the virus behavior develop and its epidemiological impact is recorded.

Free universal distribution of antiretroviral drugs and national production of most drugs that make up the so-called “cocktail” is a peculiar feature of the Brazilian policy on fight against AIDS that still remains – almost ten years later – a polemic issue. Even if the most visible feature of the Brazilian STD/AIDS Programme lays on its policy of universal distribution of antiretroviral drugs, it is necessary to take the major characteristics of Brazilian model into consideration in order to understand it. As Oliveira-Cruz *et al* (2004) states, Brazil was capable of implementing a successful program because it could balance prevention aspects with treatment, take advantage of existing conditions when epidemics sprung, and provide early response with emphasis on advocacy. Brazil succeeded in inserting AIDS into the agenda of national life. Although not always in the most suitable way, the media played a core role in disseminating information. If compared to other experiences, silence about AIDS was broken in an early stage in Brazil. Bringing sexuality, homosexuality, drug use, and prostitution to the national debate was a milestone in the political history of AIDS that Brazil is building. Pedro Chequer (2004), in an analysis on the relevance of the Program, claims that communication means having provided assistance in building sensitiveness, informing and educating Brazilians on AIDS-related issues. Brazil, he says, informed the media about technical and human aspects of the disease and its treatment, besides making huge investments in communication, with national campaigns spread by all television channels, radio broadcasters and written press. A pact of alliance with political opposition positively affects laws and budget, placing priority on the program that goes beyond political or government changes.

As previously mentioned, the positive assessment of Project AIDS I and major challenges posed by the path of epidemics allowed for the negotiation of a new loan agreement with the World Bank, with a larger national counterpart than the first agreement, and stipulated

the release of the so-called Project AIDS II, signed in 1998 and that is mainly focused on strengthening institutional development and providing sustainability to measures. For this period, financing innovations such as fund-to-fund transfer are outstanding.

Early in 2003, a new round of negotiations started with the World Bank pursuing a last loan, Project AIDS III. The National Program was then more mature to seat with its partners, and had more knowledge on the Bank's managerial mechanisms, besides holding sound experience in financial management of resources, in partnership with UNESCO, and with civil society. This experience is favorable to the technical elaboration of this process in a more efficient way. In this stage, consultations with civil society and several Program partnerships were richer than in former versions of loan negotiations.

In the light of the place that the Ministry of Health assigns to the Program, it is worth mentioning that it follows-up the movement for finding, in administrative terms, the ways to implement SUS. According to a document by the Ministry of Health, STD/AIDS programs are not – nor could they be – dissociated from other public sector actions, starting with the health sector itself. When Pedro Chequer returned to the office of Director of the National Program of AIDS, in August 2004, he stated that the Program guidelines were clearly: Strengthen Brazilian Unified Health System; insert the Program into basic health network aiming at granting its sustainability as a continuous action of public health. It is worth bearing in mind, however, that formulation and implementation of public policies take place in social scenarios marked by social powers and relationships of power, not only within the state itself but also within society. Under a Weberian perspective on the analysis of the bureaucracy role, it could be said that organizational system and culture have their own logic that demands political tools and cognitive resources to change the traditional way of running the state apparatus. The several social power interlocutors to the National Program, such as NGOs, private sector, churches, international organizations, universities, health professionals, groups

of vulnerable populations and others, are an expression of the emergence of new managerial practices within a state organization and the polyphony of voices participating in this process.

Here, a relevant aspect recalled by Parker (1997) should be mentioned, even if briefly. Such is the context of the Brazilian economy at the time when epidemics arise. Under the international perspective, Latin America as a whole was undergoing policies on structural adjustment, set forth by the International Monetary Fund, characterized by state downsizing, privatization programs and market flexibility. In Brazil, the renegotiation of foreign debt and an intensive process of inflation and market instability were impairments to implement social policies, such as education and health. This panorama comprises the state itself, increasingly more subject to determinations of circulation of major global capitals, and the civil society organizations. In a criticism to these processes, Bourdieu (2002) records the emergence of humanitarian and non-governmental organizations, which now perform duties that used to be exclusive to the state. Still according to Bourdieu, the state was more independent, and is now subject to market domain – under the appearance of great generosity – that characterizes globalization times.

On the other hand, despite the economic crisis and fight for greater shares of public budget, the implementation of a policy on AIDS had impacts on other areas of public health. For example, the control over blood quality, by performing HIV assays in all blood transfusion procedures, in force in Brazil since 1988; the enhancement of social control; incorporation of human rights into the health agenda; models of prevention to remote populations.

Despite the visibility of some advances in the rates of vertical transmission, they are far from being ideal. This is one of the major challenges posed to the current policy on prevention and assistance to HIV/AIDS; to agreement and articulation within the scope of SUS; and to women's movements. The same happens to strategies on damage reduction among users of injected drugs, actions on social security coverage to carriers, debate on homosexuality, human rights and other issues related to people infected with and/or affected by the epidemics.

2.8 AIDS AGENDA AND DEVELOPMENT

A more recent topic is the insertion of policies on HIV/AIDS control into the concept of development. An old sociological category, it appears readjusted by the speech of new participants, such as governments and organized civil society groups, as a first line strategy. In a more integrated concept of health field, the concern with development arose almost naturally. In the AIDS pandemic, the issue became crucial given the dimensions of human losses. Câmara (2004:111) suggests that building a consensual agenda on AIDS and development implies in re-elaborating, for both parties, these relationships based on the new epidemics scenario. Furthermore, he says, it implies valuing how actions performed by NGOs have interfered on the development agenda.

The concept of development and its relationship with AIDS is understood under several perspectives, as it should be. However, there is a likely consensus about the idea that AIDS is directly related to development, as a dramatic expression of social unbalances. In this view, it is understood that overcoming structural conditions that produce and reproduce social differences is a core factor to control the epidemics in particular and, in general, to health field agenda as a whole.

Within the context of National Program, strategies on epidemics control are also understood as strategies that allow for promoting development: incorporation of skills, development of sustainable structures, adjustment of economic, social and political distortions in the regions, and technical autonomy. However, they will only be efficient if they are not dissociated to remaining public policies that rule the state action, so as to make them effectively feasible and lead to the incorporation of technological innovation to Brazil. Concerning technical autonomy, for example, Brazil must become organized and create facts in short, mid and long-term perspectives aiming at reducing its dependence over great capital, in relation to technological development of new drugs. In a detailed analysis

about the impacts of the Treaty on Rights over Intellectual Property – TRIPS agreements over HIV/AIDS epidemics control, Carlos Passarelli (ABIA Newsletter 2004) informs of the Brazilian limitations in acquiring raw materials and surveying new molecules. According to him, these are major barriers towards granting public health interests over intellectual property rights, which still limit governmental action regarding the production of generic medication. According to AIDS Program Director, Pedro Chequer, in an interview to *Folha de São Paulo* newspaper (29/11/2004), the problem is even worse, since if prices continue to increase, they will strongly jeopardize the policy on universal distribution of drugs. For him, no international law may overcome the ethical commitment of providing assistance to the Brazilian population. For that, the Brazilian policy on drug production must advance towards promoting agreements that allow for developing an intensive process for technological production in the field of drugs, capable of granting its self-sustainability. This challenge is not restricted to installed capacity for final production of drugs; rather, it comprises a vertical process that should also incorporate molecule production – basic substances for the production of drugs – at least the most strategic ones.

Closely related to globalization and capital development processes, AIDS is viewed in the global scenario as impairment to economic development. As UN Secretary-General Kofi Annan states, “not only does AIDS destroy million lives, but it will also become a heavy load on health systems in the region, and shall attract required economic resources for economic and social development in the region” (15th International Conference on AIDS, Thailand, 12 July 2004). Especially concerned about the consequences on education, UNESCO General Director Koichiro Matsuura points out that AIDS is a disaster for development, since it ruins decades of investment in education and human development (6/3/2004 AFP International).

2.9 CONSIDERATIONS ON CURRENT CHALLENGES, IDENTIFYING PRIORITIES

The latest UNAIDS report on the epidemics worldwide, publicly launched in July 2004, congratulates the Brazilian STD/AIDS Programme for its capacity in managing the epidemics. Undoubtedly, Brazil has a consolidated way of lessons learned and positive experiences in facing the AIDS pandemics. However, it does not mean that AIDS is a problem solved in Brazil. Far from that, the epidemics control remains a major challenge, and new problems must be faced with vigor. Therefore, this acknowledgement assigns new responsibilities to Brazil. According to the current Program Director, Pedro Chequer (2004), if Brazil wishes to remain as successful reference in the world, it must develop to keep its vanguard position in the field of HIV/AIDS control for which innovation is crucial. The different realities that co-exist in the country of major unbalances lead Brazil to face several epidemics in its territory. Therefore, sustainable and systematic actions foreseen for controlling epidemics require for renewed efforts on behalf of the Brazilian government and its partners towards establishing current priorities. According to AIDS Program Director, Pedro Chequer (2004), the priorities include: the search for alternatives to reduce unbalances in terms of coverage of preventive measures, in addition to technologies for diagnosis and assistance. Here, it is worth mentioning the need for increased production of inputs to diagnosis. Currently, only eight (AZT, DDI, 3TC, D4T, NVP, RTV, AZT+3TC) of the fifteen drugs that are part of the therapeutic consensus are produced in Brazil; production of specialized information on cultural, demographic and economic aspects of vulnerable populations; massive implementation of strategies for other sexually transmitted diseases; expansion of activities on health promotion and sexual education; and, enhancement of social networks in their exercise of social control of the State.

In a critical view, one could say that the Brazilian STD/AIDS Programme has failed in structuring a coordinated, articulated and sustainable response, incorporating gender issues. Within this context,

it is not surprising to have epidemiological data that point out increasing trends in the number of AIDS cases among women. Even having interlocution with several kinds of women organizations, feminist movements, female sex workers, or even with women's groups and organizations oriented to reproductive health, the impact of policies on prevention, assistance and promotion of human rights have proven to be insufficient to protect women against the risk of HIV/AIDS.

Literature shows that the initial linking between epidemics and male homosexual groups, and therefore its restriction to specific groups, plays supporting role in the lack of projects specially oriented to women. In this light, women do not perceive to be in risk, nor do they identify the risk for their children during pregnancy, delivery and breastfeeding, when vertical transmission may occur. Gender relationships, permeated by complex social, historic, cultural and economic asymmetries, lead women to be vigorously affected by the epidemics (GALVÃO, 1997; GUIMARÃES, 1996; SANTOS *et al*, 2002; ALVES *et al*, 2002; CÂMARA, 2004). However, more than the denial of the risk for women – deeply rooted in a social imaginary that faces marriage or one single partner as a safe harbor, resulting in low level of consciousness about vulnerability – the major barrier, according to Barbosa (1997), refers to the lack of public policies to the sector, specifically in the field of health. Good policies and good health practices for women imply in dealing with sexuality, discussing taboos, improving reproductive health services, reducing maternal mortality, facing violence against women, dealing with abortion and other factors that must be approached to reduce women's vulnerability to HIV/AIDS.

Women's vulnerability, linked to structural living conditions, added to poverty, gender unbalance, emotional factors, self-esteem and symbolic position in society, synthesize some aspects that increase possibilities of infection for major contingents of women. The traditional models of prevention, safe sex, promotion of a healthy sexual life, must be reviewed in face of the current configuration of this epidemic. Knowledge on the lives of women living with HIV/AIDS, and their specificities, needs to be more in tune, besides properly informed in order to revert current features

of the epidemic among that population segment. Acknowledging sex, social classes and ethnics as very hierarchical power relations, is a crucial need for fighting the epidemic among women. And that is not only in Brazil, but worldwide. According to Parker (ABIA 2004), the major challenge currently posed by AIDS is the disease feminization, “since among the 14 thousand new daily cases of infection with HIV worldwide, more than half are with women”.

In a broader sense that urges for intervention, there are other issues that sectoral policies, such as that for HIV/AIDS control, have failed in efficiently overcoming. It is about the interaction of Brazilian structural factors with several faces of the epidemic in Brazil. That is to say that limitations in the field of education, health, income distribution, technological development, employment, justice – just to mention some – are elements that interact in a dynamic way with the epidemiological profile that the epidemics undertakes, and the kind of response that may be provided. Therefore, the relationship between equity and vulnerability is a crucial factor to overcome in order to reduce relational exposure to which some sectors are subject to acquire the infection, given their status in society. For example, poor women and impoverished young populations, rural areas hardly approached, as AIDS is basically a contemporaneous and mainly urban disease.

Within this context, another issue that deserves special attention is the ethnical issue hardly focused on by analysis produced by the National Program, particularly concerning black and indigenous peoples. The Program owes these populations deeper understanding about the interfaces between the categories of race and gender. It should establish actions aimed not only at surveying epidemiological trends, but, mainly, addressed to generate knowledge about the features, identities and ways how vulnerability to HIV/AIDS is produced and perceived in such ethnical groups. These actions are crucial for the improvement of the Brazilian response to the epidemic. The Program has limited cognitive resources to prepare

strategic actions in this field. It should map how several Brazilian ethnic groups experience the process of infection by HIV/AIDS, representations about the condition of carriers, models of adherence to antiretroviral therapies, factors that facilitate or impair their access to health services, how they live their individual rights, and others that allow for identifying the impact of seropositivity over their lives.

Furthermore, this agenda of challenges also comprises the identification of other social sectors that public policies hardly reach and, therefore, sectors deprived from any kind of protection against HIV/AIDS. These are sectors that became disguised by their conditions of life, and blind society refuses to perceive. Invisible due to their marginalized lives, their exclusion from the health system, education system, housing system, communication means or any other modality of legal or illicit social participation. They are a heap of men, women, children, youths and elders whose voices are not heard. These groups facing permanent structural vulnerability must come into light to break their disguise and silence through new methods of social inclusion.

Here, it is worth recalling the concept of “plagues synergy”, referred to by Paiva (2003), to agglutinate this set of negative factors that permeate social systems and allows for HIV/AIDS vulnerability. In the same sense, Parker & Camargo (2000), use the idea of “synergic effects of HIV/AIDS” to try to disclose the link among intensive poverty, social problems and different degrees of vulnerability to HIV/AIDS.

Despite successful actions by human rights advocates and non-governmental organizations working in the field of AIDS, Parker (2000) points out the Brazilian deficit in terms of incorporating citizenship values. It would be worth if, in all fields of actions, citizens face themselves as active and present subjects in shaping the destinies of Brazil. They should play more decisive roles in the social fight for individual and collective rights. They should deeply experience their citizenship. Pascual (2002) emphasizes that Brazil

insists on building a picture of incomppliance with human rights, and broad sectors of the population suffer from prejudice and social exclusion. Among them, HIV/AIDS carriers make up a group that experiences stigmatization and social discrimination. Therefore, it would be another aspect to be comprised by the agenda of challenges that Brazilian policy on AIDS urges to put into practice in the forthcoming years.

2.10 FINAL THOUGHTS

As Berlinguer (*apud* Dâmaso 1995) properly states, democratic participation necessarily implies in a “cultural reform.” In the view of those who analyze AIDS reality in Brazil, and as several major participants whose voices built up this book say, Brazilian policy is pursuing something like that. A new process of cultural organization, a set of knowledge and practices that gradually allow for endless inventions of new models of management, new agendas and renewed challenges, essentially based on participation at all spheres, simultaneously to the break of some models and the courage of some actions, make the National STD/AIDS Programme a peculiar institution.

Ultimately, the work of the National STD/AIDS Programme, or even the implementation of public policies on HIV/AIDS control, in its several stages, since epidemic outbreak until nowadays, should be understood in the light of sophisticated social, political, economic and cultural features that characterize Brazil as an essentially heterogeneous country, and this young institution as a *locus* where these differences operate.

3. TECHNICAL COOPERATION: UNESCO IN THE BRAZILIAN SCENARIO AND HIV/AIDS EPIDEMIC¹⁰

3.1 AIDS AND INTERNATIONAL TECHNICAL COOPERATION IN BRAZIL

The debate on international development comprises issues involving technical assistance and cooperation. Along the last fifty years, development has been broadly discussed, concerning the participation of international agencies in building this scenario that shifts, for example, from assistance headed by donors, to programs headed by beneficiaries; and from a focus on technology transfer and infrastructure development to emphasis on governance, when emphasizing active involvement of civil society and governments¹¹.

The construction of principles for new guidelines in technical cooperation dates back to the early 1990's. The World Bank and other multilateral donors have committed, in recent years, towards the rhetoric of "bottom to top" development and of "assisting peoples to assist themselves". Therefore, it is the idea of horizontal cooperation, where countries themselves identify bottlenecks in the implementation of their strategies to public policies. Here, the

¹⁰ Chapter prepared by Cristina Raposo – Education Officer and responsible for UNESCO AIDS Programme in Brazil, and Mariana Braga – Education Technical Assistant to UNESCO in Brazil

¹¹ Presentation UNESCO Brazil: International Technical Cooperation, UNESCO perspective. Brasilia, 2003.

beneficiaries enforce and control ongoing activities. Within this context, the exercise of social control – a role undertaken as of the 1990's by organized civil society in Brazil – is outstanding.

One of the major problems in finding suitable models of international technical cooperation in existing literature is that usually they bring forth doubts about its suitability, since sometimes they fail in taking different contexts of development into consideration. One should bear in mind that models used in developing countries sometimes do not fit developed countries, and vice-versa.

Brazil clearly fits into the category of self-benefiting, i.e., in some fields and sectors it has technology, know-how and technical capacity to meet domestic demands, besides providing horizontal cooperation to other countries. However, for specific areas, Brazil lacks technology or raw material for “leveraging” actions. Therefore, it sometimes requires the support of developed countries.

Over the years, the Brazilian government succeeded in establishing important partnerships with international organizations, aiming at implementing technical cooperation projects, both domestically and abroad. Therefore, it overcomes bureaucracy and brings into reality actions of social relevance, through projects deemed as global paradigms, as for Brazilian AIDS Programme and the Project on Electronic Vote. Over the last decade, this sort of conquest has relied on added value of the United Nations System Agencies, which contribute towards speeding up the re-ordering and modernization of the Brazilian state, in addition to the implementation of public policies.

3.2 PARTICIPATION OF UNITED NATIONS AGENCIES IN BRAZIL

For over 40 years, the United Nations Agencies and Brazil have been partners and have been outlining and implementing actions pursuant to national demands, and contributing towards the consolidation of a solidarity relationship both within Brazil and abroad. Along the years, and as a response to Brazilian demands, the

approach shifted from specific topics to integrated and multi-sectoral development, fact that allowed for some experiences to become models to other countries¹².

The construction of a new agenda on international cooperation, taking into consideration existing structures of developing countries, as well as the possibilities of assistance, technology transfer and technical cooperation from developed countries was also established and shaped along UN Theme conferences, as:

- World Conference on Children (New York, 1990);
- World Conference on Education for All (Jontiem, 1990);
- Sustainable Development (Rio, 1992);
- United Nations World Conference on Human Rights (Vienna, 1993);
- International Conference on Population and Development (Cairo, 1994);
- World Conference for Social Development (Copenhagen, 1995);
- United Nations World Conference on Women (Beijing, 1995);
- United Nations Conference on Human Settlements– Habitat II (Istanbul, 1996);
- World Conference on Food (Rome, 1996);
- United Nations Conference on Trade and Development (Midrand, 1996);

In September 2000, during the Millennium Summit, United Nations country members restated their commitment towards placing priority on eradicating poverty and contributing to sustainable development. Within this context, the following eight goals – *Millennium Development Goals* – were established as a representation of world community efforts towards measurable and significant improvement on peoples’ living conditions¹³. These goals have been serving as major guides to International Technical Cooperation in the 21st Century. (Chart 3.1).

¹² Source: United Nations ORGANIZATION. *United Nations in Brazil*. Available at: <www.onu-brasil.org.br> Accessed in: 10.oct.2004.

¹³ FNUAP. *Metas do milênio, oito jeitos de mudar o mundo*. Brasília: FNUAP, 2004. Available at: <<http://www.fnuap.org.br/metasp>> Accessed in: 10.oct.2004.

CHART 3.1 – Millennium Development Goals

Millennium Development Goals	
1st	Eradicate extreme poverty and hunger
2nd	Reach universal basic teaching
3rd	Promote gender equality and the empowerment of women
4th	Reduce child mortality
5th	Improve maternal health
6th	Fight HIV/AIDS, malaria and other diseases
7th	Guarantee environmental sustainability
8th	Establish world partnership to development

The legal framework comprised by plans of action approved in International Conferences was not easily translated into concrete improvements to developing countries. In opposition, the Conferences have generated important political commitments by United Nations country members, but have failed in granting bigger efforts in the operational plan of each country.

For instance, to reach the *Millennium Goals or Objectives* in HIV/AIDS, country members should deepen their legislative-normative processes, in addition to their processes on sustainable development, focusing on social and economic development of populations. Furthermore, they should take into consideration that:

1. The more educated a society is, the less vulnerable will its individuals be to HIV;
2. Poverty is part of the HIV infection cycle, and is a vulnerability factor;
3. Gender equality is a crucial factor for reaching the *Goals*;
4. Priority should be placed on the vulnerability of the female population, whether in maternal-infantile, whether in maternal morbi-mortality.

Regardless the field of the eight *Millennium Goals*, international cooperation is watchful to its role, by gathering information, strengthening expressive participants in the countries, and promoting acceleration in building policies for the welfare of citizens.

3.3 THE JOINT UNITED NATIONS PROGRAMME ON HIV/AIDS – UNAIDS

The Joint United Nations Programme on HIV/AIDS – UNAIDS – is the first and only joint Programme, co-sponsored by agencies belonging to the UN System.

When UNAIDS opened its office in Brazil, in 1996, it articulated actions with co-sponsoring agencies (UNICEF, UNFPA, UNDP, UNODC, UNESCO, WHO, ILO and the World Bank) towards enhancing the Brazilian response to the epidemic, involving several participants who work on the prevention of and care to HIV/Aids¹⁴. Since it started its activities in Brazil, the Programme has tried to adjust to the Brazilian reality by taking into consideration the synergy built through experiences and specific knowledge accrued by several sectors involved in the Brazilian response to HIV/AIDS.

UNAIDS works through Theme Groups (TG), a coordination mechanism that allows countries to better use the United Nations System in support to their National Programmes on HIV/AIDS. In addition to basic formation of the TG – incorporating its co-sponsoring agencies – UNAIDS works by articulating and including other organizations with offices in the countries, through information exchange, joint planning and monitoring of actions, in support to the national response to HIV/AIDS.

Taking the Brazilian specificities into consideration, UNAIDS TG in Brazil was expanded to incorporate governmental institutions, other international and bi-lateral agencies and civil society representatives, trying to gather different fields of knowledge to build effective responses that meet the dimensions of the challenges posed by the epidemic.

¹⁴ UNAIDS. *UNAIDS Integrated Plan*: final version. Brasilia: UNAIDS, 2002.

The Brazilian government, represented by the National STD/AIDS Programme, the Ministry of Health and the Ministry of Foreign Affairs, participates in the TG UNAIDS in an active and decisive way. It contributes towards building policies involving sub-systems on planning, monitoring and assessment during the process of outlining a national response to HIV/AIDS.

Organized civil society contributes by providing knowledge, experiences and proposals that significantly enhance the Group's work. Therefore, Brazilian partners and the international community effectively know the nature and path of national initiatives undertaken by this segment. Furthermore, civil society brings to the Group discussions about the needs of vulnerable populations, and contributes to lead the decision on actions to comprise different aspects of the epidemic in the Brazilian scenario. The organizations of individuals affected by the epidemic also participate in the process, by proposing and suggesting ideas. This is also a feature of civil society participation in the history of HIV/AIDS control in Brazil.

The Brazilian Entrepreneur Council for Prevention against HIV/AIDS is also represented in the Group. The Council gathers private entities committed to reverting the epidemic in Brazil, both in the workplace and in the respective regions of their economic action.

In their turn, the Agencies of the United Nations System contribute with their rich tradition in researches and pioneer projects for the improvement of peoples' living conditions. Several agencies contemplate young populations in differentiated ways, and focus on different dimensions of their needs within the framework of the Agency mandate.

In 1999, UNESCO was the organization elected to coordinate the TG UNAIDS in Brazil. In this sense, UNESCO contributed with UNAIDS mission in Brazil, developing advocacy, prevention and human rights measures aimed at the young population, communication professionals, members of the parliament and individuals living with HIV/AIDS, with the objective of:

- Preventing HIV transmission;
- Providing care and support to people affected by AIDS;

- Reducing vulnerability brought by HIV/AIDS to individuals and communities;
- Mitigating social-economic impact resulting from the epidemic.

In December 2000, the United Nations Office on Drugs and Crime – UNODC started heading the TG in Brazil, followed by the United Nations Population Fund in Brazil– UNFPA, which started heading the TG on January 2001.

Since Brazil is considered a strategic country, the TG has had a Country Programme Adviser – CPA since August 2000. According to the Integrated Plan of UNAIDS TG in Brazil¹⁵, one of the major duties assigned to the CPA is the development of advocacy, around a national commitment in HIV/AIDS, in addition to the provision of information and support to national partners, including the government and organized civil society.

3.4 WORLD COMMITMENT TOWARDS HIV/AIDS: UNGASS

Two years have passed since the historic United Nations General Assembly Special Session on HIV/AIDS – UNGASS, held from 25 to 27 June 2001, in New York. It brought together Chiefs of State, Representatives of States and Civil Society Organizations, in order to discuss the issues and serious repercussions of the pandemic, besides setting forth commitments and agreements to guarantee intensified efforts on global responses to HIV and AIDS.

UNGASS was a milestone in facing the epidemics worldwide, since it was the first time that the United Nations General Assembly met to discuss a health topic, one year after the Declaration of the Millennium Goals, which established the fight against HIV/AIDS epidemic and other diseases as one of its eight goals.

¹⁵ UNAIDS. *Integrated Plan of UNAIDS TG*. Brasilia: UNAIDS, 2002.

The Joint United Nations Programme on HIV/AIDS – UNAIDS and its co-sponsoring agencies have made great efforts towards converting the UNGASS Declaration of Commitment, signed by country members, into an effective tool of political change and strengthening of national responses (Declaration of Commitment on HIV/AIDS, United Nations. New York, June 2001).

Concerning the gigantic global contingent of youth affected by the epidemic¹⁶, UNGASS stated their commitment to face effects and challenges imposed by HIV/AIDS pandemic by adopting 103 measures recorded in a document that gathers the decisions made in that Assembly. However, although UNGASS Declaration of Commitment is clear and sets forth a broad Programme of Action, priorities established by the United Nations Secretary-General, Kofi Annan should be highlighted¹⁷:

1. To guarantee that all human beings in the world, mainly the youth, know what to do to avoid infection;
2. Put an end to what might be the most cruel ways for HIV transmission: the transmission from mother to child;
3. Provide treatment to any individual affected;
4. Duplicate efforts in the research for a vaccine and cure; and,
5. Provide care to any individual whose life was crushed by AIDS, particularly to over 13 million AIDS orphans.

The process of monitoring UNGASS Declaration of Commitment is one of the priorities to the UNAIDS Theme Group in Brazil. The TG and its members support Civil Society in the capacity of structuring and monitoring the implementation of UNGASS goals in Brazil. UNAIDS supported two meetings on this topic: a workshop in Recife – September 2003 – and a Meeting of the MERCOSUR Forum of NGOs/AIDS, in Brasilia in June 2003.

¹⁶ Seven thousand youngsters, of 10 to 24 years old, are infected with HIV per day worldwide. Five youngsters are affected each minute. Source: BRAZIL. MINISTRY OF HEALTH. *Jovens: aforça para a mudança*. Brasilia: Ministry of Health/National Programme on STD and AIDS, n.d.

¹⁷ UNITED NATIONS ORGANIZATION. *Declaration of Commitment on HIV/AIDS: global crises, global action*. UNITED NATIONS GENERAL ASSEMBLY SPECIAL SESSION ON HIV/AIDS, New York, 25-27 jun. 2001.

During the workshop in Recife, the Civil Society prepared the “Recife Charter.” It is an open chart based on discussions by the Brazilian Movement on the Fight against AIDS, held during the *UNGASS Forum – Monitoring UN Declaration of Commitment on HIV/AIDS*. During the meeting, particularly in said document, the Brazilian Movement on AIDS reaffirmed its role of sharing the commitment of following-up the goals set forth by the United Nations Special Assembly on HIV/AIDS with Brazilian government, and UN Agencies.

The “Recife Charter” was distributed during the United Nations Special Assembly on UNGASS Monitoring, in New York, September 2003. The Civil Society has also delivered it to the Minister of Health of the time – Humberto Costa – and to the President of the Republic – Luís Inácio Lula da Silva. The Permanent Brazilian Mission at the United Nations was in charge of forwarding this document jointly with Brazilian official documents to all governments in the world.

The document concludes by emphasizing the general consensus of the movement of fight against AIDS, in what Brazilian needs of monitoring should not be limited to the character of presence or absence of policies and programs towards the proposed goals; rather, it should address the capacity of governmental initiatives in promoting changes to the quality of life of individuals living with HIV/AIDS or most vulnerable groups or populations, since this sort of knowledge is crucial to assessing if established goals were successfully reached or not.

Recently, UNAIDS approved a specific project to be implemented by the United Nations Population Fund – UNFPA, to carry out a survey on UNGASS Declaration indicators, aiming at providing data to Civil Society to prepare a diagnosis on Brazilian situation in 2005.¹⁸

Taking into consideration that this chapter is inserted into the perspective of discussing UNESCO international technical cooperation in AIDS epidemic in Brazil, attention will be placed on the Brazilian AIDS Programme and its contribution towards its implementation by the UN Agencies. Nevertheless, the discussion here will not be an exhaustive one.

¹⁸ UNAIDS. *The Next Agenda*. Brasilia: UNAIDS Theme Group in Brazil, 2004.

3.5 INTERNATIONAL COOPERATION WITHIN THE SCOPE OF THE BRAZILIAN AIDS PROGRAMME

Among several partnerships supported by different international agencies, the National STD/AIDS Programme of the Brazilian Ministry of Health is outstanding, not only for its agility in the capacity of response to the epidemic, but mainly for the mobilization and effective participation of civil society. In a country of continental dimensions, as Brazil, civil society has granted continuity to actions over the two decades of the epidemic. Brazil not only followed the epidemic international scenario since the first case recorded in the country, but also played a pioneer role in outlining a government response.

According to Galvão (2000:29-30), published by ABIA, there are four stages of “political responses” to the epidemic in Brazil:

- 1982 to 1985: period of openness, election of progressist powers. Notification of first cases of AIDS; establishment of São Paulo State Programme on AIDS; foundation of first NGOs working on HIV/AIDS: omission of governmental authorities, wave of panic and prejudice.
- 1986 to 1990: José Sarney government and gradual re-democratization of the Brazilian society. Creation of a response at federal level; changes on AIDS national coordination; pragmatic approach to the epidemic; increased international cooperation; greater number of NGOs working on HIV/AIDS; mobilization of individuals with HIV/AIDS.
- 1990 to 1992: Collor government. Initial feeling of optimism due to election for the presidency of the Republic; expectations of changes to policies related to AIDS; suspension of key-elements of the National STD/ AIDS Programme, during Collor government; increasing antagonism between the National STD/AIDS Programme and other sectors involved in formulating responses to the epidemic; suspension of major international relations of the National Programme as, for instance, the WHO Global Programme on AIDS.

- 1992 to 1997: Collor impeachment. New government takes office; greater spirit of collaboration, mainly during the early years, due to the disastrous experience of previous administration of the National AIDS Programme (under the leadership Alceni Guerra, Minister of Health of the time); civil society willingness towards working jointly with the State.

Therefore, Brazilian responses to AIDS are initially encouraged by the synergy of historic facts that, jointly with political openness after dictatorship, allowed for several organized movements to have control power in the field of health. Therefore, SUS principles could become concrete in the Brazilian Constitution of 1988.

In 1983, specific groups of civil society, gay and sex professional movements started demanding to a response to the epidemic from the Public Power. In a pioneer way, public policies were shaped with permanent interlocution between both spheres of participation: civil society and government. And this is the context wherein the National AIDS Programme comes to existence, in 1986, at the same time when international responses start to be articulated (GALVÃO, 2000). At that time, the first NGO devoted to AIDS in Brazil is created, namely the *Grupo de Apoio à Prevenção à AIDS – GAPA* in São Paulo. Also in São Paulo, in that same year, the *Casa de Apoio Brenda Lee* was the first non-governmental organization to shelter people with HIV/AIDS. This fast chronology discloses how civil society responded simultaneously to Brazilian government, through institutional organization, to fulfill the needs and challenges imposed by the epidemics to the country. Moreover, it disclosed the existing gap in meeting demands for prevention and assistance.

Therefore, the premises of prevention, assistance, human rights and civil society provides unique feature of the “Brazilian model” to the epidemic. Furthermore, the principles of the Brazilian Unified Health System (SUS), grant decentralization, hierarchy, integrality and universality of health actions in Brazil, at all levels. However, it is a slow process of victories to incorporate such principles that, therefore, are not mechanically complied by governments and social spheres that define public health field in Brazil.

Another odd victory of civil society mobilization besides government was the practical application of SUS in the so-called Law Sarney. This law sets forth, as early as in 1996, universal and free distribution of Antiretroviral Drugs through SUS¹⁹. SUS principles have guided national policies on fight against the epidemic, where prevention and assistance are basically understood as complementary one to another, and inseparable.

Thus, the establishment of a specific Programme to deal with a little known disease that, nevertheless, was stigmatized since its first appearance, resulted from the matching of democratic government and increasingly mobilization of civil society sectors. In this way, homosexual groups are of great importance as they worked as key-players in the advocacy for rights to health and reduction in discrimination, calling public sector attention to a new challenge posed to the health field.

Since it dealt with challenge to and investment in health, the World Bank agenda perfectly fitted the Brazilian need for pursuing an alternative to keep the epidemic from spreading.

Within this context, the Project on Control of AIDS and STD – AIDS I, was signed in 1994, in an initial effort to control and manage the epidemic, and involved a World Bank loan. AIDS I provided technical assistance to the development of institutional capacity, identification of priority populations, besides developing activities to expand prevention, assistance to epidemiological surveillance of STD/AIDS, in the framework of health laws existing in the country (PRODOC UNESCO – AIDS II, 1998:10).

Project AIDS I defined, tried and implemented the major strategies to face the epidemic, establishing a network of assays and voluntary counseling, providing clinical services to STD and HIV/AIDS patients, besides community-based support programs. “High risk groups”, as they used to be called at the time, were priority focuses of

¹⁹ PRODOC 914BRA1101 – Project of Support to the reduction of HIV/AIDS and other STD Incidence and Improvement of the quality of life of People with HIV/AIDS Project AIDS III, 2003: 07.

behavioral interventions. It should be highlighted that this designation had great impact on populations who are now referred to as “vulnerable groups”. This change is once again a result of the strong appeal of civil society against the stigma and discrimination against homosexuals, sex professionals, travesties and other populations that suffered for being characterized as “risk groups”.

The Ministry of Health set partnership with the UNDP to execute US\$ 60 million, granted by an agreement between the Government of Brazil and the World Bank²⁰. According to the UNDP, it was an innovative and effective project of support to the development of the Programme’s technical and scientific basis; in strengthening health systems at regional and local levels concerning its human and material resources; in developing laboratories and epidemiological surveillance systems; in expanding the coverage of programs on prevention, assistance, support and treatment; in establishing partnerships with non-governmental, governmental and international organizations, and human rights advocacy networks.²¹

Yet in the light of International Cooperation, the Ministry of Health worked in partnership with the United Nations Office on Drugs and Crime – UNODC – previously named UNDCP – in executing Project AIDS I. This partnership, established by implementing the *Project on Prevention against Drug Abuse with Special Emphasis on Prevention against Infection from HIV among Users of Endovenous Drugs*, aimed at fomenting actions on prevention, which could become institutional, trying to enhance partnerships with state and municipal coordination units on STD/AIDS, Universities and Civil Society Organizations.

The actions executed by the federal government in partnership with state and municipal governments, supported by organized civil society and international cooperation agencies (which executed part of proceedings of Project AIDS I Loan Agreement), were responsible for

²⁰ Total amount for Project AIDS I is 250 million dollars.

²¹ Source: PRODOC – Project Document – PNUD BRA/98/006 – Health Promotion, 1998:7

the increased population awareness on AIDS, besides developing a sense of co-liability. Every year, more and more people adhered to this new behavior, and this led to a remarkable improvement on HIV/AIDS indicators in Brazil²².

Therefore, UNESCO has worked in tune with the ideal of Koichiro Matsuura, UNESCO General Director, according to whom the major cause of this dramatic spread of HIV and AIDS is the lack of knowledge. Since treatment does not provide integral cure, and the treatment that may lead to improvement is very expensive for most populations worldwide, prevention through education, followed by action, is still the best remedy, he adds. According to him, preventive education should be part of the objective of education for all, and if preventive education is not in fact implemented now, the world will be marked for the rest of this new century.

The possibility of establishing partnerships between the Brazilian AIDS Programme and the Civil Society allowed for significant expansion of prevention services provided by the Programme as of 1998. States and municipalities have also expanded their capacity of response, financed by the Ministry of Health. They have facilitated access to condoms (male and female), doubled the number of assays and counseling centers, thus increasing the number of HIV assays performed. Therefore, they became an institutional milestone in the control of HIV/AIDS and STD in Brazil.

Jorge Werthein, UNESCO Representative in Brazil, highlights the presence of the Brazilian Programme in the international scenario, as follows²³:

It is within this framework of concerns that the Brazilian experience in fighting AIDS becomes internationally acknowledged. Articulating governmental structures, civil society and international agencies, the Brazilian response to AIDS is concretely proving the feasibility of finding creative and efficient ways. Universal and free access

²² BRAZIL. Ministry of Health. Brazilian AIDS Programme. *AIDS: The Brazilian experience*. Brasilia: Ministry of Health/National STD/AIDS Programme, 2003.

²³ Free translation of the article *Resposta a AIDS*, published in 2001, on the following newspapers Folha de São Paulo, Diário de Pernambuco and Jornal do Brasil.

to drugs, for example, has contributed to stabilizing the curve of mortality from AIDS in Brazil. Furthermore, it is an evidence of social responsibility, since it drastically reduces costs that the State should incur to treat patients. Complementarily, preventive policy mobilizes countless entities countrywide, generating a feeling of co-responsibility, crucial to the Programme success. Challenges are many, but grounds are settled. The flexibility of the Brazilian policy on AIDS, its concern in including organized civil society in the definition of paths and the social mobilization that these entities have promoted granted Brazil the status of interlocutor for developing countries in the international arena.

In 1998, when the Second Loan Agreement of the World Bank to the Brazilian Government – the so-called Project AIDS II²⁴ – was signed, UNESCO started participating by providing technical cooperation to manage resources amounting to 102 million dollars. The Resources were allotted to convert strategies into concrete actions, which would assist in expanding preventive response, also by strengthening the relationship with civil society. These were significant steps towards advancing a new perspective of international technical cooperation.

Over the last four year, during Project AIDS II implementation, the National Programme was focused on expanding both prevention and treatment. States and municipalities have executed about 45% of Project AIDS II. The Ministry of Health transferred resources to them, according to their structures and data on epidemic spread in their localities. Therefore, resource management was decentralized, although financing remained under the responsibility of the Ministry of Health, besides being bound to the approval of an Annual Operational Plan. This Plan, after being approved by the STD and AIDS National Coordination of the Ministry of Health, should be consolidated and submitted to the World Bank analysis.

During Project AIDS II, broader steps were taken to decentralize financing, and culminated in the definition of a legal framework to start mechanisms of Fund-to-Fund transfer (National Health Fund to the State and Municipal Health Funds) to activities on STD/AIDS.

²⁴ Project AIDS II amounted to 300 million dollars, where 165 million were granted by the World Bank and 135 million as Brazilian government counterpart. It was executed from 1998 to 2002.

The Policy on Incentive to States and Municipalities in the field of STD and AIDS, with transfers amounting to US\$ 100 million a year, through automatic Fund-to-Fund transfer, aims at enhancing SUS actions in fighting AIDS epidemic all over the country.

Upon the establishment of this new policy and the Ministry of Health's resources decentralization strategy, the 27 State Health Secretariats and 412 municipalities started to receive resources for AIDS and other sexually transmitted diseases directly from the federal government. Before that, states and 155 local municipal governments used to receive the transfer directly through agreements and projects. The municipalities that received federal government Fund-to-Fund transfers were selected according to epidemiological criteria that mainly take into consideration the number of AIDS cases and the speed of epidemic spread.

Resources are used to develop actions in the fields of:

- Promotion, Prevention and Institutional Development;
- Qualification of Health Care to Individuals Living with HIV, AIDS and STD;
- Actions in Partnership with Non-Governmental Organizations.

The new incentive policy represents important advances to the AIDS Programme's structure in Brazil, since²⁵:

1. It expands Programme coverage and responds to the growing epidemic interiorization;
2. It systematizes and rules the transfer of resources of the Brazilian Unified Health System. Resources are monthly and automatically transferred to eligible states and municipalities;
3. It assists in project management, since states and municipalities are expected to submit a Plan of Actions and Goals (PAM, in Portuguese), valid for one year, as a prerequisite to receive resources;

²⁵ BRAZIL. Ministry of Health. National STD/AIDS Programme. *Technical Note*. Brasilia: Ministry of Health/National STD/AIDS Programme, jan. 2003.

4. It expands social control over resources used by the Programme. The Plan of Actions and Goals should be prepared in partnership with the civil society, submitted to Municipal and State Councils and to the Bi-partite Inter-managerial Commission;
5. Resources application should be monitored by Auditing Courts and state and municipalities instances of control;
6. It rules and systematizes financing of activities developed by the civil society, since 10% of total resources transferred to states and municipalities are earmarked to NGOs;
7. States and Municipalities should forecast their policies to purchase medication to treat opportunistic infections and purchase condoms.

Furthermore, AIDS II implementation improved tools for decentralized management. Although resources for financing civil society actions should be committed in PAM Programming, the decentralization of procurement processes and selection of NGOs subprojects to states, as well as the supervision over financed activities have not been effectively fast in their implementation mechanisms. Nevertheless, the decentralization of National Programme activities comes to provide, in mid-term, greater effectiveness and efficacy to an increasingly sustainable national response.

The Cooperation Agreement Document signed between the Brazilian Ministry of Health and UNESCO, aimed at the financial execution of part of proceedings for the Third World Bank Loan Agreement²⁶ – Project AIDS III, was signed in March 2004, in the amount of twenty-four million five hundred thousand dollars. It aims at enhancing the national response capacity by promoting equity, sustainability and universality. Still relying on concrete participation of UNESCO in its execution, Project AIDS III is expected to

²⁶ Project AIDS III amounts to 200 million dollars, where 100 million were granted by the World Bank, and 100 million as Brazilian government counterpart contribution.

maximize effectiveness in the Brazilian response to HIV/AIDS. In this sense, it places priority on expanding coverage and quality of interventions; decentralization of financing and Programme activities management to states and municipalities; enhancement of Program administration, with focus on monitoring and assessment of actions; introduction of technological innovations; and, finally, reduction of STD/HIV transmission incidence, thus contributing towards improving quality of the lives of individuals living with HIV/AIDS, thus reducing discrimination and stigma associated to HIV/AIDS.²⁷

3.6 UNESCO CONTRIBUTION TO BRAZILIAN RESPONSE TO HIV/AIDS

As previously stated, the United Nations response to HIV/AIDS epidemic, by providing technical cooperation to the development of strategies and actions, have been acknowledged and broadly supported by governments worldwide.

In 1986, the Fortieth Session of the International Conference on Education submitted the *Plan of Action in Education to Prevention and Control of AIDS*, as part of the Global Strategy to the Prevention and Control of AIDS. In response, UNESCO organized a program on education, jointly with the World Health Organization (WHO): the Global Programme on AIDS. The program activities lasted until 2000, and included international seminars, development of materials focused on school and teacher development, among other actions.

During the 24th Session of UNESCO General Conference, held in Paris, November 1987, country members discussed the importance of UNESCO developing activities specially focused on HIV epidemic in its Programme. The program encouraged countries inclusively to

²⁷ PRODOC 914BRA1101 – Project of Support to the reduction of HIV/AIDS and other STD Incidence and improvement of the quality of life of people with HIV/AIDS. Project AIDS III. Brasilia, 2003.

actively participate in youth-oriented educational programs and preventive activities. As of then, UNESCO strengthened the role it plays in Preventive Education, showing its partners the urgent and global need for concentrating efforts within the context of education on HIV/AIDS.

Therefore, since UNESCO is the United Nations specialized Agency for Education, Science and Culture, it works in these fields aiming at granting and improving the society's quality of life concerning those topics, crucial to the welfare of a nation. The document on the 30th UNESCO General Conference reinforces that the contribution of this Agency to science in service of development, besides allowing for a multi-disciplinary analysis on ethical consequences of changes that affect societies, comprises cooperation aspects in the scope of capacity-building, research and integration of several subjects of scientific and technical knowledge. In this sense, the AIDS topic perfectly fits into its mandate, since epidemic issues permeate all those fields.

All over the world, UNESCO has played a core role in initiatives of fight against AIDS. In Brazil, jointly with the Ministry of Health, it assisted in placing the country as world reference in the struggle against HIV/AIDS, as this was the executing Agency for most proceedings of World Bank Loan Agreements, which led Brazil to a level of successful experience in facing the epidemic.

UNESCO is outstanding in promoting education and valuation of social-cultural heritage of populations, as factors that favor the sustainable development of nations. The work developed jointly with the Ministry of Health, i.e., the Brazilian STD/AIDS Programme and other state and municipal programs on that subject, bring optimistic perspectives to the fight against this serious public health issue among our population.

UNESCO strategy in the field of preventive education to HIV/AIDS is focused on the following axes:

- Encourage behavioral changes through education, focused on youth;

- Empower youth, adults, education and health workers, non-governmental organizations and social communication professionals, to deal with challenges posed by the epidemic, thus reducing its negative impacts on individuals, institutions and societies;
- Eliminate discrimination and stigma experienced by those who directly or indirectly live with HIV/AIDS, through dissemination of legislative practices and public policies of excellence;
- Advocate the preventive message among major opinion-builders (members of the parliament, journalists, youth, entrepreneurs, etc.);
- Contribute with other countries in the replication of successful Brazilian practices in fighting and putting a halt to the epidemic in other national and regional contexts.

Concerning its work as partner to the National STD and AIDS Programme and the Brazilian Ministry of Health, it is worth mentioning that UNESCO follows two paths to characterize its role as a United Nations Agency: a path of proposing actions and strategies, and another path of implementing them. In the field of proposing actions, UNESCO is outstanding as a laboratory of ideas, since it discusses the implementation of actions and proposes innovations with partners such as the *Development of Systems and Circulation of Knowledge*²⁸. As implementing agency for actions, UNESCO/Brazil strongly believes in its operational role in developing the managerial capacity of its partners, by promoting technical analysis and preparatory surveys for new projects, inclusively mobilizing other national and international partners. All these technical cooperation measures are carried out through processes of political dialogue and dissemination of Brazilian experiences.

²⁸ STERN, E. UNESCO's Mid term Evaluation Report. London, Tavistock Institute, 2003.

Three contributions by UNESCO to the development of a strategy aimed at reaching the intended results with the AIDS Programme of the Ministry of Health are outstanding:

- (1) Enhance the capacity of response, concerning financial execution of resources allotted to face the epidemic;
- (2) Contribute towards managing changes brought about by reforms and adjustments in Brazilian Programme strategies;
- (3) Disseminate the experience of Brazilian AIDS Programme to other UNESCO offices and country members.

CHART 3.2 – Leading parameters for UNESCO technical cooperation in Brazil

Core Areas	Conceptual Basis	Exemplar Activities
Systems Development	Dissemination and innovation, and innovation management	Encourage processes-content innovation Increase the capacity of understanding Establish multipliers Adjust innovation to new contexts
Knowledge Circulation	Organizational learning, organizational memory and knowledge management	Access relevant information Systematize experiences and lessons learned Publication and dissemination
Institutional Enhancement	Organizational design and development	Structuring programs Enhancement of organizations and institutions Building alliances and partnerships
Mobilization and Participation	Social development and participative theory	Involvement of civil society groups Advocacy for a basis of values Develop and articulate networks

Source: STERN, E. 2003

In order to intensify its works with society, UNESCO values and supports projects based on measures with social, cultural and/or educational impact, whether by sectors bound to government, or initiatives by civil society organizations. Therefore, UNESCO promotes institutional enhancement to the third sector, while pursuing improvements to the quality of response to populations, and promote ethical and participative management towards transparency and efficiency of actions involving public resources.

The relationship between social movement and the Brazilian government in the field of AIDS allowed establishing several networks to face the epidemic. According to Cardoso (2002:12), multiple and flexible partnerships between public and private players in such different fields as education, health, alternatives for occupation and income, advocacy and environment, express the intensification, in Brazil, of a civic-democratic culture, which values dialogue and co-responsibility between leaders and citizens.

The Brazilian Ministry of Health's National STD and AIDS Programme is a successful example of partnership with several participants. When dealing with networks to the struggle, it is worth having a new player that participates in this communication channel in mind – the International agencies. In this sense, UNESCO has played an important role with the Brazilian government.

Political scientists, decision-makers, educators and activists have pointed out an important contribution provided by UNESCO in the field of preventive education: The possibility of cooperation with NGOs, in addition to a network of institutions working in the field of prevention, treatment and assistance to individuals living with HIV/AIDS. As of UNESCO/Brazilian AIDS Programme partnership, about three thousand contracts have been signed with civil society institutions working directly in the implementation of actions and activities focused on vulnerable populations.

Both the Brazilian Constitution and recent governmental plans have placed emphasis on the participation and involvement of civil society in the implementation of actions on public policies. Civil society is strongly aimed at values other than mere inclusion, like human rights and ethical standards in relation to social assistance and public administration, in general. In the field of health, new public services to vulnerable or marginalized populations were established, as part of an inclusive concept of society that pursues solidarity among different social groups, ethnical communities and regions. Health programs seem to find a delicate balance between, on one hand, professional standards and, on the other hand,

encouragement to active participation of communities and local groups. Many ideas of mobilization and participation are soundly grounded in the scope of development theory. Particularly the literature on social development, participatory education – according to Paulo Freire – and empowerment is broadly disseminated in Brazil, and has sustained UNESCO ideas and practices in technical cooperation.

Under the perspective of cooperating to institutional enhancement of the AIDS movement in Brazil, and in addition to contributing with government in its national response, UNESCO currently has over 2000 *Contracts on Activities Financing*²⁹ with civil society. Altogether, these contracts amount to over 43 million dollars addressed at the expansion of the Brazilian response, in joint actions with social movement. It also represents actions in the field of research, assistance to HIV/AIDS carriers and, above all, strategies of youth-oriented preventive education. Therefore, UNESCO has worked pursuant to the ideas of Jonathan Mann³⁰: Advocating that NGOs are key-players, since they are rooted in community and directly related to vulnerable populations, because they know better the needs of their clients, who used to be their peers.

²⁹ UNESCO designation for the kind of contract established with civil society organizations.

³⁰ MANN, J.; TARANTONA, D. *AIDS in the World II*. New York: s. n., 1996. p. 344.
“One of the major strengths of the NGOs in responding the HIV/AIDS epidemics is its roots in the community. The responses are based on the needs and priorities assessed according to the community’s wills. Therefore, it causes greater impact between the action by local organizations and the epidemic development in the community. Moreover, it may assist in guaranteeing the “property”, unity and sustainability to the efforts made by the community. Sensitive and suitable approaches have proved to be efficient, besides being replicated. Since it executes effective and positive assistance programs, for example, the NGOs plays an important role in facing local barriers to the fight against the AIDS epidemic (typically based on fear, ignorance or stigma), while the Civil Society organizations succeed in promoting preventive strategies ”.

The prevention programs, where major players are NGOs/AIDS clients, include some of the most cost-effective prevention interventions in literature, notably peer education programs to Sex Professionals (SP), Men that have sex with men (MSM) and Users of Injected Drugs (UID), STD control, voluntary tests and counseling, promotion of male and female condoms, improvement on security of blood supply and prevention against vertical transmission. In this light, Project AIDS III PRODOC, signed between UNESCO and the Ministry of Health, tries to ensure that these actions be implemented in a broader scale, with the intent of promoting a significant impact, thus guaranteeing expansion of the program coverage, promoting universality.³¹

CHART 3.3 – Prevention programs

APTA – Associação para Prevenção e Tratamento da AIDS e Saúde Preventiva ³² *It is an organization that develops awareness-building programs on the risk of infection from HIV and other sexually transmitted diseases and abusive use of drugs, taking into consideration social, economic and political contexts of target population groups. APTA develops two major projects.*

EDUCAIDS: *is the reference meeting in Brazil for programs focused on prevention and preventive education. These debate forums try to use, to the maximum extent, the potential provided by schools and universities, as privileged sites for developing measures on preventive education. These actions are intended to contribute towards developing skills for life and changing behaviors to avoid HIV infection, unwanted pregnancies and others.*

PIPA Project: *it is the only project in Brazil on reduction of vulnerability levels: STD/AIDS and unwanted pregnancy among adolescents and young adults with special needs in the city of São Paulo. It is a pilot project to the target-population aged between 18 and 30. The results shall be expanded to other regions in Brazil.*

³¹ PRODOC 914BRA1101 – Project of Support to the reduction of HIV/AIDS and other STD Incidence and improvement of the quality of life of people with HIV/AIDS. Project AIDS III, 2003: 07

³² Association for Prevention and Treatment of AIDS and Preventive Health

UNESCO's relevant contributions to cooperation with the Brazilian government in the field of HIV/AIDS are worthy of highlight.

1. Horizontal Technical Cooperation: an important element within the Brazilian government strategy relies on international cooperation with developing countries, within the scope of the HIV/AIDS epidemic. In Portuguese-speaking African Countries, UNESCO works jointly with other partners, to carry out projects in the following topics:

- Formulation of laws on HIV/AIDS;
- Training to professionals for diagnosis;
- Selection, elaboration and adaptation of materials on Information, Education and Communication – IEC;
- Implementation of treatment with antiretroviral drugs;
- Training on clinical management to doctors and nurses;
- Internships programs to health professionals;
- Establishment of youth networks;
- Institutionalization and strengthening of civil society.

In joint projects, the UNESCO Office in Brazil and the Brazilian AIDS Program disseminate Brazilian experiences on horizontal technical cooperation, mainly with countries of Portuguese Africa and Sub-Sahara Africa, where the epidemic is undertaking catastrophic proportions.

Considering the success of the Brazilian AIDS Programme, the data of which point to a situation of epidemic control, the scope of UNESCO work, allied to the availability of African countries in technical cooperation, in 2003 the UNESCO Office in Brazil was appointed by the organization Headquarters in Paris to be focal point to topics in preventive education to HIV/AIDS, disseminating Brazilian experiences to Portuguese-speaking countries.

CHART 3.4 – Sharing experiences on prevention

UNESCO offices in Mozambique and Brazil receive resources from the UN Foundation for development and execution of the SHARING BEST PRACTICES IN HIV PREVENTION AND REPRODUCTIVE HEALTH FOR YOUTH Project. The project is expected to last three years, and aims at strengthening civil society organizations that render services to youth in Mozambique, in issues related to Reproductive Health and AIDS, using youth leaderships to implement actions. Furthermore, the proposal would be to bring the experience of Brazilian NGOs with successful actions in the field of HIV/AIDS prevention to provinces in Mozambique, in order to adjust them to the reality of the youth and institutions to be served in that country. Within the scope of the exchange of experiences between both countries, and this project with resources for UNFIP, UNESCO was also granted resources from the United States Agency for International Development – USAID to execute the project on Exchange between Brazilian and Mozambican Youth for Peer Education on AIDS Prevention. Activities implementation lasted one year, and aimed at promoting the exchange between Brazilian and Mozambique youth, focusing on preventive education in the field of AIDS, through the use of art-education and elements of Afro-Brazilian culture as tools for enhancing juvenile networks on prevention against HIV/AIDS. A result of this exchange program is the consolidation of a Mozambique network of young educators, monitored by UNESCO/Maputo. Currently, a young Mozambican is in Salvador/Bahia, implementing preventive actions jointly with a NGOs participating in the exchange, still in the proposal of expanding knowledge about NGOs/AIDS working mechanisms. Then, when the youngster returns to Mozambique, he/she will be able to multiply his knowledge and effectively contribute towards enhancing civil society response to HIV/AIDS in that country.

2. Dissemination of Preventive Message: One of the major contributions of UNESCO to the Brazilian AIDS Program was, undoubtedly, enhancing education component in the field of AIDS.

The official document on the World Forum on Education, held in Dakar, Senegal, from 26 to 28 April 2000, intends to reach objectives and goals of Education for All. In this sense, it reaffirms that education is a basic right and the key for the sustainable development of a nation. Since AIDS is a threat to development, preventive education is inserted into this perspective as a priority. According to Dakar Mark, “the programs to control and reduce virus diffusion shall use the potential of education to forward messages on prevention and to change attitudes and behaviors to the maximum extent”.³³

Researches and assessments have evidenced the relevant aspect of including this behavior into the Brazilian response. Under this light, UNESCO Research Sector is subsidizing Brazilian government with researches on implementation of preventive actions in elementary, middle high and high schools in Brazil. For example, in the research coordinated by Rua and Abramovay (2001), 24206 questionnaires were applied to students, parents and teachers in 340 teaching institutions of fourteen Brazilian states in 2001. Results pointed out that 70.28% of schools had developed some sort of action on the prevention against STD/AIDS and drugs. Data also reveal that the intensity of exposure to such activities produce significant impacts in the sphere of behaviors and attitudes, mainly among sexually active students (from 31% to 50 % of students, depending on the city). Therefore, the required participation of schools as a tool to facilitate educational prevention measures is evident.

³³ UNESCO. *Educação para todos: o compromisso de Dakar*. Brasília: UNESCO, CONSED, 2001. p. 17.

CHART 3.5 – Prêmio Escola³⁴

Established by UNESCO Brazil and by the United Nations Office on Drugs and Crime, the Prêmio Escola of INCENTIVE TO PREVENTION TO STD/AIDS AND USE OF DRUGS AT SCHOOLS is an initiative supported by the National STD and AIDS Programme, and the Joint United Nations Programme on HIV/AIDS – UNAIDS /Brazil. The Award intends to mobilize students and education professionals to implement actions on preventive education. Expected results should be innovative, creative, of good content quality and potential of social mobilization, in a biennial initiative. Up to now, Brazilian public and private schools, at elementary, middle high and high school levels, have submitted about 2000 projects to run for the award. UNESCO and UNODC deem schools as privileged spaces for the development of preventive measures related to drug use and Sexually Transmitted Diseases, since youth are particularly sensitive to learning safer practices for their health.

Currently, the national response involves a large and diversified number of partners, placing priority on meeting the demands of the youth population, women and school. A relevant indicator for public policies in preventive education is the newly established *Policy on Preventive Education*, which results from the implementation of the Program Health and Prevention at Schools on. It is the first partnership between the Ministries of Health and Education in Brazil, within the scope of the HIV/AIDS epidemic.

³⁴ School Award.

CHART 3.6 – Programme on health and prevention at schools

The first Brazilian strategic policy aimed at the preventive education field, with joint participation of the Ministries of Education and Health. The major goal of the Programme on Health and Prevention at Schools is to reduce adolescents' vulnerability to sexually transmitted diseases, infection from HIV and early pregnancy. For that, they expand their access to condoms, and work on the concept of prevention within a context of education and health promotion. One of the major strategies is to provide male condoms to students enrolled in elementary, middle and high school, part of public schools network in Brazil.

The Ministry of Health provides support to teachers' qualification, while the Ministry of Education and UNESCO/Brazil are in charge of defining strategies to continuous qualification for teachers, besides reference educative and teaching aid material to professionals. Training and capacity-building should take place all over the process.

UNESCO should also be in charge for carrying out the monitoring and assessment processes, fully supported by the Ministry of Education and the National STD and AIDS Programme.

CHART 3.7 – Strengthening youth response to the epidemics

The participation of seven youths from different Brazilian regions as members to UNAIDS Theme Group was consolidated in a publication by UNESCO and AIDS, AIDS: o que pensam os jovens.

Along two years, these youths attended meetings, congresses and seminars about the most urgent discussions concerning the epidemic, discussing topics that AIDS brings to youth. Based on a participative work, coordinated by UNESCO, youths' ideas were gathered in recommendations that suggest important actions to develop policies oriented to reduce the epidemic impact over young population. These recommendations may be used by teachers, principals, municipal and state secretaries of Education and Health, Ministers of State, communication means and private initiative.

CHART 3.8 – Nucleus of Studies and Multi-lateral Cooperation Actions in Education and Health – NEAMCES

Pursuing the enhancement of education in health at the University of Brasilia, and intending to expand programs in this field, the NEAMCES – with Office in the University of Brasilia – gathers professors and students, actions and aliens (Cape Verde, Guinea Bissau, Senegal, Angola, Mozambique and Peru), aiming at developing projects in researches and/or actions, in the light of multi-lateral cooperation and exchange of experiences in the field of education and health. Its main goal is to become institutional / academic reference to provide subsidies to and allow policies and programs on cooperation and international exchange, in the field of education and health. It places emphasis on the issue of “HIV/ AIDS epidemic”, taking into consideration its complexity and transversality. The Nucleus receives technical, financial and institutional support from UNESCO, the National STD and AIDS Programme, and the UNAIDS.

3. Institutional Strengthening / Management: Another important contribution by UNESCO in the field of International Technical cooperation is its capacity of establishing new management processes to programs. Here, it almost always takes into consideration the need for strengthening institutional frameworks and other organizational ways of implementation. Typically, the team in charge of managing a program gathers new expertise, besides the existing expertise in brazilian government and other spheres – universities, private sector, independent consultants and other experts. Technical cooperation also involves works with State Secretariats, municipal authorities, universities, research institutions, hospitals and many other organizations. Conceptual and theoretical areas relevant to technical cooperation, in general, are part of the institutional strengthening, as well as of financial-administrative management of technical cooperation agreements.

CHART 3.9 –The *Abrindo Espaços* Programme³⁵

*Since 2000, UNESCO develops the *Abrindo Espaços* Programme, a comprehensive proposal to open schools during weekends with sports, culture and leisure activities. The Brazilian government recently took it as a public policy to be disseminated all over the country. Besides pursuing solutions to several problems faced by Brazilian students, such as violence and lack of interest in the school environment, it intends to ensure youth the right to culture, arts, leisure and sports. Furthermore, the program established a crucial space to promote dialogue among students. Therefore, it allows for the insertion of far-reaching preventive actions to great number of youths, besides discussing the broad range of topics related to sexual education, violence, tolerance, gender and others, with active participation of students and the school community. UNESCO carried out surveys about the program that point out high level of interest by the students in discussing such topics.*

3.7 CONCLUSION

In Brazil, the history of AIDS epidemic is marked by intensive interaction between government and civil society, in formulating or implementing responses to this disease, with strong impact over social development in the country. Yet in 1987, Jonathan Mann used to call AIDS social consequences as the third epidemic³⁶. However, only in 1999 did the United Nations Security Council acknowledge that AIDS is a threat to peace among peoples, since it generates a vicious circle of disease, impoverishment, violence and, eventually, war. AIDS, and those who live with it, are still stigmatized and disrespected in their human rights; low-income and inland

³⁵ Opening Spaces

³⁶ Source: MANN, J.; TARANTONA, D. Op. cit. p. 344

populations have difficulties in accessing public services; lack of information still victimizes people; schools demand for support to structure their programs on preventive education; communication means are still shy in their support to the AIDS cause; an civil society needs support to seek for sustainability to their actions. This is the third epidemic mentioned by Mann, with social and economic consequences that place the countries' sustainable development in danger.

In Brazil, consequences are not very visible, since the indicators for this epidemic are stable in some regions. Undoubtedly, the country still needs to face barriers of resistance, prejudice and stigma that remain subduing HIV carriers and AIDS afflicted populations. However, this picture is less terrifying than the picture for African countries where, for example, HIV incidence ratio reaches an incredible 35% of population. In short-term, it represents the possibility of no-construction (or self-destruction) of a healthy society, capable of responding to their challenges.

The sustainable development of countries is directly affected by the stigma and prejudice, resulting from the combination of lack of information, fear and shame, imposed by AIDS. In a scenario where this is a permanent picture, epidemics lead to marginality, thus hindering prevention, assistance and the exercise of human rights of those living with HIV/AIDS.

It is on the stage of seeking for citizenship that rights to health and education become a crucial component to public policies. Universal distribution of antiretroviral therapy drugs, implementation of laws that grant rights to HIV carriers, and the consolidated structure of specialized support in the Brazilian Unified Health System are acquired rights, directly related to the role of social control played by civil society. One could say that challenges posed by AIDS bring, in its heart, the challenges and fights for democracy.

The vigor of civil society in the field of HIV/AIDS goes beyond its working field, including networks and scientific meetings. The exchange of experiences, also strongly encouraged and promoted

by UNESCO, brought considerable knowledge to the development of strategies for facing the epidemic. They are applied to the dimensions and cultural specificities of a country like Brazil. This exchange has also contributed to disseminate information that publicized alternatives to fight the challenges posed by the epidemic. As an external assessment requested by UNESCO headquarters in 2001 points out, the activities undertaken by the government, civil society and international cooperation agencies were responsible for increased awareness in relation to the epidemic, towards developing a sense of co-responsibility. Still according to such assessment, along the years it attracted new partners, and contributed towards improving HIV figures in Brazil. The report concludes that epidemiological, humanitarian and social consequences of AIDS in Brazil remain huge challenges; but that nevertheless, the Brazilian experience has successfully demonstrated that it can mitigate the disease effects both at individual and collective levels.³⁷

The joint work between government and civil society in Brazil clearly deserves special attention concerning how this partnership was established. While in most countries the NGOs are considered as threats to governments, because they disclose and point out weak points in government programs, the partnership between historically uncooperative sectors proved that, when autonomies and independency required for working in both sectors are respected, expanded actions and concrete results arise, as for example: efficiency in approaching vulnerable populations; agility in executing projects; methodological creativity; reduced operational costs; and efficiency in taking Brazilian experiences to other countries.

The seeking for solutions to this agenda in Brazil relies on UNESCO's contribution with Public Power and civil society efforts. The partnership with UNESCO has allowed for opening

³⁷ STERN, E.; DEFOURNY, V. *UNESCO Brasil: relatório de avaliação das atividades do Escritório de Brasília*. Brasília: UNESCO, Sep. 2001. (mimeo).

spaces towards innovation, as for example, the support to actions on institutional enhancement of federal, state and municipal governments; insertion of youth into spheres internationally acknowledged as policy-building spheres; involvement of members of the parliament in thinking new laws that point out more equalitarian treatment to epidemic issues, among others, prove that United Nations expertise may contribute to the building of new ties, that further enhance the brazilian response.

4. PROFILE OF NGOS IN THE FIELD OF AIDS

4.1 INTRODUCTION

In this chapter, NGOs are mapped in Brazil, according to institutional characteristics, partnerships with other agencies and target-groups. This mapping intends to provide a better understanding on the situations where those organizations face HIV epidemics, and mainly on their relationship with the state. It uses information collected in an extensive survey, where questionnaires were sent by e-mail and traditional mail. Therefore, this map is similar to records obtained from members of such NGOs, especially at the coordination levels. Before presenting the profile of NGOs in the field of AIDS, a brief summary of this participant in such scenario is presented below.

In terms of conceptualizing NGOs/AIDS, the study is oriented by consensual recommendations made by entities and that to some extent implies the degree of diversity in institutional shapes. For example, according to NGOs/AIDS Forum in the State of Rio de Janeiro, it would be hard to accurately define what NGOs/AIDS are. According to ABIA (2004: 01):

It is hard to accurately define what NGOs/AIDS is. There is a trend towards considering it as organizations established especially for bringing an organized response of civil society to the HIV epidemic, although this set may comprise very different organizations in terms of political and religious affiliation, size, undertakings, kinds and shapes of structure and work.

Usually, when referring to NGOs, its “non-governmental” feature is emphasized. In principle, that was so because they do not represent any government in the *United Nations Assemblies*³⁸. In Brazil, such organizations arise in a scenario characterized by military dictatorship, and basically gather left-party activists, university professors with no room for political expression in the academic arena and, later, former expatriated individuals (LANDIM, 1998). NGOs are characterized for advocacy actions for several populations, mainly by rendering services and working for public policies, with a higher degree of institutionalization than the social movements. Nevertheless, they comprise several different shapes. In many instances, especially in its early legitimating – in the 1980’s – frontiers between NGOs and social movements were not clear, and had a style that was more related to activist claim for the rights of a constituent group and challenging the State.

Simultaneously to the attempt of consolidating an identity that was more related to NGOs parameter, and within the social context of the time, the groups that emerged in response to AIDS epidemic started referring to themselves as “NGOs/AIDS”. However, many of their practices are also mistaken with the shaping of social movements, and usually use performances in streets as protest, interventions in medical surveys, public denouncements in defense of people with HIV/AIDS, and interlocutions with governmental spheres matching collaboration and social control. In brief, NGOs/AIDS built a peculiar intersection within and among notions of NGOs, social movements and mutual assistance groups.

³⁸ According to FERNANDES, R.C.; PIQUET, L. (1997: 25-33), the prevalence of the expression ‘non-governmental organizations’ (NGOs) arose in Continental Europe, and is originated in the nomenclature of the United Nations representations system. It was stipulated that international organizations that, despite not representing governments, seemed significant enough to justify a formal presence in the UN, should be called NGOs. The World Council of Churches and the International Labor Organization were some examples. Therefore, upon the formulation of international cooperation programs to development, encouraged by the UN in the 1960’s and 1970’s, Western Europe experienced an increase on NGOs oriented to promote development projects in Third World. By formulating or seeking for projects in non-governmental scope, European NGOs sought for partners worldwide and, ultimately, fomented the emergence of NGOs in continents of South Hemisphere”.

In this survey, grounded on the above-mentioned database, NGOs/AIDS were considered as non-profitable civil society organizations that develop some sort of action in facing the HIV/AIDS epidemic. Such action is performed through activities on prevention and education, assistance, production and dissemination of knowledge and information, in addition to activism. Thus, the roster of NGOs/AIDS comprises entities of diversified profiles, one different from another in terms of political and religious affiliation, size, undertakings, kinds and shape of structure and work, and also if they are exclusive to AIDS issues or not.

In 1986, acknowledging the relevance of civil society contribution towards facing AIDS, the Ministry of Health, through the National STD/AIDS Program³⁹, called some professionals and university professors dedicated to the anti-aids struggle, to comprise the workgroup that should draw up guidelines and alternatives to HIV control in Brazil.

In parallel to the intensified dialogue with the government sector, the organization of groups working on AIDS expanded and increased. In 1989, the number of such organizations had grown and expanded their activities enough to require for articulation to enhance several initiatives. That is when almost thirty persons and fourteen organizations attended the I National Meeting of NGOs/AIDS. As of 1989, NGOs/AIDS National Meetings are held on a regular basis, and become the highest sphere for discussing and making decisions on guidelines for actions carried out by NGOs/AIDS in Brazil.

The expansion of the thematic and political scope of NGOs actions is simultaneous to changes in relationship between the

³⁹ From 1986 — when it was established — to 1998, the National Programme undergoes several reformulations, including its name is changed. For the purposes of this study, it is sometimes referred to as National STD/AIDS Programme and sometimes National STD and AIDS Coordination. In 1998, it is named National STD and AIDS Coordination. In 2004, it is once again called STD and AIDS National Programme.

National STD and AIDS Programme and those organizations. Due to the maturity of social movement, NGOs/AIDS representatives are acknowledged as legitimate interlocutors in scientific forums, as well as in the elaboration and implementation of public policies. Despite the participation of activists as consultants since the Programme outlining, they are not considered as representatives to a group or an organized movement. In opposite, the government almost refused to have formal dialogues with organized movements of fight against AIDS. This posture gradually changed when, in 1992, the Ministry of Health provided financial support to hold the V National Meeting of NGOs/AIDS in Fortaleza, besides sending a representative to attend it. The representation of NGOs to make up the National Commission of Vaccination was voted during such meeting (ENONG). It was the starting point to the practice of holding Meetings to elect NGOs representatives to formal rooms of interlocution with National STD/AIDS Programme, including the National AIDS Commission.

In 1994, upon resources granted by the World Bank Loan Agreement – project AIDS I – the National STD and AIDS Programme started providing technical and financial support to NGOs projects. These projects were selected through procurement, and represented a new stage to the relationship with civil society. The policy of financial resources transfer to non-governmental organizations has existed since 1988. It aimed at implementing projects defined by the Ministry of Health, such as PREVINA, oriented to groups considered as more vulnerable – prostitutes, prisoners and drug users; and the EMPRESAS, in partnership with the Brazilian Industry Social Service – SESI. However, selection through procurement and the amount of resources allotted in this initiative were a novelty, and its impact was translated into increased quantity of organizations that were adding AIDS-related matters to their agenda. Therefore, as of 1994, the Ministry of Health became the major financing agent to actions developed by NGOs/AIDS in Brazil.

It is also worth recalling that, at that time, the Brazilian Unified Health System – SUS – had already been implemented. Among its five major guidelines, it included social control. In fact, Brazil had accumulated some degree of experience in controlling governmental actions in the field of health through National State and Municipal Health conferences. This process was expanded and intensified in the scope of the national response to the epidemic. In fact, if there is any “Brazilian model of epidemic control”, it is worth acknowledging social participation as one of its tripods – jointly with the State and international organizations. This converts civil society into an unprecedented differentiating factor in relation to other experiences.

With AIDS II – the second World Bank Loan Agreement – in addition to the support to actions of fight against AIDS, priority was also placed on the promotion of sustainability for such actions so as for the creation of strategies that could allow for their continuity. Here, sustainability should be understood not only in relation to financial dimension, but also to its technical and political grounds. This application of the concept of sustainability is also justified by taking the required partnership between NGOs and National and State STD and AIDS Coordination into consideration, in addition to municipal programs and activities related to the implementation of projects aimed at granting financial resources.

4.2 PROFILE OF NGOS/AIDS IN BRAZIL

In order to select survey samples on NGOs/AIDS, the database of the Projects Monitoring System (SIMOP), National STD and AIDS Program was used. To send questionnaires to be answered by NGOs, both through Internet and the postal service, the following criteria were considered: Does the NGOs have projects

supported by UNESCO or UNODC, and ongoing projects within the scope of AIDS II. The NGOs register of Civil Society and Human Rights Unit of the National STD and AIDS Programme served as basis for the questionnaires to be forwarded.

Therefore, 576 questionnaires were forwarded, of which 328 were answered. Answered questionnaires (328) account for 57% of the universe of AIDS-related NGOs. The survey universe is very close to the number of NGOs/AIDS existing in Brazil, since according to the mailing list of NGOs articulation sector, National STD and AIDS Programme, there are six hundred addresses, including organizations that, despite working with AIDS, are not considered typical NGOs/AIDS. That is so for feminist groups and AIDS commissions of union trades. Estimates by the organizers of the National Meeting of NGOs/AIDS, held in April 1999, already pointed to the existence of 350 non-governmental organizations whose basic objective is the fight against AIDS. These NGOs develop actions in prevention and education, assistance, production and dissemination of knowledge and information, and activism.

Following, the map of NGOs surveyed, considering the following dimensions: geographic area of work; NGO's sphere of action; founding date; starting date of activities with STD/AIDS and institutional objectives.

The **geographic area of work** comprises indications on the State wherein their work, and the city they are located, associated to nominal identification of each NGOs (see Annex 2).

Table 4.1 brings a brief summary on the scope of the survey, according to States.

TABLE 4.1 – Number of questionnaires issued and received on NGOs/ AIDS, according to regions and states – 2003

Questionnaires on NGOs/AIDS			
Region / states	Issued	Received	Ratio between Issued and Received Questionnaires
	N	N	%
Total	576	328	56.94
North Region	41	20	48.78
Acre	5	1	20.00
Amapá	4	0	0.00
Amazonas	8	4	50.00
Pará	15	12	80.00
Rondônia	7	2	28.57
Roraima	1	1	100.00
Tocantins	1	0	0.00
Northeast Region	130	65	50.00
Alagoas	3	0	0.00
Bahia	31	22	70.97
Ceará	41	22	53.66
Maranhão	7	2	28.57
Paraíba	12	6	50.00
Pernambuco	19	9	47.37
Piauí	6	1	16.67
Rio Grande do Norte	4	0	0.00
Sergipe	7	3	42.86
Midwest Region	68	32	47.06
Distrito Federal	18	10	55.56
Goiás	15	7	46.67
Mato Grosso	12	7	58.33
Mato Grosso do Sul	23	8	34.78
Southeast Region	249	157	63.05
Espírito Santo	10	3	30.00
Minas Gerais	19	11	57.89
Rio de Janeiro	92	52	56.52
São Paulo	128	91	71.09
South Region	88	54	61.36
Paraná	29	17	58.62
Rio Grande do Sul	33	21	63.64
Santa Catarina	26	16	61.54

Source: UNESCO. *National Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003.

Out of the 328 NGOs that answered the survey, 27.7% are in the State of São Paulo, 15.8% in Rio de Janeiro and 6.7% in Bahia and Ceará. In Rio Grande do Sul there are 6.4%, followed by Paraná, with 5.2% and Santa Catarina, 4.9%. Altogether, these states represent 73.0% of NGOs. Thus, the standard of distribution of NGOs working with AIDS, recorded in 2003, points to a concentration of organizations in the São Paulo-Rio de Janeiro axis, with 43.4% of the total (Table 4.2).

TABLE 4.2 – Percentage of questionnaires received, according to states – 2003

Percentage of Questionnaires Received, according to States – 2003	
States	Questionnaires Received (%)
Total	100.00
North Region	6.10
Acre	0.30
Amapá	0.00
Amazonas	1.22
Pará	3.66
Rondônia	0.61
Roraima	0.30
Tocantins	0.00
Northeast Region	19.82
Alagoas	0.00
Bahia	6.71
Ceará	6.71
Maranhão	0.61
Paraíba	1.83
Pernambuco	2.74
Piauí	0.30
Rio Grande do Norte	0.00
Sergipe	0.91
Midwest Region	9.76
Distrito Federal	3.05
Goiás	2.13
Mato Grosso	2.13

TABLE 4.2 – (continuing)

Percentage of Questionnaires Received, according to States – 2003	
States	Questionnaires Received (%)
Mato Grosso do Sul	2.44
Southeast Region	47.87
Espírito Santo	0.91
Minas Gerais	3.35
Rio de Janeiro	15.85
São Paulo	27.74
South Region	16.46
Paraná	5.18
Rio Grande do Sul	6.40
Santa Catarina	4.88

Source: UNESCO. *National Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003.

Concerning the NGO's **sphere of action**, figures point out that more than half of NGOs actions are concentrated at the municipal sphere (56.4%), followed by state (45.4%) and regional (39.3%) spheres.

Within the national scope, percentage is 30.8%, while only (25.4%), of them report to perform district- or district group-based actions as observed in Table 4.3.

TABLE 4.3 – Number and ratio of ONGs/AIDS according to action sphere – 2003

Action sphere	N	%*
Municipal	185	56.4
State	149	45.4
Regional	129	39.3
National	101	30.8
Districts or District Groups	83	25.3

Source: UNESCO. *National Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003.

The question was: "At which sphere does your organization work?"

* Percentages sum does not total 100.0%, since each organization could inform more than one sphere of action.

NGOs beneficiary population, heard in focal groups, positively acknowledge the work performed at local communities, stressing its relevance, mainly for reaching out to the young population. Many have referred to previous experiences in participating in several activities promoted by the NGOs in the district, such as ludic and cultural works. Furthermore, participating in the NGOs, they claim, implies in building an alternative space to the street – a place considered as one *filled with drugs and violence*.

Highest focus on municipality is consonant to the dynamics of social life, mainly in the field of health. According to d'Ávila (2001:60), Brazil is committed to decentralizing public management and regionalizing health actions, what assigns to municipalities an important role in expanding and maintaining integral care to the population health. According to him, this responsibility implies in applying strategies that allow for carrying out this duty, which does not mean that federal and state public spheres are released from their responsibility. In opposition, he continues, the Brazilian health system organization undergoes clear construction of roles and duties assigned to each sphere.

When dealing with **founding date**, most NGOs/AIDS answered a point in time between the early 1980's and 2003. In 1985 there was a surge in the faster creation of NGOs, exactly after political openness was concretized in the campaign for prompt direct elections. This accelerated growth of NGOs has new peaks in 1991, 1992, 1994 and 1999, and a short decrease in the number of NGOs established in the remaining years. The 1991 and 1992 peaks can be explained by the popularization of “non-governmental” movement, mainly concerning the ecological movement in 1992. 1994 and 1999 are also outstanding because of the effectiveness of World Bank Loan Agreements, respectively known as AIDS I and AIDS II.

Considering the material collected, the most valued periods are those when institution emergence was greater. Thus, five moments are elected, due to results reported by the survey. They are: a) Until 1983; b) from 1984 to 1988; c) from 1989 to 1993; d) from 1994 to 1998; and, e) from 1999 to 2003.

Table 4.4 discloses that out of the 324 NGOs that answered the question, 31.2% were established from 1989 to 1993, corresponding to 101 organizations. From 1994 to 1998, 26.9%, i.e., 87 institutions were established. In the following moment, from 1999 to 2003, 61 institutions arose (18.8%).

TABLE 4.4 – Number and ratio of NGOs/AIDS according to founding period – 2003

Foundation period	N	%
Before 1983	36	11.1
From 1984 to 1988	39	12.0
From 1989 to 1993	101	31.2
From 1994 to 1998	87	26.9
From 1999 to 2003	61	18.8
Total	324	100.0

Source: UNESCO. *National Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003.
Question: "Foundation Date".

When one identifies, according to the founding date, the NGO's priority field of work, it can be noticed that, along the period, the only area that reported constant growth was Human Rights. The STD/HIV/AIDS Prevention field reports the greatest percentage of NGOs, with 27.2%; followed by Assistance to HIV carriers and/or individuals living with AIDS (23.8%). The percentage of NGOs working on Movements for Women and Children and Adolescents is 8.8%, respectively, losing room during selected periods. (Table 4.5)

Initial activities on STD/AIDS among 328 NGOs surveyed are concentrated between January 1978 to March 2003, with the following specificities according to periods considered and taking the literature on remarkable moments in Brazilian public life into consideration, according to topics that, somehow, influence AIDS-related mobilization:

- I. Before 1983, only 0.9% NGOs had started activities on STD and AIDS. At that time, consciousness and the relevance of sexuality in social movements started being configured, in an incipient way;

TABLE 4.5 – Ratio of NGOs/AIDS according to founding date and priority field of work (in %) – 2003

Priority Field of Work	NGOs/AIDS foundation date					Total
	Until 1983	1984 until 1988	1989 until 1993	1994 until 1998	1999 until 2003	
Human rights	3.7	6.1	9.0	13.0	14.0	10.0
Homosexual movement	3.7	-	6.0	-	7.0	3.3
Women's movement	-	12.1	14.9	8.7	2.3	8.8
Sex professionals	-	3.0	1.5	1.4	9.3	2.9
Children and adolescents movement	14.8	15.2	6.0	7.2	7.0	8.8
STD/HIV/AIDS prevention	18.5	30.3	25.4	27.5	32.6	27.2
Assistance to HIV carrier and/or individuals living with AIDS	11.1	18.2	34.3	24.6	18.6	23.8
Other movements	48.1	15.2	3.0	17.4	9.3	15.1
Total	100.0	100.0	100.0	100.00	100.0	100.0

Source: UNESCO. *National Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003. Question: "Field of Work".

II. From 1984 to 1988, when first responses to AIDS epidemics came about, the percentage increased from 0.9% (until 1983) to 8.3%. That period was characterized by the emergence of a huge number of non-governmental organizations, working mainly on advocacy to HIV/AIDS carriers, besides assistance and social mobilization towards political pressure.

By 1985, at least eleven states had already organized policies related to AIDS, by establishing control programs. Their actions were focused on investments in epidemiological surveillance, medical care and prevention, basically through information disseminated in the media. Until that year, the Ministry of Health had not undertaken any expressive action to fight the epidemic. In 1985, the first non-governmental organization specifically focused on fighting the epidemic – the *Grupo de Apoio à Prevenção de AIDS* – was established in São Paulo.

It was only in 1986 that the Ministry of Health, through the recently established National STD/AIDS Programme, acknowledged the contribution of civil society to fight AIDS, and became organized to an

urgent response to AIDS epidemic. In 1986, as one of the major milestones in Brazil, the VII National Health Conference was held, and implemented the basis for the Brazilian Unified Health System (SUS). According to Teixeira (1997), the National STD and AIDS Programme, although acknowledging the relevance of inserting STD/AIDS actions into the new model, delayed in advancing in its policy, because it did not take SUS guidelines as referential to STD/AIDS control actions. Rather, it decided for centralizing policy and financial resources.

III. From 1989 to 1993, the percentage of organizations that started working with STD and AIDS was of 25%. These were times of advances in proposals to face AIDS. As observed, there was an increase, as of 1989, in the number of such organizations, thus requiring for articulation to develop several initiatives. In this period, mainly from 1990 to 1992, the federal government underwent a crisis that affected the National STD and AIDS Programme and that was reflected in State Programs. At that time, Brazil also interrupted its relationship with some international organizations (see TEIXEIRA, 1997; PARKER; GALVÃO; and BESSA, 1999).

IV. Between 1994 and 1998 a process of restructuring and expansion of national response was started. The National STD and AIDS Programme reestablished relationships with states, municipalities and NGOs, retaking international articulations.

Upon the first World Bank loan, known as AIDS I, the percentage of NGOs/AIDS jumped to 34.9%. Such increase happened mainly in 1994, when the National STD and AIDS Programme started providing technical and financial support to NGOs projects, with proceedings from the Loan Agreement.

V. From 1999 to 2003, the percentage of NGOs claiming to develop activities with STD and AIDS was of 30.9%. The percentage remained in 30% during the two last periods selected, probably because of the World Bank loans (AIDS I and II). With the AIDS

II Loan Agreement, the National STD and AIDS Programme assigned more managerial autonomy to State and Municipal Health Secretariats. Thus, institutional development was enhanced and increased investments were made on management process organization, qualifying local teams in planning, programming, executing, monitoring and assessing projects. To ensure sustainability to actions, the National STD and AIDS Coordination regularly develops a work to build sensitiveness among health managers at collegiate bodies, discussing the competencies of the three governmental spheres and reaching consensus on some issues (Table 4.6).

TABLE 4.6 – Number and ratio of NGOs/AIDS according to when they started working with STD/AIDS – 2003

Period when they started dealing with STD/AIDS	N	%
Before 1983	3	0.9
From 1984 until 1988	27	8.3
From 1989 until 1993	81	25.0
From 1994 until 1998	113	34.9
From 1999 until 2003	100	30.9
Total	324	100.0

Source: UNESCO. *National Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003.
Question: “Date when it started working on STD/AIDS”.

During the first World Bank Loan Agreement to support actions to fight the HIV epidemic, the Ministry of Health improved the criteria to select and monitor projects. Simultaneously and with government support, the increasing participation of NGOs/AIDS in different spheres and activities of the National STD/AIDS Programme contributed towards improving the understanding on what “executing projects” means. By the end of the first Loan Agreement, in 1998, 437 NGOs projects had been financed by the National STD and AIDS Programme, including different target populations, such as adolescents, youth, women, individuals living

with AIDS, sex professionals and male homosexuals, besides a significant number of events, including seminars and meetings (National STD and AIDS Coordination, 1998).

In a first stage, the Loan Agreement with the World Bank, mainly its strategic component of financing to NGOs projects, is subject to analysis and criticisms by activists (GALVÃO, 1997). They point out the transitory disarticulation of NGOs/AIDS policy, resulting from competition for resources, either one to another or to other organizations, many of which more experienced and prepared to elaborate projects.

In the first projects bidding, within the scope of the second World Bank Loan Agreement – project AIDS II – 250 projects were approved, including new ones, continuity of old projects and accomplishment of events. However, the main guideline to AIDS II in supporting actions on fight against AIDS in Brazil is the promotion of sustainability to such actions, since was no forecast for a third loan by that time.

As governmental actions and loans remained, the number of NGOs starting their activities on STD and AIDS increased. It means that governmental actions effectiveness is strictly related to the sustainable and organized movement of civil society and, therefore, guides public health policies. A process of mutual conditionally replication starts – since governmental actions strengthening, and its aggressiveness, directly affects the organization and sustainability of civil society actions, thus providing required means for several agencies to continue actions. (ALTMAN, 1995).

Concerning the analysis on the institution objectives, it is worth noticing the broad range of different objectives, which reached eighteen categories, namely: *Prevention* (164 cases), is the most mentioned category, accounting for 50% of statements, followed by *Human Rights and Citizenship* with 47.6%, equivalent to 156 cases. Ranked in third, there is *Assistance to HIV Carriers Population* (93 cases), or 28.4%, while *Human Rights and Gender* with 23.5% (77 cases) is the fourth category. The NGOs claiming to be oriented to *Develop and Disseminate Knowledge* amount to 19.5% (64 cases), standing for the fifth most quoted category. *Promote*

Knowledge Articulation (financial, technical and relational), *Participation in Social Control and Public Policies*, *Promote Sustainable Development* range from 11.6% to 9.5% (38 and 31 cases), respectively. The NGOs oriented to *Coordinate Programs* (7.0%), *Professional Qualification* (5.5%), *Others* (5.0% – unspecified), *Qualification towards Sustainability* (4.0%), *Assistance to Chemical Addicts* (3.7%), *Human Rights – Sex Professionals* (3.4%) and *Human Rights – Racism* (3.0%), are less expressive. Finally, there is the *Promotion of Damage Reduction* with 1.2% and *Behavioral Change in face of AIDS* with 0.3%, and accounts for one single case. (Table 4.7)

TABLE 4.7 – Number and ratio of NGOs/AIDS according to objectives – 2003

NGOs/AIDS Objectives	N	%*
Prevention – Pv	164	50.0
Human Rights and Citizenship – HRC	156	47.6
Assistance to HIV Carrier Population – As-HIV	93	28.4
Human Rights and Gender – HR-G	77	23.5
Develop and Dissemination Knowledge – DDK	64	19.5
Promote Knowledge Articulation – PKA	38	11.6
Participation in Social Control and Public Policies – PSC-PPP	35	10.7
Promote Sustainable Development – PSD	31	9.5
Coordinate Programs – CP	23	7.0
Professional Qualification – PQ	18	5.5
Qualification towards Sustainability – QS	13	4.0
Assistance to Chemical Addicts – As-CA	12	3.7
Human Rights – Sex Professionals – HR-SP	11	3.4
Human Rights and Racism – HR – R	10	3.0
Promotion of Damage Reduction – PDR	4	1.2
Behavioral Change in face of Aids – BCA	1	0.3
Others	15	4.6

Source: UNESCO. *National Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003. Question: “Objectives of the institution”.

* Percentages do not total 100.0% because each organization could point out more than one objective.

4.3 TYPES, MANAGEMENT WAYS, ARTICULATION AND SOCIAL VISIBILITY

Still based on questionnaires employed, the next step is to analyze NGOs/AIDS classification pursuant to type of organization; shapes of organization (NGOs decision-making spheres); target population of NGOs programs; field of work – highlighting the major one; implementation of advocacy actions; institutionalization; political partnerships at national level; partnerships at international level; NGOs intake sources; participation in social control spheres; participation in the formulation of governmental public policies; membership to the Brazilian Association of NGOs/AIDS — ABONG and to other networks and articulations of movements; participation in NGOs forums at the state; participation in NGOs meetings; participation in the latest NGOs Regional meeting; ways for disseminating works developed by NGOs and disclosure of the organization work abroad.

Aiming at better characterizing NGOs/AIDS according to the type of organization, the survey asked NGOs to respond with three examples of its purposes / objectives, as follows: *services provision, advocacy and social movement*. Therefore, the type of organization is mixed to its objective.

A preliminary analysis identified the type of organization based on the NGOs Taxpayer Identification Number (CNPJ), its self-designation and the institution name. Then, it places priority on the diversity of information received from NGOs, trying to valuate both information on the type of organization and its objective. Table 4.8 brings the results of this analysis.

Except for two cases, the NGOs had CNPJ and, therefore, it could be observed that the universe of this survey is basically made up by seven categories: *Society and other types of Association, Services Provision, Social Movement, Advocacy, Research and Information, Religious Entity and Others*. It is worth noticing that these are descriptive categories and do not exclude one another.

The fact that most NGOs/AIDS had CNPJ points out greater trend to become NGOs. It suggests that the ten last years of financing have contributed to increase the institutionalization of social movements

that, in principle, made up the scenario of fight against AIDS. This phenomenon of “Ngozation” is understandable, since it was a requirement for IRDB resources transfer to the third sector. Therefore, social movements were led to become formal institutions, through the CNPJ. It changed the characteristics of social movement proposal, if one takes into consideration that social movements would not employ the practice of official registration, through CNPJ.

Table 4.8 points out the absolute prevalence in the four categories firstly mentioned, i.e., 36.6% state to be *Society and other kinds of Association*; 25.9% work on *Services Provision*; 23.5 % claim to be *Social Movement* and 18.9% are *Advocacy* NGOs. Meanwhile, only 2.1% work on *Research and Information*; and 1.5% is *Religious Entity and Others*.

TABLE 4.8 – Number and ratio of NGOs/AIDS according to the kind of organization – 2003

Kind of organization	N	%*
Society and other kinds of association	120	36.6
Services provision	85	25.9
Social movement	77	23.5
Advocacy	62	18.9
Research and information	7	2.1
Religious entity	5	1.5
Others	5	1.5

Source: UNESCO. *National Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003.

Question: “Kind of organization”

*Percentages do not total 100.0%, because each organization could state to belong to more than one category.

The category of **Societies and other kinds of association** comprises the following sub-items: non-profitable beneficent association of private right, community-based, cultural and non-profitable, of small producers and non-profitable, prostitutes, HIV carriers and their family members, Civil Society Organization of Public Interest – OSCIP, non-profitable civil society entity, entity, philanthropic entity, non-profitable entity, trade union entity, NGOs, institution, non-profitable autonomous institution, Civil Society Organization – OSC, NGOs/AIDS, social organization, of public interest, private corporations, municipal public utility.

The category of **Services Provision** comprises the following sub-item: shelter, support to individuals and institutions, assistance, health, education, supporting shelter/accommodation, prevention, moral, social, professional and cultural strengthening of HIV carriers, support groups, housing, popular education, social development, women, culture, food, social campaigns, transportation, nursing, service provision, service to community, social service, advisory, needy population, reduction of the infection incidence, voluntary help, political articulation, doctor’s office, leisure center, ambulatory, qualification, environment, agricultural and forestry production, health unit, social attendance, drugs, professional qualification, income generation program, human promotion, several services, fight against prejudices, capacity-building.

The category of **Social Movement** comprises the following sub-items: AIDS movement, community-based movement, movement for better conditions to HIV carriers, prostitute movement, homosexual movement, Landless Movement – MST, social movement of rural zone, social movement.

The category of **Advocacy** comprises the following sub-items: construction of black populations’ rights, social awareness on inequalities, democratization, citizenship recovery, children, adolescents, individuals living with AIDS, HIV carriers, gays, travesties and lesbians, trans-genders, homosexuals, gender, mentally diseased people, human childbirth, advocacy, defense of reproductive rights, prostitutes’ health, student representatives, promotion, community radios, feminist groups.

The category of **Religious Entity** comprises the following sub-items: religious entity, religious organization, and religious with holistic view on man, social service to Church.

The category of **Research and Information** comprises the following sub-items: Center of study, communication, information, research nucleus at university, teaching, research, expansion of knowledge.

Others comprise: social purposes, civil society, social, volunteers.

The identification with advocacy in the context of fight against STD, HIV/AIDS, remains the mark for entities described in the survey. It is amazing to notice that this observation is also applicable to organizations bound to more specific social movement. The set of entities discloses a profile differentiated in relation to exclusivity of work in the field of STD/AIDS. Surely, there are more flexible and diversified institutions, expanding their field of work.

It is worth noticing that when NGOs answered the question on “type of organization”, they did not necessarily know about legal aspects that support the creation/possible types of organization. The “field work” of this survey was carried out from May to June 2003, when changes to the Brazilian New Civil Code were under elaboration and implementation, besides new legal definitions of OSCIP – Civil Society Organizations of Public Interest.

Apart from the discussion on what an NGOs would be in legal terms, here OSCIP is perceived by the kind of response to the questionnaire, when self-designation as one or other kind of organization does not necessarily disclose mutual profiling according to legislation or literature. Furthermore, there are even discrepancies between the organization designation and its classification – this ambiguity concerning identification also existed in the qualitative survey, where services provision prevails. Several authors point out that such datum would be another indication of some degree of tutoring in movements against AIDS, what would lead organizations to become more vulnerable and dependent on financing. That would reduce civil society to government services providers, instead of promoting citizenship and a relationship of respect between State and civil society (GALVÃO, 2000; PARKER, 2000; CAMARGO Jr., 1999).

Following are the cases used to support the argument on tutoring:

- (i) Between the World Bank and the Government, where the Bank suggests policies development, regardless governmental assessment, thus limiting budget allotment to several areas – prevention, assistance, etc. This posture is defended by Vianna, 2003 (also see World Bank, 2003), among others;

- (ii) Between Federal Government and lower governmental spheres, concerning resources transfer, guiding and defining how expenditures should be processed; between the federal government and OSC, where the definition on public policies priorities and where resources should be spent does not consider the end assessment on what should a priority or not.

Some authors point out the lack of investments on capacity building and development towards strengthening lower governmental spheres and OSCs, thus leading to a perspective of urgency and lack of organization and planning by NGOs, which contemplates Government demand rather than its own agenda of needs.

Concerning the organization shape – NGOs decision-making spheres – four (4) categories were established, based on the grouping of legal aspects related to how should be participation in associations – the kinds of existing management – and descriptions provided when answering the question: *restrict decision-making, expanded decision-making, restrict and expanded decision-making, unidentified and not applicable (others)*.

For the purposes of this survey, *more restrict participation* is understood as that where only the Board of Directors and Presidency (NGOs leadership) played core role in decision-making. In opposite, Board of Directors and Presidency make up *broader participation*, additionally to partners, beneficiaries, volunteers in decision-making process. The *unidentified* are basically those lacking information enough that could allow for understanding the kind of management. Finally, the *not applicable* group dealt with Governmental Organizations, universities, public foundations and pastoral linked to diocese / church administration.

According to Table 4.9, the profile for this activity would be:

1. Restrict decision-making: 45.7% of responses. Here, the core element to decision-making is restricted to directors and leaders, any collegiate or groups other than assemblies, where

the participation of all spheres in the decision-making process is not clear.

2. Expanded decision: for 22.6% of NGOs, decision is made by directors and leaders, including partners, beneficiaries and volunteers, usually employing the term “general assembly”.
3. Combination of restrict and expanded decision: 13.7% of NGOs/AIDS have spheres with features of both ways of decision-making, without definition on which decision is made through which way.
4. Unidentified: in 18% of the cases information is not enough to understand what kind of management the NGOs undertakes.

TABLE 4.9 – Number and ratio of NGOs/AIDS according to decision-making spheres – 2003

Decision-making spheres	N	%
Restrict decision-making	150	45.7
Expanded decision-making	74	22.6
Restrict and expanded decision-making	45	13.7
Unidentified	59	18.0
Total	328	100.0

Source: UNESCO. *National Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003.
Question: “Organization shape (NGOs decision-making sphere)”.

Target-audience of NGOs programs broadly varies: HIV/AIDS carriers; homosexuals (male and female); trans-genders, travesties sex professionals; women; serum-discordant couples; prison populations; waste pickers; beggars; children and adolescents involved in drug trafficking and in poverty situation; children, adolescents (students) and young adults and drug users. It also focuses on health and education professionals, besides governmental institutions (police, municipal and state secretariats).

Target-population to NGOs activities is presented at Table 4.10 below. Please note that one NGO may serve several populations.

TABLE 4.10 – Number and ratio of ONGs/AIDS according to target population – 2003

Target Population	N	%*
Population in general (1)	206	62.8
Children, adolescents and youths (1)	198	60.4
Individuals with HIV/AIDS/STD/Hepatitis	105	32.0
Women	73	22.3
Sex workers	60	18.3
Homosexuals	46	14.0
Drugs users	31	9.5
Health and education professionals	25	7.6
Others (2)	62	18.9

Source: UNESCO. *National Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003.

Question: “Target-population (to NGOs programs):”

Percentages do not total 100.0%, since each organization could point out more than one target-population.

(1) These populations also include HIV/AIDS carriers and their family members.

(2) Researchers; Managers; Patients suffering from chronicle diseases; Mentally Diseased People; Media Rural Workers; Rural workers; Several institutions; Public policies and human rights institutions; Security workers; Local/night clubs/ pubs; Semi-vocational courses; Big events.

Along over 21 years of epidemic, different civil society sectors have joined the fight against HIV/AIDS, even by performing activities that are not directly oriented to AIDS as, for instance, trade unions, philanthropic and religious entities, research nucleus in universities and non-governmental organizations.

NGOs develop several kinds of activities, ranging from works on social control and expressive influence on public policies, until those basically working on assistance activities.

There are major NGOs, in the light of visibility in political works, mainly in the axis São Paulo and Rio de Janeiro. Currently, any non-governmental policy on AIDS is directly influenced by those states. Assistance is the mark of works by NGOs directly working with people living with HIV/AIDS, but it is qualified, as groups of co-existence and mutual support, oriented to build a “life with AIDS”, intending to provide better alternatives to quality of life, both at social and physical and mental health scope.

Nevertheless, there are NGOs working directly with people living with HIV/AIDS, with expressive political work. Those with political activities also participate in spheres of social control. Therefore, major NGOs are inserted into national, state and municipal representations, in order to follow-up, discuss and propose alternative responses to public health. Another strategy employed is to establish partnerships and try to enhance NGOs/AIDS, aiming at better community-based response and sustainability. Assistance-oriented NGOs work by distributing basic food baskets and preservatives, while taking the opportunity to make interventions concerning vulnerable behaviors.

Another kind would be made up by NGOs devoted to prevention actions. They do not develop expressive political activities, nor do they provide any kind of direct assistance to people living with HIV/AIDS. Here, NGOs are better characterized by those oriented to educational interventions towards STD/HIV/AIDS prevention, mainly among youth, drug users, low-income population, by delivering speeches in public and private schools, university and corporations, besides participating in events, fairs and other preventive activities. Furthermore, they disseminate information on HIV/AIDS among civil society in general (where they associate experiences by people living with HIV/AIDS to information required for preventing AIDS and other sexually transmitted diseases).

Within this context, some NGOs are characterized for HIV/AIDS prevention. They re-think strategies on sexual education to youth and children, besides mobilizing efforts towards enhancing preventive actions, and those oriented to minimize social impacts of HIV/AIDS epidemic.

Some activities developed by NGOs, according to information provided by their leaders, are described below. It is worth noticing that activities related to AIDS epidemic control are one of the several activities performed by NGOs.

Prevention: (1) Development of preventive actions, by disseminating information (lectures, seminars – in health units, schools, police stations, night clubs, street) and distributing devices (condom, Damage Reduction kit to drug users); (2) Community Development (leadership strengthening) aiming at replicating preventive actions; (3) Capacity-building / training to professionals (health and education, social development, public security) and volunteers (social educators); and (4) Projects of adherence to treatments to HIV carriers.

Assistance: (1) Activities on co-existence / self-assistance (assistance, counseling, prevention, orientation) to several audiences: MSM, women, youth, etc; (2) Social reinsertion – development of workshops or agreements towards promoting reinsertion of HIV carriers living in poverty; (3) Inputs distribution (basic food baskets, snacks, clothes) to assist HIV carrier population and their family members living in poverty; (4) Legal assistance aiming at advocating for human rights and citizenship to people living with HIV/AIDS (continuous benefit, work discrimination); (5) Home visitations to HIV carriers who need care during disease period; and (6) Supporting shelters to house HIV carrier needy population.

Political articulation: (1) Set leaderships at health councils; (2) Establish partnerships with universities to monitor public policies; (3) Public policies formulation (Councils, forums, etc.); (4) Seminars promotion, participation in congresses, events organization (e.g. Gay Proud Parade) that provide visibility; (5) Advocacy at forums, councils to inter-sectoral policies formulation; and (6) Actions on institutional development and enhancement of community-based response.

Many NGOs also provide services in fields such as food, housing, schools and daycare nurseries, domestic violence, labor and unemployment. Many NGOs/AIDS leaders mentioned that in their agendas they emphasize debates and actions related to human

rights, citizenship, prejudice and discrimination. Some NGOs also claimed to provide several kinds of support, including to school works (they mentioned the use of computer with resource to Internet) and information on STD/AIDS (kinds of disease, transmission means, kinds of prevention), cooperating towards a posture with less prejudice and discrimination by population.

Thus, it recognizes the need for more resources allotted to NGOs, in order to provide other activities, especially vocational courses. Professional qualification is another requirement, additionally to knowledge transferred by the NGOs.

For NGOs/AIDS developing works in the field of damage reduction among population, inserting support is not an easy duty. Although damage reduction proposals have been enhanced upon AIDS epidemics, dialogue and interaction between these two social movements is still hard, since the problems they face and strategies employed are different. AIDS issue has encouraged the discussion about drugs and damage reduction policies. However, these topics require for specific ways of fighting. Similarly to users, reducers do not join a place in civil society. AIDS prevention is a sort of fight that cannot be confused with the advocacy of citizenship to drug users, avoiding their criminalization.

Furthermore, the number of injected drug users and reported cases of drug-related AIDS has actually decreased. It leads activists in damage reduction to seek for other causes to support their own cause. It is not an easy duty, since damage reduction work faces high resistance by governmental organizations that, sometimes, fear that the NGOs may advocate for drugs instead of working on prevention. This fact points out the difficulty in sustaining projects and activities promoted. Another fact that brings further complications to damage reduction is the difficulty that governments have in understanding the proposals oriented to drug users, which go beyond the plan on prevention and “recovery” care.

Many reports approached prevention work in broader view, extrapolating the mere distribution of preservatives and lubricating gel. Instead, they approach prevention as a public policy, with social and political commitment, debating sexuality, HIV/AIDS, access to health, access to medications and vaccinations, for example.

Concerning the set of activities performed by NGOs, Table 4.11 discloses the percentage of entities oriented to each activity.

Many NGOs answer that their field of work is *local* – 142 cases, corresponding to 43.3%. Maybe this happened because the question was not clearly stated.

Many of such NGOs work in the field of assistance, reaching 24%. This field comprises assistance to people with HIV/AIDS and prevention against STD; treatment; integral assistance; care; and social assistance. The NGOs that reported to work in the field of prevention correspond to only 14%. This percentage, lower than the expected, is probably explained by the incorporation of part of prevention in the field of assistance. Furthermore, prevention is also part of other areas such as education and health. Prevention includes: Prevention against STD/AIDS in vulnerable populations and Damage Reduction.

NGOs working in the field of education accounted for 16.7% and comprise the fields of food education; popular education in urban and rural areas; schools; behavioral intervention; social-educational intervention and professional qualification.

The field of health embraces 12.5% of total NGOs, comprising those dealing with public health, collective health; community-based health; state and national health council; preventive health and help; actions oriented to community-based development and prevention against STD/AIDS; mental health; drugs and related issues; sexual and reproductive health; and information on mental health.

The survey differentiates field of works in right and advocacy. Therefore, the field of Rights comprises human, sexual,

reproductive rights and those of group identity, accounting for 10.3% of NGOs. In its turn, advocacy accounts for 7.9% and comprises feminist movement, activism, political articulation, representation in civil spheres and forums, social integration, institutional development, Rights Council, formulation of HIV/AIDS public policies, legal actions, social movements, adolescents movements, women movements, children and adolescents movements, homosexual movement and trade union.

Following come NGOs working in the field of capacity building (6.1%). They comprise several training and specific programs, such as actions oriented to sustainable local development focusing on health promotion, youth program and professional qualification and education, application of methodology resulting in social projects incubators; training in shows of oppressed theater; qualification of social educators; qualification of local and regional players; training to multipliers; community centers; associations / cooperative associations; production; social promotion.

Other field of works of NGOs: *Leisure* (4.9%) – activities on movies and social development; culture and arts; and social communication (community-based radio stations); Specific Groups (3.6%) – volunteer services of mental health professionals; health professionals; families in the state; population in social risk; children and adolescents in situation of street or serving social-educational measures; children; youth; special need bearers; homosexual audience; HIV/AIDS carriers; STD/AIDS. *Several institutions* (1.8%), made up by specific agencies not bound to health and education, public and private institutions, corporations and churches. Finally, there are the NGOs classified as *Other Fields of Action* (4.5%), comprising: recovery and prevention; prevention / others – community-based organization; Health / education / income generation / qualification; supervision of care programs; protagonist; psychosocial; preservative marketing; and bioethics. (Table 4.11)

TABLE 4.11 – Number and ratio of NGOs/AIDS according to field of work – 2003

Field of work	N	%*
Local	142	43.3
Assistance	67	20.4
Education	55	16.8
Prevention	46	14.0
Health	41	12.5
Rights	34	10.4
Advocacy	26	7.9
Survey	22	6.7
Capacity building	20	6.1
Leisure	16	4.9
Groups	12	3.7
Several Institutions	6	1.8
Others	15	4.6

Source: UNESCO. *National Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003.

Question: "Field of Action".

* Percentage does not total 100.0% because each organization could select more than one field of action.

Notes:

- 1) Assistance comprises: Assistance to people with HIV/AIDS and prevention against STD; Treatment; Integral assistance; Care; Social Assistance.
- 2) Prevention comprises: Prevention against STD/AIDS among vulnerable populations; Damage Reduction.
- 3) Education comprises: Food Education; Popular education at urban and rural areas; Schools, Behavioral Intervention; Social-educational intervention; Professional qualification.
- 4) Health comprises: Public Health; Collective Health; Community-based Health; State and National Health Council; Preventive Health and help; Actions oriented to community development and prevention against STD/AIDS; Mental Health; Drugs and related issues; Sexual and Reproductive Health; Information on Mental Health.
- 5) Research comprises: Information dissemination; Lectures; Textbooks; Information; Publications Advisory; Consultancy services
- 6) Rights comprises: human, sexual, reproductive and of groups in identities (e.g., gender and race); Human rights defense; Human rights; Citizenship; Environment; Violence; Violence against women; Gender; Sexuality; Race.
- 7) Qualification comprises: varied and specific programs – Actions oriented to local sustainable development programs, focused on health promotion, Youth and professional qualification and education programs; employment of methodology resulting in social projects incubators; Qualification in exhibiting oppressed theater plays; Qualification of social educators; Qualification of local and regional players; Capacity building; Qualification; Qualification of multipliers; Community-based centers; Associations/Cooperative Associations; Production; Social Promotion.
- 8) Leisure comprises: Movies and social development activities; Culture and arts; Social communication – community-based radio stations.
- 9) Specific groups comprise: Volunteer services of mental health professionals; Families in the state; Population in social risk situation; Children and adolescents in situation of street or serving social-educational measures; Children; Youth; Special needs bearers; Homosexual audience; HIV/AIDS carriers; STD/AIDS.
- 10) Several institutions comprise: Specific agencies not bound to health and education – Public institutions; Private institutions; Corporations; Churches.
- 11) Advocacy comprises: Feminist Movement, Activism, Political Articulation; Representation in Civil and Forums Spheres; Social integration; Institutional development; Rights council; Formulation of Public Policies in HIV/AIDS, Legal, Social Movements, Movements of Adolescents in Brazil; Women movements; Movement of children and adolescents; Homosexual movement; Union trade.
- 12) Others comprise: Recovery and prevention; Prevention/Others – community-based organization; Health / education / income generation / qualification; Supervise care programs; Protagonism; Psychosocial; Preservative Marketing; Bioethics.

Concerning **priority field of work of NGOs surveyed**, Table 4.12 discloses the prevalence of STD/HIV/AIDS (27.0%) and assistance to HIV carriers and/or individuals living with AIDS (23.7%).

The fields of human rights, women’s movement and the movement of children and adolescents report similar percentages, respectively 10.4%; 9.1% and 8.7%. Only 2.5% elected gay and female sex professional movements as priority to NGOs work. Probably, the fields of prevention and rights influence this percentage lower than the expected, since many NGOs working on gay and sex professional movements have prevention and rights as their core fields. These are very organized and active groups, besides the most combative in the fight for their rights. Probably, most NGOs surveyed include these movements in “prevention”. The statements based on interviews carried out record the importance of prevention and action by homosexual groups, besides entities of women movement in the field of AIDS.

It is worth noticing that the lesbian movement (0.8%) and the male sex professionals’ movement (0.4%) are not priority in actions developed by those NGOs.

TABLE 4.12 – Number and ratio of NGOs/AIDS according to priority field of work – 2003

Priority field of action	N	%
Prevention against STD/HIV/AIDS	65	27.0
Assistance to HIV carriers and/or individuals living with AIDS	57	23.7
Other movements	29	12.0
Human Rights	25	10.4
Women movements	22	9.1
Movement of children and adolescents	21	8.7
Gay movement	6	2.5
Female sex professionals	6	2.5
Landless movement – MST	4	1.7
Religious movement	3	1.2
Lesbian movement	2	0.8
Male sex professionals	1	0.4
Total	241	100.0

Source: UNESCO. *National Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003.
Question: “Which is the priority field of work to your NGO?”

Actions in advocacy, according to Table 4.13, is a priority area. Over 61% of surveyed NGOs implement advocacy actions, corresponding to 198 organizations. In fact, one basic axis to activism is the work in face of discrimination and prejudices within family and social environments, besides the seeking for rights.

TABLE 4.13 – Number and ratio of NGOs/AIDS according to implementation of advocacy actions – 2003

Implement Advocacy Actions	N	%
Yes	198	61.5
No	124	38.5
Total	322	100.0

Source: UNESCO. *National Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003.
Question: “Does the organization implement advocacy actions?”

According to d’Ávila (2001:61), the fight against AIDS epidemic effectively inserted the issue into the agenda of implementation of public health policy. The clear role played by civil society in constitutional definition of Brazilian Unified Health System – SUS, and the defense for it, have contributed towards redefining the concept of solidarity, by expanding and integrating the role of OSC within the field of assistance and mobilization of social segments and communities, to guarantee their rights.

According to Bobbio (1992), Faria (1994), Mann (1993), Moscoliato (1995) and Ventura (1993), the democratic process opening in Brazil, jointly with the formulation of a new political chart (1988) and limitations of traditional channels of claims – such as political parties and trade unions – civil society is compelled to diversify social organization shapes, and even be in charge of specific State policies (residents associations, cultural centers, entities on human rights defense, environmental protection, consumer defense, children, adolescents and youth, among other members) to intervene in the constituent process, developing political actions to concretize the population’s rights.

The creation of legal assistance services as a tool to guarantee citizens' rights at NGOs/AIDS is inserted into this national context. It is justified by the need for implementing public policies that allow for full exercise of citizenship to people living with AIDS and seropositive individuals. Initially, GAPA/São Paulo created this service, followed by Grupo Pela VIDDIA in Rio de Janeiro (in 1989). Currently, several NGOs working specifically with AIDS – and others with own identities (feminists, gays, lesbians, black people, among others) – develop AIDS-related prevention and assistance works, and weakly acts in services of legal assistance to its target-public, financed by the National STD and AIDS Coordination, of the Ministry of Health.

These initiatives were – and remain – crucial, whether for their political-social aspect, or because they allow the access of individuals living with HIV/AIDS to the state structure. The legal service proposed was replicated to several NGOs all over the country, and provided national visibility to most frequent rights violations. Furthermore, it guarantees the minimum individual and social rights, besides access to Judicial Power in a faster and more specific way.

Jurisprudence incorporated important developments, such as: right of HIV virus carriers to raise the severity fund for time of service for health treatment purposes; mandatory coverage by group medicine and health insurance corporations to AIDS treatment; Government and States accountability for blood contamination through transfusion or use of blood products; reintegration of worker fired due to discrimination against seropositivity; mandatory supply, by public service, of free drugs and exams. (See MOSCOGLIATO, 1995). In the previous health system, health care was not a social right of citizens, but a right endowed by the affiliation to the Brazilian Social Security Institute – Inamps. Few actions were provided to population, regardless their adhesion to Inamps.

NGOs legal services are free, and most professionals involved work as volunteers. This brings about difficulties due to constant changes in staff involved. As the demand for NGOs legal services increased, the alternatives implemented are: agreements and partnerships with model offices at law schools, thus allowing for expanding services

and providing law students the opportunity of developing specific knowledge on the issue; and provision of specific capacity-building courses to new lawyers, by encouraging and building sensitiveness among professionals towards advocating for these new issues. Therefore, they intend to provide sustainability and continuity to developed projects.

The status of NGOs institutionalization may be assessed through its status concerning official registration. Taking all of the NGOs surveyed all over the country (328) into consideration, most claim to have a Corporation Taxpayer Identification Number – CNPJ, equivalent to 99.4%, corresponding to 321 organizations. That is to say that such institutions are eligible for financial resources for projects supported by federal, state and municipal governments, and even by international cooperation agencies, through partnerships. (Table 4.14)

TABLE 4.14 – Number and ratio of NGOs/AIDS according to CNPJ – 2003

Have CNPJ	N	%
Yes	321	99.4
No	2	0.6
Total	323	100.0

Source: UNESCO. *National Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003.
Question: “Does the organization have a CNPJ?”

Among the fourteen alternatives for political partnership at national level, according to Table 4.15, major public institutions that hold partnership with NGOs surveyed are, in descending order, State STD and AIDS Coordination, Municipal STD and AIDS Coordination, Health Secretariat, Education Secretariat, the Office of Attorney General (Ministério Público), Ministry of Justice, Program Coordination Offices Human Rights Secretariat.

More specifically, when the survey asked NGOs leaders about partnerships with other programs and/or Health Ministry secretariats, 43.3% have signed this option.

Concerning partnerships with other non-governmental organizations, NGOs/AIDS report percentages equivalent to 65.9%, while mixed NGOs account for 50.5%.

The most acceptable explanation for such percentages concerning these kinds of partnerships is the gradual waste of other international resources, in the 1990's, to programs on fight against AIDS in Brazil. Therefore, NGOs were led to establish local partnerships to maintain community-based actions. To face this new panorama, the NGOs perceived the relevance of NGOs/AIDS sharing technology to develop managerial skills, external relationships, strategic planning and similar topics.

Concerning other social movements and private institutions, 60.4% and 43.3% of NGOs leaders, respectively, have stated to hold such partnerships (Table 4.15)

TABLE 4.15 – Number and ratio of NGOs/AIDS according to partnerships at local and/or national level – 2003

Partnership	N	%*
State STD/AIDS Coordination	264	80.5
Municipal STD/AIDS Coordination	238	72.6
Health Secretariats	230	70.1
NGO/AIDS	216	65.9
Other social movements	198	60.4
Mixes NGO	164	50.0
Private institutions	142	43.3
Other programs and/or secretariats of the Ministry of Health	142	43.3
Education Secretariats	108	32.9
Government Prosecutors Office	105	32.0
Ministry of Justice	92	28.0
Programs coordination units	89	27.1
Human Rights Secretariat	73	22.3
None	6	1.8

Source: UNESCO. *National Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003.

Question: "Which partnerships (political) does the organization hold at local and/or national level?"

* Percentages do not total 100.0% because each organization could point out more than one partnership.

According to d'Ávila (2001: 63) the establishment of proper conditions to settle articulations and partnerships towards an effective response to STD/AIDS means that social sectors, whether governmental or not, developing joint works at their level of competence and representativeness, with their knowledge and qualification, would make up a network of technical, financial and operational cooperation. D'Ávila adds that this network would solely and clearly imply the clear definition of the object of said articulation, i.e., reduction of damages and diseases caused to population, resulting from HIV/STD/AIDS epidemic, through actions to promote the fight against those conditions that increase vulnerability to the transmission of AIDS virus and other diseases. He adds that, as according to Health Organic Law health levels point out the country's social and economic organization, thus conditioning and determining factors to such vulnerability should be taken into account.

The survey also pointed to the need for agreements with other secretariats, not only with the health secretariat, but also those of education, culture, justice.

In general, all interviews asked for more effective presence of financing agencies and the National STD and AIDS Program to follow-up and discuss issues related to works developed by NGOs and Governmental Organizations.

As regards partnerships at international level, the major organizations with which surveyed NGOs usually establish partnerships are, in descending order: 76.2% with UNESCO, followed by far by UNODC (39.6%) and 23.2% is and little more than 1/10 with UNAIDS. The other international organizations, such as UNICEF, UNFPA and the European Commission report much lower percentages, respectively 9.5%, 6.1% and 3.7%. Table 4.16 below shows equivalencies in absolute numbers of data referred to.

TABLE 4.16 – Number and ratio of ONGs/AIDS according to partnerships with international organizations – 2003

Partnership	N	%*
UNESCO	250	76.2
UNODC	130	39.6
Private international cooperation agencies	76	23.2
UNAIDS	36	11.0
UNICEF	31	9.5
UNFPA	20	6.1
European Commission	12	3.7
None	37	11.3

Source: UNESCO. *National Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003.

Question: “Which partnerships does/did the organization hold with international organizations?”

* Percentages do not total 100.0% because each organization could point out more than one partnership.

The high percentages reported to UNESCO and UNODC are probably bound to one of the criteria set forth to select NGOs for this survey, i.e., the NGOs commitment to actions related to AIDS, specifically supported by UNESCO and UNODC. However, as previously stated, the survey universe (576 NGOs) is very close to the total number of NGOs/AIDS existing in Brazil. The direct mail of the NGOs articulation sector of the National STD and AIDS Programme has about six hundred addresses, including organizations that, despite working with AIDS, should not be considered as typical NGOs/AIDS. Therefore, the result is very likely to have no biases. Furthermore, the outstanding roles played by the financial support of some international organizations in early stages of Brazilian non-governmental response to AIDS, in the 1980’s are worth mentioning. Also outstanding was the articulation and technical and political exchange with the international movement of fight against AIDS. According to ABIA (2004:02), international cooperation still plays core role in providing financial support to anti-AIDS actions in Brazil, whether through the World Bank, United Nations agencies or private agencies. Similarly – still according to ABIA – the articulation with foreign community-based organizations and the

participation in international forums have been important to political consolidation and intensification of strategies on the struggle against AIDS among civil society.

Furthermore, it should be outlined that UNESCO holds over 2000 agreements for financing activities with NGOs, encouraging ideas and projects from sectors typically isolated from public policies, thus facilitating access to basic health services.

Brazil is outstanding worldwide for its actions on the struggle against the epidemic and assistance to those who, in different ways, are afflicted by AIDS. This outstanding role is due to the Brazilian model of establishing partnerships between civil and political society. On the other hand, international cooperation plays a very important role, such as UNESCO, in this network that has mainly contributed towards enforcing one of the agreements within the framework of the “2001 Declaration of Commitment on HIV/AIDS,” i.e., international cooperation and technology transfer to other countries.

Reviewing the NGOs sources of resources, Table 4.17 shows that percentages range from 78.0% to 39.9%. The first and major sources of resources are from: agreements with public bodies (78%), and donations by individuals (72.6%). The remaining sources account for about 40.0% and are through corporate donations (48.2%), punctual sponsorships (43.6%), international cooperation agencies (40.9%) and other non-specified sources (39.9%).

Major NGOs hold partnerships with local, national and international institutions for the planning, execution and assessment of implemented projects and activities. They also rely on donations by community individuals and corporations.

This situation clearly portrays the crucial role that partnerships with the government play, whether at federal, state and/or municipal level. Undoubtedly, it interferes with NGOs financial sustainability and continuity of transfers through agreements.

TABLE 4.17 – Number and ratio of ONGs/AIDS according to sources of resources – 2003

Sources of resources	N	%*
Agreements with public bodies	256	78.0
Donation by individuals	238	72.6
Donation by corporations	158	48.2
Punctual sponsorships	143	43.6
International cooperation agency	134	40.9
Others	131	39.9

Source: UNESCO. *National Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003.

Question: "Which are the sources of resources of this organization?"

* Percentages do not total 100.0% because each organization could point out more than one source of resources.

According to Lório (2001:55), when the institution mobilizes resources, mainly local and national ones, it usually reorganizes and changes its structure of leadership, execution and administration. Some steps that follow the decision on raising funds are to try to involve the team as a whole, including high-level officers, induce efficiency, efficacy and institutional transparency – he adds.

Many volunteer professionals provide valuable contributions to organizations, like support of graphics, advertisement agencies, among others. These contributions were and remain important contributions to develop the organizations.

When referring to the concept of sustainability, it is worth noticing that it is not only about sources of financial resources, but also technical and political resources to execute health policies and programs. According to d'Ávila (2001:59), sustaining would mean to provide support, grounds, basic support to re-order such necessary resources, and health public policies sustaining would mean to grant them as priority, acknowledging them as a structure with nontransferable elements and, ultimately, means defending them from fragmentation and demobilization of such elements; this is the requirement to generate favorable conditions to make up its resources.

The speech by NGOs leaders provides three common views in relation to the concern about new challenges brought about by changes in the perspectives of social projects financing. Therefore, NGOs with more resources are those sponsored, since

their early stages, by international organizations. Then, they have more projects sponsored by the government, since they have invested more, became more professionals and are better prepared.

Some NGOs have reported great interest in retaking financing to their works. Currently, many of them work without any sort of governmental financing, and this was a prevailing topic in interviews held with leaders. Such NGOs lack government financial support to projects executed or activities being developed with population. However, some interviews clearly disclosed the existence of NGOs closing their works for lack of working space, personnel, project and resources. The problem has not yet been dimensioned, but it can be observed, besides important works interrupted for lack of resources, the establishment of some NGOs due exclusively to the existence of such resources.

NGOs face similar problems, regardless their focus on gender, race, human rights or AIDS. NGOs financial sustainability seems to be one of the most serious problems nowadays, not only in the field of AIDS.

The survey asks if the NGOs participates in social control spheres. Most organizations participate in Health Councils (51.2%). In second place, the State STD/AIDS Commissions are mentioned (39.0%), closely followed by other non-health institutions, which account for 38.4%. The participation of these NGOs at the National STD/AIDS Coordination Committee (18.3%) and Inter-managerial Councils (12.2%) is less expressive. It is interesting to notice that almost 1/5 of the surveyed NGOs (18.9%) state that they do not participate in any sphere of social control. (Table 4.18)

TABLE 4.18 – Number and ratio of ONGs/AIDS according to their participation in social control spheres – 2003

Social control spheres	N	%*
Health Councils	168	51.2
State STD/AIDS Commissions	128	39.0
Other non-health institutions	126	38.4
None	62	18.9
Advisory Committee to the National STD/AIDS	60	18.3
Inter-managerial Councils	40	12.2

Source: UNESCO. *National Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003.

Question: "Does the organization participate in any of the following social control spheres?"

* Percentages do not total 100.0% because each organization could point out more than one social control sphere.

According to the Brazilian STD and AIDS Programme (June 2003), additionally to State Strategic Pluri-Annual Plans, the annual Plans on Actions and Goals for the 26 Brazilian States, the Federal District and 411 municipalities now participate in planning actions to fight HIV/AIDS, reaching 53.34% of the population and 91.48% of AIDS cases reported in Brazil. That would mean a 14.05% expansion in coverage to population, and 23% in relation to AIDS cases in Brazil, from 2001 to 2003. It is worth mentioning that Strategic, Actions and Goal Plans are prepared with the effective participation of all participants involved, including Civil Society Organizations (OSC), thus ensuring the required transparency to the process and more effective social control.

For d'Ávila (2001: 60), there is a gradual increase on articulations with other health programs, as well as with other Ministries and civil society sectors. The commitment towards fighting the AIDS epidemic in Brazil is gradually shared with other Ministries, showing required joint liabilities to fight the epidemic. Thus, the Ministry of Education undertook measures aimed at children and youth enrolled in the Brazilian public school network, and the Ministry of Health took measures aimed at prisoners.

Major strong points identified for the sustainability of civil society actions in fighting HIV/AIDS are: NGOs union; room conquered at several social control spheres such as municipal, state or national councils. These spaces are converted into effective partnerships of visibility, actions and activities.

Some NGOs would like to have deeper insertion into local and national movement against AIDS, either because they lack political representation or sometimes because they are located in remote areas. These NGOs receive information through the Reference Centers they are bound to. Other NGOs actively participate and have political representation at local, state, federal and international levels, like: *international level* (ILGA, ASICAL, YOUNGALAK); *federal level* (ENNGO, National STD/AIDS Coordination, National Committee on Anti-HIV Vaccinations, National Forum of Rights of the Children and Adolescent, National Committee of Fight against

the Abuse and Sexual Exploitation of Children and Adolescents); *state level* (State STD and AIDS Commission, NGOs/AIDS Forum, State Council of Rights of the Children and Adolescent); and *municipal level* (Municipal and District Health Council, Municipal Council of Rights of the Children and Adolescent, Human Rights Defense Steering Committee), among others.

Most organizations surveyed somehow participate in the formulation of governmental public policies, by qualifying NGOs (54.3%), in human rights and citizenship (48.5%), access to preventive devices (46.6%), free access to treatment (39.0%), free access to drugs (38.7%), access to early diagnosis (27.4%) or supply of HIV assay during pre-natal care (22.3%). Only 22.6% of these NGOs are not inserted into the formulation of public policies. (Table 4.19)

TABLE 4.19 – Number and ratio of NGOs/AIDS according to participation in the formulation of governmental public policies – 2003

Participation in the formulation of public policies	N	%*
NGO qualification	178	54.3
Human rights and citizenship	159	48.5
Access to preventive devices	153	46.6
Free access to treatment	128	39.0
Free access to drugs	127	38.7
Access to early diagnosis	90	27.4
Supply of HIV assay during pre-natal	73	22.3
None	74	22.6

Source: UNESCO. *National Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003.

Question: "Have your NGO participated, in any way, in the formulation of public policies related to?"

* Percentages do not total 100.0% because each organization could point out participation in the formulation of more than one kind of public policy.

The highest percentage is reported to NGOs qualification activities. This is so probably due to loans granted by the World Bank that, in AIDS II (1999 to June 2003), placed emphasis on the "technical qualification" component that aimed to provide continuity to institutional support provided along AIDS I (1994 to 1998). The focus of AIDS I was placed on institutional

development for the strengthening of NGOs infrastructure, without prioritizing aspects related to technical qualification.

Furthermore, the I Workshop on Sustainability to Community-Based Actions against HIV/AIDS, held in Rio de Janeiro in October 1998, was attended by representatives from the most relevant Brazilian NGOs/AIDS of the five geographic regions. The Workshop pointed out the development of capacity-building programs to leaderships as a stage towards sustainability.

Therefore, the articulation between state and civil society has allowed for the approval of two huge projects with the World Bank, namely AIDS I (ended in 1998) and AIDS II (ended in 2003). In face of the perspective of interruption in financing, most of the 600 organizations working in the field of public health were threatened of being extinguished. In order to avoid a crisis in NGOs/AIDS activities, the National STD/AIDS Coordination launched a national program on institutional sustainability, where 180 organizations countrywide participate. These organizations are being trained to adopt modern managerial techniques, such as strategic planning, local resources intake and social market, to grant a continuous process of sustained development.

Within the universe surveyed, there are different degrees of institutional development. Without the allotment of resources to NGOs development and capacity building (“core funding” GALVÃO, 2000:160) to assist them in finding their *actual sustainability*, NGOs/AIDS are now even weaker than in other times. In fact, with guidelines centralized by the National STD/AIDS Coordination (AIDS I and II), the NGOs were mostly configured as service providers for a myriad of actions. Therefore, their role was mainly of representing and rendering services to audiences that are not supplied with Governmental actions.

The Brazilian Association of NGOs – ABONG was established in 1991, and aimed at representing and promoting exchange among NGOs committed to strengthening citizenship, expanding social rights and democracy. Despite this purpose, it is worth noticing that only 22.6% of the surveyed NGOs are members of the

Brazilian **Association of NGOs**. That is probably because the ABONG gathers many other NGOs that are not representative to the movement against AIDS. (Table 4.20).

TABLE 4.20 – Number and ratio of ONGs/AIDS according to affiliation to the ABONG – 2003

Member of the ABONG	N	%
Yes	72	22.6
No	247	77.4
Total	319	100.0

Source: UNESCO. *National Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003.
Question: “Is the organization a member of the ABONG (Brazilian Association of NGOs)?”

According to Table 4.21 below, most of the NGOs surveyed (68.1%) are affiliated to some network and/or articulation of the movement.

According to ABIA (2004: 5), the organization of activists and groups from several and different structures – such as meetings, networks and forums – has succeeded in providing visibility and resonance to the fight against AIDS. This diversity allows for intensive information exchange and partnership between peoples and organizations, fact that enhances representatives’ position in the dialogue with government and civil society, while preserving different political standings, specificities of interest and work.

TABLE 4.21 – Number and ratio of ONGs/AIDS according to affiliation to network and/or articulation of the movement – 2003

Member of the network or articulation of the movement	N	%
Yes	218	68.1
No	102	31.9
Total	320	100.0

Source: UNESCO. *National Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003.
Question: “Is your organization affiliated to any network and/or articulation of the movement?”

One of the major networks in the field of HIV/AIDS is the National Network of People Living with HIV/AIDS – RNP+, comprised of HIV carriers. The core principles of RNP+ are: To allow actions against discrimination; to ensure the participation of seropositive individuals in governmental decision-making spheres and daily life of NGOs; and to qualify HIV carriers to exercise their citizenship rights. These are principles formulated based on the document that justifies RNP+ establishment. An important issue in RNP+ establishment was that it should be an association of individuals, rather than of organizations, although most of its members are bound to some NGOs.

One strategy of the RNP+ is to establish and consolidate local, state and regional nuclei. Currently, RNP+ has five regional secretariats and 27 state representatives, besides municipal representatives in several states. In São Paulo – the state with the highest number of AIDS cases in Brazil – there are seventeen municipal representatives of the RNP+.

According to information provided by ABIA (2004: 7), in the light of horizontality, characteristic to a network, each nucleus works with some degree of autonomy, complying with the network's general principles. However, this proposal is a major challenge to RNP+, i.e., its maintenance as an organized social movement, although not institutionalized. Another major challenge is to grant the network enhancement keeping the horizontality in political decisions. The network's financial sustainability depends on each nucleus. In general, self-management is the most suitable approach, through local projects on income generation. Nevertheless, some nuclei propose converting the network into an NGOs, to facilitate resources intake.

It should be stressed that almost 78.0% of the organizations participate in state NGOs forums. Only 1/5 of the NGOs do not participate in such forums, probably due to lack of financial resources, as reported during person-to-person interviews held with NGOs leaders. (Table 4.22)

TABLE 4.22 – Number and ratio of NGOs/AIDS according to participation in state forums – 2003

Participation in state forums	N	%
Yes	251	77.7
No	67	20.7
Total	323	100.0

Source: UNESCO. *National Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003.
Question: “Does the organization participate in state NGOs forums?”

NGOs Forums are a response to the need for setting collective spaces for discussing articulated strategies of political action concerning AIDS, aiming at achieving more actions than would be possible through isolate action by an NGO. These organizational structures facilitate and enhance the articulations at national level.

The forums’ principle is to reach autonomous articulation at state level, despite their differentiated structures of working and regulation. By definition, only NGOs/AIDS can participate in the forums, where isolated individuals or any other kind of NGO are not accepted. These forums have succeeded in developing their activities thanks to the cooperation of the NGOs/AIDS, additionally to the support of State STD and AIDS Coordination Units. However, the expansion of these organizational structures brings about sustainability issues – mainly financial sustainability – according to the representative of São Paulo Forum, who also warns about the need for greater and more agile budget to afford with increasingly demands. Simultaneously, there is a resistance against converting the Forum into a NGO, since it could change its characteristic as a sphere for political articulation.

A remarkable aspect of NGOs/AIDS Forum development is the specialization and intensification of its activism actions, through the creation of Theme Commissions – such as ERONG, ENONG, Legal and Communication – additionally to Work Groups – HSH, Adolescents and Children and Damage Reduction.

The Forum is acknowledged beyond its actions in fighting AIDS. It actively works with other social movements such as the Forum of Pathologies and Forum of NGOs (initiative of ABONG). It has seats

in State and Municipal Health Councils. Among its partners, additional to STD and AIDS Programmes at Municipal, State and Federal levels, there are the Executive Power, Legislative Power and Government Prosecutors Office.

The first NGOs/AIDS Forum was established in 1996, in the State of São Paulo, with the objective of discussing proposals on joint actions among NGOs, both inland and in the capital. In principle, the forum did not have a formal legal bylaw. Only in 1997, the bylaw was enacted. Nevertheless, it is worth noticing that, previously to 1996, efforts were made to pursue more agile political articulation to NGOs/AIDS at local level. The decision to establish the forum was made based on increased epidemics in terms of number of cases and complexity, its spread towards the Brazilian inlands, and the increasing number of NGOs/AIDS in cities far from decision-making, political articulation and knowledge dissemination centers. Furthermore, the temporary political disarticulation of NGOs, resulting from issues related to projects financing, served to encourage the forum establishment. As defined in the Chart of Principles of São Paulo NGOs/AIDS Forum (1997), “Forum is a place to discuss topics of public interest”.

São Paulo NGOs/AIDS Forum claims as its major successes: more intensive and horizontal articulation with inland NGOs; formal partnership with State STD and AIDS Coordination, which attends the Forum meetings; enhancement of NGOs/AIDS in the State of São Paulo.

In the same year when the São Paulo State NGOs/AIDS forum was established, Rio de Janeiro also settled its forum. In its chart of principles, they set forth that Rio de Janeiro State NGOs/AIDS Forum is the representative sphere for Non-governmental and Non-profitable Entities developing activities in fight against HIV/AIDS epidemic in the State. According to the Chart of Principles of Rio de Janeiro State NGOs/AIDS Forum, its objectives comprise exchanging experiences, information, skills and resources among NGOs/AIDS; elaborating proposals to strengthen the set of NGOs besides Public Bodies and the Civil Society; debating, thinking about and preparing

public health policies in prevention and assistance to STD/AIDS; articulating, integrating and cooperating with NGOs/AIDS at municipal, state, national and international level. Its highest deliberative sphere is the National Meeting of NGOs/AIDS.

As concerns participation in national meetings, 40.9% of the surveyed organizations have never participated in any National Meeting. Furthermore, only 27.4% claimed to have participated in the NGOs National Meeting held in Belo Horizonte in 1999, while in 2001, in Recife, 37.2% of the NGOs participated in the meeting. However, although 33.8% did not participate in such meetings, they have attended other events. (Table 4.23)

TABLE 4.23 – Number and ratio of NGOs/AIDS according to participation in National NGOs Meetings – 2003

Nationals Meetings	N	%*
None	134	40.9
Recife (2001)	122	37.2
Others	111	33.8
Belo Horizonte (1999)	90	27.4

Source: UNESCO. *National Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003.

Question: "Did the organization attend the National NGOs Meeting?"

* Percentages do not total 100% because each organization could point out participation in more than one National Meeting.

It is worth recalling that the I National NGOs/AIDS Meeting was held in 1989, and attended by approximately thirth individuals and fourteen organizations. As of that year, the National NGOs/AIDS Meetings were held on regular basis, and became the highest sphere for discussing and reviewing the guidelines to NGOs/AIDS actions in Brazil. Nevertheless, since 1987 the Groups of Support to AIDS Prevention, in different Brazilian states, used to meet to establish a consensual platform of actions.

As previously mentioned, the expansion of NGOs/AIDS in Brazil, and their articulation with the international anti-AIDS movement set forth the need for an organizational jump in the movement. It was accomplished through the National Meetings and, later, through State and Regional Meetings.

The survey asked if the NGOs attended the last Regional NGOs Meeting. In 2001, 56.7% of the surveyed NGOs attended the ERONG. According to the interviewees, the NGOs do not stimulate their target-audience towards participating in meetings, due to the lack of financial resources (Table 4.24).

TABLE 4.24 – Number and ratio of NGOs/AIDS according to participation in the latest regional NGOs meeting – 2003

Participation in the latest Regional NGOs Meeting	N	%
Yes	183	56.7
No	140	43.3
Total	323	100.0

Source: UNESCO. *National Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003.
Question: “Did the organization attend the latest Regional NGOs Meeting (2001)?”

The major ways for advertising works developed by the NGOs surveyed, in descending order, are: Meetings (80.2%), seminars (73.2%), printed material (71.6%), congresses and conferences (50%), videos, journals and magazines (30%) and books (15.9%).

Table 4.25 below discloses the figures corresponding to the way of advertising the works developed by NGOs.

TABLE 4.25 – Number and ratio of NGOs/AIDS according ways for advertising the work developed – 2003

Ways for advertising the works	N	%*
Meetings	263	80.2
Seminars	240	73.2
Printed material	235	71.6
Congresses	186	56.7
Conferences	172	52.4
Videos	111	33.8
Journals	105	32.0
Magazine	90	27.4
Books	52	15.9
Others	175	53.4

Source: UNESCO. *National Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003.
Question: “Ways for advertising the works developed by your NGO”.

* Percentages do not total 100% because each organization could point out more than one way of advertising.

It is outstanding that over 53.0% of the leaders of surveyed NGOs point out other unspecified ways for advertising. Probably, works are advertised through the NGOs beneficiary audience, as reported during the interviews carried out in the survey. These so-called “multipliers” disseminate the NGOs work, and inform their community, or field of work (for example, sex professionals) or the area wherein the NGOs is located.

NGOs visibility is also measured by presentation of the organization work abroad. 58% of surveyed NGOs works have been quoted or presented abroad, according to Table 4.26 below. One third of said works were advertised through international congresses (33.5%), and through Internet, by the organization itself or visited by foreign agencies and technicians, both reporting the same percentage of 31.4%. Other ways of acknowledgement abroad, such as: foreign financial support (24.7%) and those mentioned by agencies abroad or foreign experts in works, through Internet or international press (20.1%). Furthermore, 20.1% of the surveyed NGOs mention “other kinds”. (Table 4.27).

TABLE 4.26 – Number and ratio of NGOs/AIDS according to works commented or presented abroad – 2003

Works commented or presented abroad	N	%
Yes	189	58.0
No	137	42.0
Total	326	100.0

Source: UNESCO. *National Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003.
Question: “Were the works by your organization commented or presented abroad?”

In brief, the field of NGOs/AIDS in Brazil – according to dimensions reviewed herein – is diversified and heterogeneous and thus hinders the task of establishing an accurate profile of what would bea NGOs/AIDS. They are extremely dependent on articulations, whether among entities, or with the State and international organizations. Nevertheless, they are legitimated by mobilizations in different ranges concerning audience and interlocutor.

TABLE 4.27 – Number and ratio of ONGs/AIDS according to how works have been presented or commented - 2003

Means of presentation or comment	N	%*
International congresses	110	33.5
The organization disseminates through Internet	103	31.4
Visitations by foreign agencies and experts	103	31.4
Foreign financial support	81	24.7
Quoted by agencies abroad or foreign experts in works, through Internet or international press	66	20.1
Other kind of acknowledgement abroad	66	20.1

Source: UNESCO. *National Survey on Responses to AIDS Challenges in Brazil: limits and possibilities*, 2003.

Question: "If the answer to the question above is year, how have these works being presented or commented?"

* Percentages do not total 100% because each organization could point out more than one way of presentation or comment.

Here, it is worth underlining that this diversified range of target-audience and kind of services provided, besides the referential activity, provide these NGOs/AIDS with flexibility and relevance to disseminate actions and policies beyond the mere care to people with AIDS and their family members. NGOs/AIDS have highly contributed towards challenging a homophobic and stigmatizing culture. Many of them move among community-based, local and social control activities, as well as the field of proposing policies. Therefore, they do not necessarily fit into collective, although individually many of them fit more into one or another type, between working at micro/local level, or macro/national level. Such smooth flowing, or broad demarcations, brings sophisticated issues for their sustainability – whether political or financial – as well as to the sustainability of the State system that support them. This system also highly depends on them, i.e., the civil society. This issue will be deeply discussed in further chapters.

5. SOME EXPERIENCES BY CIVIL SOCIETY AND THEIR PERSPECTIVES IN THE FIELD OF RESPONSES TO THE AIDS EPIDEMIC

5.1 PRESENTATION

Following are some examples of civil society work in the field of AIDS, as well as some experiences of certain states. The selection was fortuitous, aiming at better representation of the myriad of NGOs and social movement entities, taking into consideration the variety of target-audiences, size and services provided. Some are NGOs/AIDS; others are mixed in relation to projects and audiences.

Additionally to characteristics, their projects, methodology, types of participation in networks, partnerships and background, it also includes perceptions and reflections on the relationship between civil society and State, sustainability – political, technical and financial –, autonomy and perspectives to the AIDS movement.

Their posture, criticisms and suggestions concerning the States' and NGOs' dynamics are noted, pursuing records with no assessment and totaling and comparative inferences on the AIDS movement or about the field of civil society organization in this area. The major purpose here is to map experiences, itemize practices and a plural imaginary, rather than to carry out a comprehensive analysis or make generalizations about such a heterogeneous and diversified universe.

That is why this study elected individual profiles of entities, stressing that they were not necessarily selected pursuant to performance criteria. The selection does not mean that entities are not outstanding in relation to others missing in this random sampling,

nor does it intend to assess their criticisms and postures as “right” concerning the object of their references or representative to a single prevailing trend in this field. In opposition, what is outstanding in individualized cases reviewed is the rich diversity of postures and practices, besides working structures and sustainability. Nevertheless, it also underlines the concern of all the selected NGOs for the continuity of their work, with their autonomy besides the State – although different NGOs qualify this issue in different ways – and the distress in relation to their sustainability, at several levels, especially in medium- and long-term.

5.2 CORE ISSUES

Currently, one of the major debates within the context of NGOs/ AIDS concerns two issues deemed as extremely important to continuity, both for the quality of services provided to individuals living with AIDS in Brazil, and to actions on prevention. One issue concerns the difficulties faced in the field of sustainability – mainly financial but also technical – of organizations basically aimed at actions to fight the epidemic. The other refers to the field of political legitimacy that, in a broader level, converges to an assessment on political interlocations by these institutions, one to another and with governmental spheres, at municipal, state and federal levels.

Nowadays, in face of significant changes on dilemmas comprised by a context where people live and co-exist with the AIDS epidemic, there is a trend towards retaking crucial issues that have followed early Brazilian experiences in their path towards dealing with pressures related to deaths from AIDS, which have strongly marked the first decade of this epidemic in Brazil.

This context brings back the difficulties faced by people living with AIDS in having access to specialized services, besides the threat to Brazil, taking into consideration the global context in relation to the difficulty in maintaining access to latest antiretroviral drugs. If people and civil society organizations working in the epidemic field

make pressure towards effective access to treatment and drugs that alleviate the harms caused by AIDS, currently new mobilizations are taking over the political scenario of fight against the epidemics, with new or even recurring claims, trying to avoid recurring threats in the quality of the important Brazilian Program.

The field of prevention faces quite similar issues. Tensions here range from maintenance of continuous activities on the promotion of knowledge and information required to control HIV spread, to standings of political coherence being challenged by most NGOs. These NGOs ideologically claim that full exercise of rights and citizenship is directly related to epidemic control.

In this sense, the historic construction based on a broad dialogue between the Brazilian movement of fight against AIDS and the competent governmental spheres, in this case the current National STD and AIDS Programme, should be highlighted.

This chapter intends to describe the current – 2003 and early 2004 – Brazilian scenario of debate on sustainability of national actions, especially those developed by the diversified set of NGOs/AIDS, and including some institutions that have added the topic to their political and activities agenda. Nevertheless, it tries to point out the major perceptions and tensions existing in the relationship between the organized civil society agencies and the Brazilian government, through the introduction of governmental financing, which encouraged the “Brazilian response to HIV/AIDS epidemic” (expression employed by Jane Galvão, 1997).

5.3 THE ISSUE OF SUSTAINABILITY TO NGOS

According to ARMANI (2001), in his paper entitled “*O desenvolvimento institucional como condição de sustentabilidade das ONG no Brasil*,”⁴⁰ the debate on this issue within the scope of the Brazilian

⁴⁰ The institutional development as a requirement for NGO sustainability in Brazil.

Non-governmental Organizations should take the following into consideration: 1) the framework of substantial changes in the context of current scenario wherein the NGOs work in Brazil; and 2) current parameters employed for the analysis of the institutional development used by NGOs as a strategy to sustain their actions.

Concerning shifts in the context, the author highlights important factors that have changed international and national plans. At the national level, Armani (op. cit.) highlights three major movements that headed such changes in context and structure: the democratizing movement, the privatizing movement and the identity-building movement. When combined, they interfere in the field of action of social movement and the Brazilian NGOs. Although Armani (op. cit.) considers the integration of these three movements as very relevant – an acceptable argument – this study places emphasis on the democratizing and identity-building movements. These movements seem to provide more theoretical contributions to explain the current context of tension experienced by NGOs dealing with HIV/AIDS.

5.3.1 THE DEMOCRATIZING MOVEMENT AND THE ARRIVAL OF THE AIDS EPIDEMIC TO BRAZIL

The democratizing movement, or so-called ‘Age of Rights,’ took place in the 1980’s and early 1990’s. This movement was a process of intensive social mobilization and increased participation and social control over public policies. The milestone for this moment was the 1988 enactment of the Brazilian Constitution referred to as the ‘Citizen Constitution’.

Armani’s article (2001) points out that, in that period, the introduction of new social and economic rights into civil society is outstanding. They resulted in expanded rights of political citizenship and principles of decentralization, besides institutionalized popular participation in the promotion of social policies.

This new context led the social movements and NGOs to improve their technical and political interventions, aiming at meeting the new demands and disputes now existing in the social field.

According to Armani (op. cit.), these processes have also represented new challenges to social movements and NGOs, concerning greater public exposure and requirements in relation to their legitimacy, autonomous organization and quality of work.

Parker (1994) highlights this period as a very relevant one, since the HIV/AIDS epidemic started to be shaped in Brazil within the context of such changes in the Brazilian policy. In fact, the Brazilian society responses were conditioned by some elements of this specific set of circumstances, such as: contradictions resulting from several social changes; fast growth and urbanization, which changed the old society basically a rural one and created new economic and social dimensions that expanded the Brazilian structure of life; the economic model based on external debt and structural dependence, thus producing many serious economic crises and extreme recession at the end of the 1980's and in the early 1990's; the end of a military dictatorship that lasted twenty years (1964 to 1984); and the start of a democratization process in Brazil.

Parker and Daniel (1991) consider that this 20-year period of authoritarian military government, followed by a gradual return to democracy – from the mid to late 1980's – jeopardized the legitimacy of several political institutions. Altogether, these processes have resulted in an extensive deterioration of public health and social welfare systems, thus limiting the Brazilian society capacity of approaching the countless existing health problems. Furthermore, that period conditioned how the Brazilian society could respond to the outbreak of a new infectious disease – explosive in social, cultural and epidemic terms.

Concerning the struggle against the AIDS epidemic – that had recently arrived in Brazil at that time – one consequence of such political and economic contexts, according to Parker and Daniel (1991) was the lack of a pragmatic posture on behalf of the Brazilian government as regards the formulation of public policies suitable to

the epidemic spread. The epidemic was then considered limited to ghettos and stigmatized and marginalized groups (prostitutes, male homosexuals and drug users).

Only in 1985, in response to huge international pressure, did the Brazilian government enact the administrative rule that set forth the establishment of a National Program of Fight Against AIDS. A national division of STD and AIDS control, within the Ministry of Health, should prepare the Program. In 1986 this new division became functional in a relatively limited way, and started working on the development of an initial 5-year plan, aimed at leading the Ministry of Health's response to the epidemic until 1991 (Ministry of Health, 1987).

From 1986 to 1993, the health promotion actions developed by the Ministry of Health in relation to the AIDS epidemic were marked by the employment of information-based education. In 1987 and 1988, a large-scale educational program started to be implemented. In this regard, television – as a communication means that, in principle, reaches all layers of the society and different regions in the country – became the vehicle for educational campaigns on fight against AIDS, at national level, additionally to several materials that followed TV campaigns (posters, folders and outdoors).

In 1993, when the Minister of Health appointed by ex-President Fernando Collor, Mr. Alcení Guerra, resigned and Mr. Adib Jatene was appointed to the office, several important decisions were made within the scope of the National Programme on Fight against AIDS. One of the most relevant decisions was the establishment of political articulation, with scientific and research communities and non-governmental and community activists organizations, through the creation of liaison unit with NGOs⁴¹, within the framework of the National Program on Fight against Aids⁴².

⁴¹ DANIEL; PARKER (1991) stress that, in middle 1980's, even before the establishment of the National Program on Fight against AIDS, the epidemic had already become the focus of attention of several kinds of organization. Many existing organizations, and mainly the organizations of gays, started working in several preventive and educational activities, aiming at responding the known risk faced by homosexuals. Following the broader trend of NGOs creation in Brazil, new organizations emerged specifically oriented to AIDS, as their solely concern.

⁴² In that year, the Programme started dialogues with the World Bank in order to negotiate a financing, based on a loan to the Brazilian government.

Almost twenty one years after the notification of the first case of AIDS in Brazil, and based on experiences by organized civil society sectors in the field of prevention against HIV/AIDS, education and health promotion proved to be, in short-term, the only efficient strategic actions capable of fighting the spread of the Acquired Immunodeficiency Virus.

Within this context, Parker (1994) mentions three significant areas where strategies on education and health promotion towards fighting the AIDS epidemic are concentrated, due to the population of individuals engaged in risk behaviors to HIV transmission. The areas would be: 1) mass communication means⁴³; 2) information and education campaigns at national level, under the leadership of the National AIDS Program, of the Ministry of Health; and 3) health promotion activities developed at local and state level, mainly through the work by non-governmental organizations providing AIDS-related services⁴⁴.

It is worth noticing that, for a long period, the discourses on education towards prevention against HIV/AIDS placed their focus on the issue of risk reduction dissociated from a broader set of issues that, within a more sophisticated understanding on the epidemic, should also be taken into consideration. In this regard, the risk reduction approach should loose its individualistic, reductionist and fragmented content, and incorporate new dimensions of human existence, such as sexuality, identity, values, symbolic representations, power relationships and citizenry.

In 1993, upon the signing of the first Loan Agreement with the World Bank (IRDB) – AIDS I, the National STD and AIDS Programme mobilized financial and human resources that allowed it to establish the required infrastructure for the Public Health Network to meet several aspects resulting from the epidemic. Still in this context, the Brazilian government considered the enhancement of mobilization

⁴³ The press, radio broadcasters and television have contributed towards establishing what could be defined as a record of basic information – crucial to build up attitudes and practices related to HIV infection and AIDS (PARKER, 1994).

⁴⁴ Several NGOs have actively participated in the development of a set of specific material to health promotion, oriented to different groups of the Brazilian civil society, besides providing such materials to other organizations working on AIDS.

and participation of the organized civil society as a priority to the federal program. Another priority would be strengthening non-governmental organizations oriented to assistance to and/or prevention against STD/AIDS, within the scope of social actions to promote social networks capable of shifting attitudes and behaviors, reinforcing the need for adopting safe sexual practices to control the epidemic.

The documents of current National STD and AIDS Program (NP STD and AIDS) allowed the identification, from 1993 to June 1998 – as of the first Loan Agreement with IRDB – of financing granted to 559 NGOs projects oriented to several specific population segment, involving 174 institutions of different nature and objectives, countrywide, employing the strategy of qualifying information multipliers.

5.3.2 IDENTITY-BUILDING MOVEMENT AND TENSIONS OF THE AIDS MOVEMENT

Identity-building movement results mainly from the foregoing processes⁴⁵. According to Armani (2001), it brought to public arena the emergence of new social players and changes in the relationship between the State and civil society, induced by a tension on the identity plan of social players. Therefore, it threatened its own existence and the institutional sustainability.

The article also points out that this movement experienced an increasing articulation and action in networks, both of movements and NGOs, in national terms. It is so, for example, for the *Movimento dos Sem Terra*⁴⁶, Indigenous movement, female rural workers movement, Human Rights

⁴⁵ One of these processes is the privatizing movement that, as previously explained, was not approached herein, not in damage to its relevance, but because of elected priority to issues managed here. However, it is relevant to delimit the period of this movement. Privatizing period was marked by the insertion of neo-liberal policies in Brazil, as of Collor government, in 1990 and, more effectively, in 1995 with FHC Government.

⁴⁶ Landless Movement

movement, entities working with children and adolescents, social-environmental networks and NGOs/AIDS. It promoted theme forums to articulate joint actions, and assigned special role to the Brazilian Association of NGOs (ABONG) at national, regional and global scenario, fomenting and expanding spaces for debates and strategic dialogues.

The 1990's were also characterized by the establishment of partnerships between several social movements segments and NGOs with the Public Power. However, these partnerships that basically relied on financial support, additionally to logistic and political support, have stretched and challenged the principle of autonomy and identity of the social movements and organized civil society.

Intervene on public policies process, participate in councils and enter into dialogue with public bodies, while simultaneously developing joint projects, became mandatory line of action to social players in civil society. However, it poses new issues concerning the specific role of the movement and NGOs, besides trending to strengthen the institutional dimension and not necessarily the social dimension of these movements. On the other hand, many ex-activists of movements and ex-members of NGOs are now working to governments. This fact highly eclipses the political dimension of the relationship between civil society and State, besides bringing a huge risk for the government to become the key-actor, almost exclusive, in the social change. This would exhaust social movements and broader civil society. A core issue here is the identity of the Brazilian social players. The changes in the Brazilian state, the new trends in international cooperation, additionally to the emergence of new players in social field (Social Organizations, Social Organizations of Public Interest - OSCIPS, entrepreneur philanthropic foundations, Institute for Social Responsibility, new generations of identity within third sector, etc.) lead social movements and NGOs to reinvent themselves as relevant social players.

Another relevant factor in the field of context and structural changes concerns international cooperation relationships, inscribed in the broad process of transition from the liberal model of welfare state to the neo-liberal model, since early 1980's,

underwent constant and significant processes of reconfiguration. These processes match streamlining and/or resources reduction, intensification of spaces and mechanisms for dialogue and articulation, with greater requirements and controls on the performance of supported organizations. In this sense, Armani states in the article "*o desenvolvimento institucional como condição de sustentabilidade das ONG no Brasil*"⁴⁷(2001: 4) that events like reduction in governmental cooperation towards development, decreased contribution by public in general, reduced priority to Brazil, challenges on the efficacy of cooperation towards development, increased unemployment and social problems, etc. , have led the European cooperation agencies to: I) deeper process of institutional restructuring, which redefined their identity and public image, reinforcing their comparative advantages and competence in resources intake, placing greater emphasis on lobby and advocacy duties; ii) greater dependence on governmental resources; iii) resources streamlining, favoring Africa and Eastern Europe and reduced support to Latin America; iv) reduced number of supported organizations in Brazil and greater rigor in the selection of new partners; v) theme and regional concentration for Brazil; vi) more requirements in issues of organizational efficacy and institutional development, mainly in the fields of planning, assessment, monitoring, management and accountability; and, finally, vii) expanded opportunities of non-financial partnerships with the supported organizations.

Still in the international field, some events have enhanced the civil society works in new spaces and international networks of articulation and joint action. They are: conferences of the UN cycle, which allowed for building consensual political agendas, promoted strategic dialogues to enforce agreements and action

⁴⁷ The institutional development as a requirement to NGOs sustainability in Brazil.

strategies signed within the scope of said Cycle; public bidding for projects financed by the World Bank, the European Community, besides the emergence of events that demanded organic articulations to fight damages against acquired rights, as for instance the global mobilization to the Ministerial Meeting of the World Trade Organization (WTO), held in Doha in 2001, trying to avoid damages to acquired human rights, such as Right to Health, emphasizing the problems of the Trade-Related Aspects of Intellectual Property Rights (TRIPS), in force at the WTO since 1995, and which threatens accessibility to essential drugs.

This panorama of huge changes, transformations and realignments has challenged the capacity of civil society organizations to improve their institutional features and pursue new strategies that provide sustainability to their acts and works.

Referring once again to the article by Domingos Armani (*op. cit.*), the institutional development of organized civil society became a steady concern, “in the circles of cooperation towards the organizations’ development”. According to him, institutional development comprises processes and initiatives oriented to grant the sustainable achievement of the institutional mission, besides strengthening the strategic position of a given organization in the society. Therefore, it requires for measures (i) that strengthen the capacity of articulating initiatives and promoting social change processes; (ii) that expand the organization’s social basis / legitimacy and trustworthiness; besides (iii) pursuing managerial and operational improvement. (ARMANI, 2001: 6)

In the light of the debate on the composition of Brazilian early responses to the AIDS epidemic and, above all, tensions brought about by the current international and national scenarios – that threatens the continuity of those actions resulting from the set of responses –, this chapter brings some organizational features of institutions working with the syndrome. It further enlists representations related to interlocution between government and the organized civil society involved in the fight against AIDS.

5.4 SOME EXPERIENCES BY CIVIL SOCIETY IN THE FIELD OF AIDS: WORDS BY THEIR LEADERS

A. PARÁ

A. 1. PARAVIDDA

- 1) **Organization Name:** PARAVIDDA
- 2) **City/State:** Belém/Pará.
- 3) **Date of Foundation:** 27/01/1992.
- 4) **Started Working with STD/AIDS in:** 1992.
- 5) **Address/Phone:**
E-mail: grupoparavidda@aol. com. br
Phone: (91) 272-39-88 / (91) 272-46-45
- 6) **Situation Concerning Headquarters**
Space provided by the government. It belongs to the Labor Secretariat – SETEPS. The government contributes with payment of electric power, water, gas, telephone bills and security services.
- 7) **Where it Performs the Activities:** NGO headquarters.
- 8) **Field of Action:** Children and Adolescents Movement, Gay Movement.
- 9) **Priority Field of Action:** Assistance to people carrying HIV and/or living with AIDS.

10) Geographic Area of Work: State

11) General Purposes

Provide support and assistance to HIV/AIDS carriers, promoting integration with their family members. Build awareness on the importance of their participation in the disease evolution and involution, treatment result and quality of life, besides complementing works developed by governmental organizations of fight against the AIDS.

12) Target-audience

Seropositive individuals and family members. Concerning HIV/AIDS carriers, the audience is diversified and it provides services to children, adults, men, women, homosexuals, travesties, drug users, housewives and beggars.

13) Core Activities

- Psychosocial-therapeutic assistance;
- Lectures on STD/AIDS prevention;
- Daycare nursery services to carriers' children;
- Pharmaceutical services;
- Shelter with 14 beds;
- Supply (following given criteria) of 190 basic food baskets every month;
- Group therapies;
- Theater, painting, serigraphy and bijouterie workshops;
- Home visits;
- Reintegration of carriers into family life;
- Reintegration of carriers into labor market

They are usually committed to issues of advocacy to carriers, mainly concerning services, lack of hospital beds, lack of drugs to opportunistic diseased, CD 4 and viral load

assays, through denouncements and mobilizations. Currently, their main claim is connected to opening beds to HIV/AIDS patients in public hospitals. Since most of this NGO target-population live in shelters, services are rendered at the NGO headquarter.

14) Services Provided to Population

- Exhibition of educational theater plays with topics related to AIDS;
- Lectures on prevention against STD/AIDS at schools, corporations, community centers.

15) Works only with AIDS: Yes

16) Advertises the Work Developed Through:

Printed material, meetings, lectures and videos.

NGO Background

17) Origin of the Institution

The institution was created due to the increased number of people suffering from family rejection and, therefore, with no place to stay. This fact brought about the need for creating a group to shelter them and provide worthy care.

18) Organization's Motivation Towards Working with STD/AIDS

Since the NGO was established, in 1992, they work with STD/AIDS. What led them to work on this issue were the difficulties faced by members of the institution in dealing with family members of HIV/AIDS carriers, and the death of such carriers.

19) Resources and Financing Sources

The sources of financial support to PARAVIDDA are: International cooperation agencies; agreements with public bodies; donations by individuals and corporations.

The organization has about 150 collaborators. Most of them contribute, on average, with R\$ 6.00. It also raises funds by selling T-shirts, napkins, embroidery works, and sandals, all of them manufactured at its serigraphy shop. Furthermore, it raises funds in bazaars, where it sells second-hand clothes, stove, refrigerators, and TV sets, material received as donations.

20) Human Resources

To qualify its team, the PARAVIDDA delivers training, where professionals and/or volunteers receive information about the institution: its mission, purpose, target audience. After this stage, they approach the STD/AIDS issue, dealing with some infections presented by the beneficiaries, such as meningitis, toxoplasmosis, tuberculosis, and their transmission means. The professionals and/or volunteers also receive training in bio-security.

21) Work Methodology

The NGO registers all beneficiaries, separated by sex and age group. There is another record, kept in the pharmacy, concerning medications. These records allow for identifying who is homosexual, drug user or sex professional. Therefore, depending on the situation, the beneficiary is referred to social service, psychotherapy, and health service. The NGO also provides home visits.

The NGO plans the actions to be developed in a quarterly basis, with the participation of its board of directors, when they work on the priorities. However, sometimes there are unexpected situations that require for solution and are not comprised by the planning, like situations involving assistance issues.

In the issue of beds, we had planned to receive 22 individuals, but sometimes we have 30, 35 persons. It is something like if I say: "look, I will not assist you, and you will go to the street", they really go! There are some to whom you say: "you will go to the street, I am

sending you away”, but there is always a family, a friend. We are watchful to avoid this mistake, and then we try to work with the family, get another shelter, and insert the person into another market, so that he/she leaves here with some perspective.

22) Specific Problems with Experiences

As the institution specific problems, concerning the execution of its actions, they claim that if resources were better employed in the field of prevention, vulnerability would decrease.

It requires for more systematic work, I feel some failures in this issue of government, because you will notice that campaigns are like seasonal: Summer, carnival, World Day. These are the times when they remember of talking about prevention, vulnerability. But it seems that the State, or municipality, does not invest in this issue of preventions. We do not participate in the elaboration of any advertisement; we accept whatever Brasilia sends to us. We miss baseline works in the field of prevention, because what I know up to now is that in our country the number of infected people remains increasing.

Concerning the target-population, the NGO mentions that the problems are in the field of cultural values. People have no responsibility with their own lives and with the others' lives. The NGO also mentions the need for baseline work as a major challenge to be faced to reduce individual and collective risks of infection. It would be necessary to start talking about AIDS at school, inserting into the curriculum a specific subject on STD issue.

Despite huge problems, the NGO claims to perceive changes in the beneficiaries' lives, since many of them – who were trained by the organization – already work as multipliers, providing guidance to their communities on prevention against HIV infection and the problems it entails, on medications and adhesion to the treatment.

23) Political Articulation

PARAVIDDA participates in the Pará State Forum of OSC/AIDS, Pará State NGOs Forum and the ABONG.

24) Partnerships

It establishes partnerships with other programs and/or Secretariats of the Ministry of Health.

25) Incidence on Social Programs and Public Policies

The NGO informed it has not yet tried to win its room in discussions on policies and governmental programs of fight against the HIV/AIDS epidemic, like other organizations did (for example, GAPA and GEMPAC). The Institution is acknowledged only for the denouncements it makes. PARAVIDDA is a NGO working on assistance, and is different from those working on prevention. Therefore, PARAVIDDA usually works with the Government Prosecutors Office, jointly with the Juvenile Justice System (Juizado de Menores), health forums and secretariats.

26) The Organization Sustainability, in Medium- and Long-Term

The debate on sustainability has increased in the State of Pará. Some corporations (e. g. CELPA Network) have already sought the institution to know about the possibility of providing financial assistance to maintain the daycare nursery (meals to children, hygienic material and customary materials used in daycare nurseries). They consider the state action towards the institution as insufficient.

I think it could do much more, because our state has huge demands, but it does what it can and, in the second half of 2005, the labor market-oriented qualification workshops, held by the institution, will be delivered by the state. It represents costs savings to the institutions. So, the state undertook another commitment.

To the NGO, the sustainability of actions on fight against HIV/AIDS remains a challenge, due to the lack of financial incentive and human resources.

There is no such incentive. It is hard to work without incentive, and I have observed it even with the experts. Now, they are voluntaries, but if they were granted incentives, they would not leave the NGO, to go to another labor market. For the issue of AIDS, there used to be an investment by the state

itself, but we have disguisedly heard that such investment will be reduced because of deficit issues.

27) Interlocution with Governmental Spheres, in the Field of AIDS Epidemic

PARAVIDDA considers that the implications of governmental financing to priority issues in the agenda depend on the institution and how it will employ the resources granted. The PARA VIDDA depends on financing to grant better quality to services rendered to carriers. The NGO is resentful because financing agents should be closer, should be more present.

We miss it, because when we are to render accounts we face major difficulties, due to the lack of support of the financing agent, be it the state, municipality or the Coordination, and I think that work would flow more smoothly. Our major difficulty is the support of such financing that we miss. When we have doubts, we cannot ask to anyone. And more, when I have a doubt, I have to call Brasilia. It generates high costs for us who, as an NGO, survive from donations. Sometimes there is a manual, but we hardly understand those papers, mainly for the rendering of accounts. Last year I rendered accounts for a project and only in this year I heard it was not approved. I mean, they took over a year to inform; so, when we wait two, three months, we believe everything is OK. So, more than one year later, they send you – you cannot even remember any longer what it was about. You don't remember what you bought, what you spent. Then we have to look for information in the files, and it is hard. I think we should receive systematic training.

The Organization highlights as successful Brazilian actions on fight against AIDS the break of drugs patent, existing investments in prevention and the work performed by NGOs/AIDS: “Any NGO working in STD/AIDS should feel as part of this growth, we are serving as mirrors”.

For PARAVIDDA, the relationship between organized civil society and governmental spheres highly depends on each government. According to them, along the eleven years of existence, their relationship improved, services expanded. Currently, there are fewer lawsuits at the Government Prosecutors Office to request for medication. “We still fight for

medications, but if compared to eleven years ago, we now file lawsuits to the Government Prosecutors office for about five drugs, but we used to do it for all drugs”.

The NGO considers that financing on STD/AIDS cannot be bound to losing its autonomy or identity:

We have strongly discussed this issue in our meetings, our loss of identity because of financing: ‘look, we can’t lose our identity, if we are going to establish a partnership, we check to which extent such partnership will restrain us. If a partnership is likely to hold us back, as PARA VIDDA, we don’t accept, because we can’t lose our identity, and we are a NGO that denounces, even because it is an assistance institution that can’t be negligent and wants to improve the carriers’ living quality. Now, the state and municipality are already conscious about it.

A. 2. GAPA – Grupo de Apoio à Prevenção a AIDS

- 1) Organization Name: GAPA/PA – Grupo de Apoio à Prevenção à AIDS**
- 2) City/State: Belém/PA.**
- 3) Date of Foundation: 22/05/1987.**
- 4) Started Working with STD/AIDS in: 1987.**
- 5) Address/Phone:**
gapa@ufpa. br
Tel: (91) 3272-39-88
- 6) Situation Concerning Headquarters**
The Federal University of Pará (UFPA), according to an agreement, assigns the space. The university grants

electricity, water, security, a telephone line, and GAPA pays for the telephone bill. The counterpart obligation of the NGO to the University is that any activity carried out in the university should be taken over by the NGO, from reception to freshmen and Freshmen Week specific to each academic centers, to national meetings of students and congresses of professors and staff members. The NGO leader stated that he does not feel ease occupying a space that does not belong to the NGO, but to the University.

- 7) **Where it Performs the Activities:** ONG headquarters.
- 8) **Field of Action:** Population in general.
- 9) **Priority Field of Action**
Prevention and defense of HIV/AIDS carriers' human rights.
- 10) **Geographic Area of Work:** State and municipal levels.
- 11) **General Purposes**
 - Plan and execute actions on prevention against STD/AIDS, and promote human rights for those living with AIDS and their family members.
 - Interfere in the elaboration of public policies;
 - Support any advocacy initiative;
 - Work against the exclusion of individuals living with HIV/AIDS;
 - Contribute towards disseminating information on sexual health;
 - Sensitiveness-building among population concerning the HIV/AIDS issue, by providing prevention and education.

12) Target-audience

Seropositive individuals and family members, health professionals, men who have sex with men, children and adolescents, population in general. Others: law professionals, imprisoned population, health agents and community leaderships. GAPA works with community in general.

13) Core Activities

- Training;
- Consultancy services;
- IEC;
- Participation in the Brazilian Unified Health System – SUS forums on social control;
- Education, prevention against STD/AIDS;
- Lectures, workshops.

14) Ongoing Programs and Projects

GAPA's major project is the *DIGNIDADE E DIREITO*, which they consider as sustainable.

Another project is the *MARÉ CHEIA*, which works the HIV/AIDS issue with adolescents.

There is also the project *ELAS POR ELAS*, which provides training to SUS network women, in the metropolitan area of Belém, capital of the State of Pará.

The program *CONVERSANDO SOBRE AIDS*, is extremely comprehensive, because it ranges from interventions at the community center – such as school, parish – or great multinational corporations, providing training, qualification, to simple chats in collective interviews.

The project *UNIDADE E DIREITO* is oriented to assistance and provides legal and psychological counseling.

15) Services Provided to Population

- Legal and psychological guidance to people living with AIDS and their family members;
- Support to campaigns on prevention, carried out in schools and universities;
- Lectures;
- Telephone and Internet information services.

16) Works only with AIDS: No.

17) Advertises the Work Developed Through:

Books, journals, printed material, conferences and seminars.

NGO Background

18) Origin of the institution

Members of the university community, who gathered aiming at supporting actions to fight the epidemic in the State of Pará.

19) Organization's Motivation Towards Working with STD/AIDS

The NGO is said to have arisen from the motivation of UFPA staff members, students and professors, because the first AIDS case reported in Pará was with a UFPA staff member. *Then, some friends and relatives started to hold meetings in a room, like a group of study; rather than a support group of self-help, it was a group of discussion.* There was no systematized, planned, strategic response, neither the members intended to build alliances with governments or other partners. There was no NGO. GAPA/PA is the first NGOs/AIDS in the Northern region. So, it started in Belém, it started in Pará. GAPA/PA started with the proposal of institution, with foundation clauses and, soon after, official registration.

20) Resources and Financing Sources

GAPA/PA financing is granted by agreements with public bodies, individual's and corporation's donation. These resources basically occur through projects and provision of remunerated services, such as training to human resources team in private corporations, lectures, and campaigns.

Furthermore, GAPA/PA is accredited to the Superintendence of the Federal Revenue in the Northern Region as another way for raising resources. Through this accreditation, the NGO may receive donations and sell the products, thus raising funds to the institution. They hold partnerships with governments through agreements, transfer of resources granted by the World Bank, Ministry of Health, other Ministries, Municipality Health Secretariat, State Health Secretariat, and UNESCO. Moreover, the corporations pay them to deliver lectures to staff members.

21) Human Resources

Whoever joins GAPA to work specifically on the issue of HIV/AIDS, receives training and sensitiveness-building information to the issue. They undergo individual and group interviews, where is asked why they want to become a GAPA volunteer – since this is a non-remunerated work –, what do they think about HIV, the issue of values, how do they deal with prejudice. During the group interview, GAPA team observe what candidates have, if they are good listeners, how they organizes in groups, how they deal with situations. They select individuals with such a profile that they can, at least, deal with the problem.

GAPA members attend qualification courses provided by the Ministry of Health on bio-security rules, HIV issue, and transmission ways. Furthermore, they are also introduced to the institution literary collection.

Therefore, volunteers undergo a selection process. Forty-six individuals applied to the latest selective processes, but only fourteen were selected. They participated in a workshop – financed by the Ministry of Health, National Coordination, supported by

the Management Science for Health – MSH – aimed at training the volunteers. “People say that people working in GAPA usually become consultants to the Ministry, undergoing courses in Rio de Janeiro”.

The NGO uses to insert its professionals within a dynamic of personal growth, since their development as professionals entails the institution development. For the training, they have a volunteer group of studies, where each one chooses a topic related to AIDS or a general topic to discuss during the meetings.

The Ministry of Health’s delay in releasing resources or complementing projects resources lead technical professionals to leave GAPA. Dialogue is the only way for the NGO to keep their professionals.

They are trying to qualify law operators. During the latest training, the NGO noticed an increasing number of people participating, law operators becoming interested in AIDS issues and health field, as well.

22) Work Methodology

They have strategic planning, employed to assess the actions performed in a 6-month basis.

They distribute condoms to the community, jointly with information and folders, since the major challenge in reducing individual and collective risk in HIV infections is the lack of information on prevention. GAPA enjoys reputability in the community.

23) Specific Problems with Experiences

Problems identified in target-audience are: Outlook, housing issues, social issues, social deprivation, environment, people without access to education and health means. Therefore, the impact of actions on the NGO beneficiary audience is a change on their point of view and posture in face of HIV/AIDS; better knowledge about AIDS. GAPA holds events on prevention ways, infection ways, and women becoming acquainted with their bodies, their sexuality.

24) Political Articulation

GAPA participates in the State Health Council, National AIDS Commission. In the State Health Council, it represents the Pará State Forum of Pathologies, which approaches cancer, Hansen's disease and kidney issues. GAPA also represents the State of Pará at its Forum of NGOs/AIDS.

Furthermore, the organization attends conferences on social responsibility, promoted by the Rômulo Maiorana Organizations. They participate in events in the field of public policies, held by the Municipal, State and National Health Councils, and in Regional, State and National meetings of NGOs/AIDS.

25) Partnerships

The major partnerships are with the State STD/AIDS Coordination, Municipal STD/AIDS Coordination, Health Secretariat, Education Secretariat, Human Rights Secretariat, Government Prosecutors Office, Ministry of Justice, NGOs/AIDS, NGOs/mixed and other social movements.

They claim that NGOs should have access to the Secretariats, Forums, and actively participate in them. GAPA holds seat in State and Municipal Coordination, special meetings, where decisions are made. "I think that these organizations should increase their participation, become more active, and get people knowing them".

26) Incidence on Social Programs and Public Policies

Jointly with the government, the NGO participated in public policies concerning free access to drugs and prevention devices, NGO qualification and human rights and citizenship. "GAPA has political representativeness, instead of social only".

Health professionals still have prejudice against AIDS, when taking care of the patient, facing the patient as subject to social recognition. The NGO said they "perceive the health field discourse full of prejudice, stigmas".

27) The Organization Sustainability, in Medium- and Long-Term

Sustainability is considered crucial, because sometimes they need means and material. Projects provide this sustainability to continue sustaining GAPA. Within the sustainability projects, they believe they need to develop their scientific production posture, in order to grow, following the example of ABIA. “Write and produce to provide visibility to the institution”. Sustainability goes through the action of preparing more projects.

The organization has two strategies: one is the governmental, legal, institutional construction, which grants sustainability to actions that produce positive results. One of such actions with governments was the construction, all along 2002, of the Act on Financing of Fund-to-Fund Incentive: “as of 2003, the federal, state and municipal governments should be engaged in establishing a Brazilian fund to grant sustainability to the actions”. The other strategy is to build awareness among civil society, mainly the private initiative. “A corporation in a given community should be aware about its role, which goes beyond producing products or services and paying taxes. The empathy with the community surrounding such corporation must be broader”.

The NGO already perceives, in some corporations, leaderships responsible for the interlocution between the corporation and the community. “The civil society organizations make this interface between the corporation and community, because they know the history, the reality and know how to make this intervention”.

The major concern is not about the financing sources, which “could and should be exhausted”. Here, the concern is to make all entities self-sufficient – sustainability is not about granting cash flow – and managerially skilled to develop projects and follow-up changes and socioeconomic and political scenarios that may come to arise. If an institution is capable of managing its cause in a competent, transparent and objective way, it will surely rely on the society’s support to any of its request to financing agencies.

Concerning technical sustainability, the NGO mentioned the turnover of volunteer staff, even because they are not remunerated. They are working with the institution today, but tomorrow they may leave it.

A strategy that could be applied for this problem would be to seek for strong partners who could sustain the institution work, and be creative.

The establishment of the NGOs/AIDS improved this situation. The Forum is debating the possibility of stability – a concern that they did not use to have – “since the NGOs emerged in houses yards, garages and the volunteers’ houses”.

The debate on sustainability emerged in face of the threat of the Ministry of Health suspending investments in projects. The institution emphasized that NGOs in Northern Region face many difficulties, since they are hardly contemplated and still trying to walk.

What I challenge is how this sustainability is placed, because the government is used to treat NGOs very badly. The NGOs started preparing projects, started submitting to the Ministry of Health, the projects were selected, these projects were approved but, all of a sudden, all this time of project during AIDS I and AIDS II, we noticed that NGOs were automatically bound to projects financed by the Ministry of Health, the National Coordination. Then, the NGOs sought for different alternatives, because suddenly they come and say ‘look, you have to have sustainability’, but if they don’t show us the way to this sustainability, I think it is too much hard. In fact, many NGOs have no ways to run here in the North, because we don’t have big corporations, great financing agencies, as happens in São Paulo and Bahia. We have not yet had any farmer who died and left the lands to an NGO, as happened to GAPA in Bahia. So, an NGO can hardly talk about sustainability tomorrow, if thing were not worked out for that.

28) Interlocution with Governmental Spheres, in the Field of AIDS Epidemic

According to the institution, the governmental spheres are not negligent and do what they can, but sometimes the state holds back. The NGOs occupy a broad space, which the state cannot reach.

The state and municipality must get closer to civil society and establish mechanisms, a structure that allows for consensual policies in the field of AIDS.

A strong point of the movement would be the groups’ initiative of establishing the NGOs/AIDS Forum, “because they know the agony of each NGO”. This is the room for the political discussion on the situation. A weak point would be “NGOs suffering, because they lack support from the state and the municipality”.

GAPA claims that institutions lose autonomy to some extent, because government affords tickets and per diem for the participation in state and federal NGOs meetings to debate public policies. However, concerning the institution work, they perceive it in a different way, i. e., there is no damage at institutional or political standing levels:

The government finances state and federal NGO meetings. There is the possibility of co-optation in the discourse, and I think it is dangerous and, somehow, a way of losing autonomy. So you don't negotiate project, don't negotiate votes, don't negotiate financing participation, but you negotiate words.

We meet at every two years, all the Brazilian NGOs, financed by international agencies, UNAIDS, the Ministry of Health, governments. No one has the autonomy of speaking, but if you analyze the content of these debates and the outputs of the meetings, they are not qualified or leveled by the sponsorships we receive. Instead, these meetings produce things, sometimes very incisive, which are part of the diplomatic game.

A. 3. GEMPAC - Grupo de Mulheres da Área Central

- 1) Organization Name: GEMPAC – Grupo de Mulheres da Área Central.**
- 2) City/State:** Belém/PA.
- 3) Date of Foundation:** 01/05/1990.
- 4) Started Working with STD/AIDS in:** 1994.
- 5) Kind of Organization**
Public utility organization, social movement and advocacy.
- 6) Address/Phone**
gempac@expert. com. br
Tel: (91) 241-83-76

7) Situation Concerning Headquarter

Assigned by the state government, as long as GEMPAC remains public utility.

8) Where it Performs the Activities: ONG headquarter.

9) Field of Action

STD/HIV/AIDS prevention, women's movement, children and adolescents movement.

10) Priority Field of Action: Female sex professionals.

11) Geographic Area of Work

Regional, state, municipal and districts or district groups.

12) General Purposes

- Foment self-organization towards granting access to mechanisms of citizenship, by promoting activities on qualification, information and exchange that induce class organization, adoption of safe sexual practices and the seeking for full citizenship to adult sex professionals.
- Fight against child labor.
- Income generation, right to preventive health.
- Acknowledgement of prostitutes as citizens, women and human beings. *Finally, work on the issue of stigma and prejudice.*

13) Target-audience

Female sex professionals, women with fixed partner, adolescents in risk situations, gold miners and truck drivers.

14) Core Activities

- GEMPAC develops its qualification and self-organization actions based on four thematic axes: preventive health, fight against child labor, political organization of female sex professionals and income generation.

15) Ongoing Programs and Projects

They develop projects in the field of preventive health in partnership with UNESCO and other institutions.

In the field of income generation, deal with qualification and access to credit.

In the field of children and adolescents, they execute the ATELIÊ DA VIDA project, exclusively oriented to children and grandchildren of female prostitutes.

In the field of gold mining, there is the QUILÔMETRO DO TAPAJÓS IV Project.

They also execute a project named ROTA SEGURA for truck drivers.

The REDE NORTE project, which intends to strengthen the whole region in self-organization and self-determination and, when dealing with sexually transmitted diseases and AIDS, in prevention.

Project LUA, MULHER E PREVENÇÃO, with focus on women with one single partner.

Project CAMU deals with women human resources qualification.

The BOLSA-ESCOLA and the MOVAS, are executed in partnership with the Municipal Government of Belém, and work on literacy building to youth and adults.

Now, they also have the PRIMEIRO EMPREGO.

Additionally, they execute the project ESQUINA, oriented to work on issues of organization and prevention, strengthening institutions interested in dealing with sex professionals.

16) Services Provided to Population

- Preventive and organizational intervention in areas where sex professionals are concentrated;
- Advisory and exchange;
- Articulation and grant of access to citizenship mechanisms;
- Qualification program;
- Information and supply of male condoms;
- Training;
- Workshops;
- Meetings of the category;
- Campaigns;
- Late literacy programs;
- Preparation and production of materials;
- Representing the category in several forums;

17) Works only with AIDS: No

18) Advertises the Work Developed Through:

Education materials, posters, brochures and studies, journals, printed material, congresses, conferences, meetings and seminars.

NGO Background

19) Origin of the institution

It started in the 1980's, with the *Pastoral da Mulher Marginalizada* of the Catholic Church. Later, feeling the need for orienting the actions on qualification, information and valuation, and self-determination to the category, they separated. Thus, in 1990, the female sex professionals founded their own organization.

20) Organization's Motivation Towards Working with STD/AIDS

The motivation was that, with the event of AIDS, female sex professionals became a group of risk.

21) Resources and Sources of Financing

GEMPAC sources for raising funds are international cooperation agencies; agreements with public bodies; individuals' donations and eventual sponsorships. The major financing agent is the National STD and AIDS Programme, providing financing to projects in the field of truck drivers, gold miners, women and other audiences.

Additionally to proceedings from projects, the NGO transfers to the institution ten percent of resources from fees for services individually rendered, like training to health professionals, workshops held in the field of gold mining, lectures at schools, and sales of clothes. Proceedings from the private networks are deposited in a separate account. The Municipal Government of Belém also transfers resources to afford telephone bill, Internet services and parking.

22) Human Resources

To train its members and volunteers, the NGO uses to allow its team to participate in several kinds of training, besides upgrading courses. For example, in the field of childhood and youth, the Institution assigned a person to participate in a capacity-building course. In the field of sexually transmitted diseases, they qualify female replicating agents, including in the gold mining area.

23) Work Methodology

GEMPAC makes strategic planning to assess the actions it develops.

Regarding issues related to daily experience, the Institution mentions factors of vulnerability to the beneficiaries: alcohol problems, low self-esteem, and socioeconomic status, non-use of condoms, cultural values and lack of information. Another problem is the women's resistance against participating in the organization.

However, the changes on the lives of beneficiary population are perceived through the improvement in self-organization, the relation of cultural values, information, and access to inputs.

24) Political Articulation

GEMPAC is member of the Brazilian Network of Sex Professionals and the Network on Sexual Exploitation of Children and Adolescents. It is part of the Pará State NGOs/AIDS Forum.

25) Partnerships

The major partnerships of the NGO are established with the State STD and AIDS Coordination, Municipal STD and AIDS Coordination, Health Secretariat, Education Secretariat, Program Coordination Units, Government Prosecutors Office, NGOs/AIDS, NGOs/Mixed, private institutions and other social movements.

26) Incidence on Social Programs and Public Policies

Jointly with the government, the NGO participated in governmental public policies concerning access to early diagnosis, free access to drugs, free access to treatments, access to prevention devices, NGO capacity-building, human rights and citizenship, and pre-natal HIV tests.

It is part of the Health Council, State STD and AIDS Commissions, Advisory Committee to the National STD and AIDS Programme, Advisory Committee of Sex Professionals, Municipal Health Council, Female Condition Council, State Health Council, Rights Commission of the Brazilian Bar Association Human Rights Commission and Municipal Women Council.

27) The Organization Sustainability, in Medium- and Long-Term

The institution should be better organized to fight for sustainability. It is aware that projects are sporadic, lasting only six months, and the Institution must survive – regardless the resources – since it stands for a commitment undertaken with the female prostitutes.

The NGO faces sustainability as a complex matter, which threatens actions developed in STD/AIDS. It requires for deeper

debates, and “the government should show the ways for NGOs to seek for sustainability, both financial and technical”.

28) Interlocution with Governmental Spheres, in the Field of AIDS Epidemic

The *Grupo de Mulheres da Área Central* claims that governmental financing does not impact over the institutional priorities, since resources are not enough for any project. Therefore, they have to seek for partnerships, as a complement to the financial needs of each project. For example, the project ATELIÊ DA VIDA needs food, transportation allowance and volunteers.

The National AIDS Programme is outstanding in some issues, such as capacity and internal human resources, since its staff has already experienced the organized civil society. Furthermore, it is acknowledged worldwide as the best Programme, because of the access to medication, access to condoms, communication facility. GEMPAC also emphasizes that success is due to the partnership with organized civil society. “The National Programme, even with all these things (. . .) they provide conditions only by providing monitoring, advisory services, and we do everything, because we know our target-audience. So, they provide trustworthiness, and it is crucial”.

Concerning the relationship between civil society and governmental sphere towards fighting AIDS and providing assistance to HIV carriers, the Group stated that, whenever it needed the support of the National STD and AIDS Programme, they showed respect and promptly complied with the request, whenever possible.

People in the National Coordination are sensitive and competent professionals, who know the whole policy. They always cooperate with the NGOs, providing working conditions and advisory to assist them in executing projects with their target-audiences.

B. BAHIA

B. 1. APROSBA – Associação das Mulheres Profissionais do Sexo da Bahia

1) Organization Name: APROSBA – Associação das Mulheres Profissionais do Sexo da Bahia

2) City/State: Salvador/Bahia.

3) Date of Foundation: 07/1997.

4) Started Working with STD/AIDS in: 1997.

5) Kind of Organization: Social movement and human rights.

6) Address/Phone

aprosba@hotmail. com

Tel: (71) 322-26-98

7) Situation Concerning Headquarter

They do not have own premises. They pay rental. Who affords for rental, telephone and electric power bills are some *sponsors, clients wanting to help* (individual's donation). In the event of remunerated project, expenses are summed and then apportioned, and each leader donates the salary to pay the telephone bill, condominium fees, rental, and electric power bills.

8) Where it Performs the Activities: ONG headquarter.

9) Field of action

Prevention against HIV/AIDS among female sex professionals, travesties, whore, clients, sexual partners, fixed sexual partners.

10) Priority Field of Action: Female Sex Professionals.

11) Geographic Area of Work: State.

12) General Purposes

Minimize infections from STD/HIV/AIDS.

Re-education of female sex professionals, appraising them as citizens who are aware about their rights and obligations, guiding in the seeking for better quality of live, and investing in the capacity-building and class organization for their inclusion into society.

13) Target-audience

Seropositive individuals and their family members, female sex professionals, seropositive female prostitutes, truck drivers.

14) Core Activities

- Educational, reproductive and preventive health;
- Legal support.

15) Ongoing Programs and Projects

“Mulheres da Vida”: this project exists since 1998 and was renewed for the third time.

“Beira de Estrada”: with truck drivers.

“Quando a noite cai”: with sex professional and tourists.

“Trottoir”: with travesties.

“Maria Madalena”: previously named “Porto Seguro,” since it works in the Harbor with sex professionals.

16) Services Provided to Population

- Distribution of condoms and information material;
- Legal support;
- Referral to public health units;
- Issuance of documents;
- Weekly lectures at the entity headquarter, schools and universities;
- Visits to and mapping of prostitution areas;
- Person-to-person contacts;
- Psychological care;
- Puppet-show — references to prostitution, rights, violence and prevention.

17) Works only with AIDS: No.

18) Advertises the Work Developed Through:

Pamphlets, folders, posters, advertisement in radio broadcasters, magazines, videos, congresses, conferences, meetings, seminars.

NGO Characterization and Background

19) Origin of the institutio

It was founded due to the need for prostitutes to get organized and gathered to advocate for their rights as citizens.

20) Organization's Motivation Towards Working with STD/AIDS

APROSBA initial objective was the issue of citizenship and human rights to sex professionals, which did not want to be faced as “group of risk”.

Currently, there is the need for working the issue of STD/AIDS, reducing the number of pregnant girls, besides the need for prevention among its target-audience.

21) Resources and Sources of Financing

APROSBA source of financial resources are agreements with public bodies; individuals' donations; and eventual sponsorships. As intake strategies, they employ: local government donation of material; and the collaboration of clients and nightclub owners.

22) Human Resources

The NGO holds seminars to train its members. The volunteer multipliers spend one week involved with APROSBA and, by the end of the course, receive a certificate.

23) Work Methodology

APROSBA employs theater exhibitions in public places, focusing topics such as prostitution, rights, violence and prevention. This practice was employed, for instance, in a project sponsored by Pathfinder of Brazil and the Ministry of Health, named "Quando a noite cai". After the exhibition, they distribute condoms.

Furthermore, it works on campaigns like "Parceiro seguro e companheiro", where it approaches condoms use with partner and not only with clients.

For the NGO, the major challenge to be faced concerns the owners of massage houses and night clubs, who prohibit women to participate in APROSBA meetings during working hours. On the other hand, the NGO mentions resistance from the prostitutes towards attending the meetings, which they consider *waste of time*.

24) Political Articulation

The Association is member of the Brazilian Network of Prostitutes. Furthermore, it integrates the local NGOs Forum, the Bahia State NGOs/AIDS Forum and the Women Forum.

25) Partnerships

The institution has partnerships with the State STD and AIDS Coordination, the Municipal STD and AIDS Coordination, Health Secretariat, with NGOs/AIDS and NGOs/Mixed. It has participated

in other projects with the Ministry of Health secretariats. Furthermore, the NGO developed a partnership with the **Pathfinder of Brazil S/C Ltda.** – a non-profit Non-Governmental Organization (NGO), mainly oriented to expand population access to high-quality information and services in reproductive health, including prevention against sexually transmitted diseases (STD) and AIDS.

26) Incidence on Social Programs and Public Policies

Jointly with government, the NGO participated in the debates on the elaboration of governmental public policies concerning free access to medications, and other policies related to human rights and citizenship.

It is part of the Local Health Committee; Health Unit Council; State AIDS Committee; State STD and AIDS Commissions; and the Advisory Committee to the National STD and AIDS Programme.

27) The Organization Sustainability, in Medium- and Long-Term

Sustainability is a concern to APROSBA, because sometimes the NGO does not have any financed project. To solve this issue, at least partially, it plans to implement the social marketing model, by selling the Prudence condoms donated by DKT of Brazil – a non-profit organization, specialized in implementing Social Marketing Programs. The projects are focused on the fields of Family Planning, Control of Sexually Transmitted Diseases and Prevention against AIDS. As part of its Social Marketing strategy, the NGO sells condoms at prices affordable by population. The Association also intends to set a cooperative association, and deliver sewing courses. This would allow sustaining APROSBA and older sex professionals, who can work no longer.

APROSBA expects to be self-sufficient before the projects end. However, for this year the NGO still relies on the Fund-to-Fund cooperation, which is a governmental incentive plan towards State actions sustainability, including NGO.

28) Interlocution with Governmental Spheres, in the Field of AIDS Epidemic.

The *Associação de Prostitutas da Bahia* emphasizes that one of the most relevant implications of STD/AIDS-related financial resources relies exactly on the concern and uncertainty about the continuity of the actions developed in this field, and the organization sustaining, due to the lack of financial resources.

We don't know if these new plans – like sewing course, social marketing – will develop. Well, I think we will have serious problems when this project ends, because we won't have financial resources for displacement, tickets, to remain working with people who lack access to information.

Usually, APROSBA faces difficulties in negotiating financial support, because prostitution is a stigmatized topic to the most accessible sources of financing. Therefore, it urges the discussion on solutions for those NGOs working with this topic, in order to provide them with support to continue their actions.

I think there is some prejudice here, some resistance [at municipal government level]. In my opinion, they think that when society gets to know our work, they imagine we are stimulating prostitution. By the beginning, when we were dealing with this issue of STD and AIDS, the girls and us, when the society talked about this issue of AIDS, imagined that they thought we were a mine of diseases. We didn't want to be faces as a source of disease; prostitute is a group of risk and things like that. We know that everybody has its behavior of risk. But the society thinks it is still something linked to travesty, to bitch. But we had never thought about working on this issue, but when we started working, we noticed it was necessary.

The Association points out an improvement concerning the quality of information provided by mass campaigns and the media, with emphasis on actions by the Brazilian Programme. Furthermore, it believes in a positive assessment concerning Government action with prostitute associations in general: “Brazil works very well on the issue of AIDS, much better than other countries in regard to prostitution”.

According to APROSBA, the relationship between organized civil society and governmental spheres led to some victories in the field of fight for citizenship and Human Rights. However, it requires social commitment towards minimizing the violence that victimizes people participating in the NGO programs. APROSBA also stresses that there is no financed project exclusively oriented to citizenship rights. All of them are somehow connected to STD/AIDS.

B. 2. GAPA/BA – Grupo de Apoio à Prevenção à AIDS/BA

- 1) Organization Name: GAPA/BA – Grupo de Apoio à Prevenção à AIDS/BA.**
- 2) City/State: Salvador/Bahia.**
- 3) Date of Foundation: 02/07/1988.**
- 4) Started Working with STD/AIDS in: 1988.**
- 5) Kind of Organization: Advocacy and educational services.**
- 6) Address/Phone:**
gapaba@uol. com. br
Tel: (71) 328-42-70
- 7) Where it Performs the Activities: NGO headquarter.**
- 8) Field of Action**
 - HIV/AIDS and children and adolescents movement;
 - Assistance to HIV carriers and/or individuals living with AIDS;
 - Prevention against STD/AIDS for vulnerable populations;
 - Advocacy for groups in situation of exclusion.

9) Priority Field of Action: HIV/AIDS carriers

10) Geographic Area of Work: State.

11) General Purposes

- Reduce levels of contamination from HIV/AIDS in Brazil, especially in the State of Bahia, by developing works on information, education and communication, oriented to preventing the disease;
- Psychosocial support to HIV/AIDS carriers, aiming at improving their quality of life;
- Fight for human rights, to grant access to information and health services, against discrimination, requiring the state to play its role towards seropositive individuals, to enforce constitutional guarantees to which every citizen is entitled;
- Increase the community capacity to deal with AIDS issue.

12) Target-audience

Seropositive individuals and their family members, sex professionals – male and female–, man that has sex with other man, travesties, women, children and adolescents, health professionals and population in general.

Over these years, GAPA has benefited low-income population, socially excluded population that, for their characteristics of low-level education and adverse economic conditions, is more vulnerable to the epidemic. Among these populations, the following groups are considered, according to their

specificities: women, Afro-descendant population, gay population, bisexuals, youths at school, youths out of school, youths in institutions, youths in freedom restriction, children with HIV/AIDS, besides adults affected by the epidemic.

13) Core Activities

- Educational, reproductive and preventive health;
- Legal support.

14) Ongoing Programs and Projects: GAPPA renders continuous services.

15) Services Provided to Population

- Psychological and legal support to people with HIV/AIDS and their family members;
- Hospital and home visits to people with HIV/AIDS;
- Playhouse (ludotherapy for seropositive children or children to individuals with HIV/AIDS);
- Sociability group;
- Donation of basic food baskets;
- Legal guidance and workshops oriented to sexual minorities (travesties, transsexuals, prostitutes);
- Condoms distribution;
- Hotline services, named Dial-AIDS;
- Support to and referral of population in need to shelters, overnight houses and transit shelters;
- Vocational courses.

16) Works only with AIDS

Yes. GAPA core topic is AIDS, and all of its actions and focuses of attention are related to AIDS. However, the field of prevention has some topics transversal to the AIDS epidemic, because they believe that AIDS cannot be dealt separately from other topics, such as gender, race, human rights and education.

17) Advertises the Work Developed Through:

- Manuals, textbooks, bulletins folders, posters, magazines, books, journals, videos, printed material, congresses, conferences, meetings and seminars.

NGO Characterization and Background

18) Origin of the institution

It was established in 1988, when a group of friends met and decided to work on prevention against STD/AIDS, aiming at providing guidance to the community on the epidemic. GAPA Bahia became organized based on the experience of other GAPA groups existing in Brazil, adjusting the experience to their local reality.

19) Organization's Motivation Towards Working with STD/AIDS

GAPA was the first response of the organized civil society to the AIDS epidemic in the Brazilian North-Northeast regions. According to the NGO representative:

The major factor that led to community mobilization towards responding to the epidemic was the lack of response by the State, in the light of Public Power, in relation to an efficient policy on AIDS. So, the organization emerges as a civil society tool of pressure over the State, demanding efficient responses to the AIDS epidemic in the state of

Bahia. Therefore, the major reason was a political issue. Thereon, came the assistance to HIV carriers, aiming at reintegrating them to society, and the educational and preventive work to reduce the number of contaminations in Bahia.

According to the respondent, today the incentive for GAPA to continue its work is increasingly the desire for becoming an institution that promotes knowledge on AIDS, *knowledge applicable in Bahia, but that may also be taken to other structures, other peoples.*

20) Resources and Financing Sources

The NGO basically has three sources of financing: agreements with the federal government; generation of its own income, through events, services trading, products, consultancy services; and international cooperation agencies.

According to GAPA, concerning resources intake, it employs different strategies to different sources. For local source, they employ telemarketing and events. On the other hand, they identify foundations to which AIDS is a strategic topic and present programs and projects to them.

21) Human Resources

The field of education and prevention against HIV/AIDS gathers the highest number of actions and activities in the NGO programs and projects. In this field, the organization has specific programs developed for specific groups, “always aiming at qualifying popular promoters as the more legitimate and major agent that transmits information on AIDS for the community”. For that, it identifies potential leaders in communities such as schools, district associations and women groups, and qualifies them as community educators on AIDS.

For volunteers, it focuses the work on information and qualification, through general institutional training, followed by a more specific one, taking into consideration the field where the person will work.

Therefore, the new professional receives information on AIDS and training in transversal topics, over which GAPA works, i. e. , gender, race and human rights.

When they identify a relevant topic to be worked with the team, like projects, they hire a consultant to deliver courses on projects elaboration.

Moreover, the leaders undergo capacity-building trainings on management and sustainability. In fact, GAPA is considered as sustainability model also at international level.

It is a consequence of the investments by the organization, in cooperation with partners. For example, the organization attended a 3-month internship program in Oxford to learn about local resources intake. Thereof, GAPA Bahia established its department of marketing and local resources intake, and started providing consultancy services to other institutions. The Ministry of Health hired GAPA, jointly with the Fundação Getúlio Vargas, to providing training on sustainability and management to 300 NGOs in Brazil.

It is worth highlighting that social issues are increasingly present in GAPA strategic policy, also as part of capacity building to promoters and educators. Currently, GAPA develops the qualification of community educators and popular promoters related to oriented social control.

It is made up by 60 individuals, among staff members, trainees and service providers, duly registered according to Brazilian labor laws, additionally to 120 volunteers.

Today, its staff is multi-professional and interdisciplinary, oriented to planning and executing actions. The volunteers have different academic backgrounds. Some are not specialized, but cooperate with the institution by performing several duties. The technical team comprises staff members and trainees, and is made up by lawyers, psychologists, social assistants, anthropologists, historians, administrators and economists.

22) Work Methodology

GAPA actions are oriented to education and assistance. The major axis is the concern in expanding consciousness on rights, aiming at empowering communities and individuals. This would lead them to feel stronger to fight for their rights, including the right to life, to health: “the right to live a life without AIDS, or live a worthy life with AIDS”. In this regard, GAPA identifies community leaders and qualifies them as promoter and educator agents on AIDS. Furthermore, GAPA follows-up and monitors the qualification of these leaders, who are qualified not only in AIDS, but also in transversal topics such as right, citizenship, gender and race.

Actions assessment is understood as a process. It employs timely assessments, supported by indicators of output. It gathers monitoring processes – part of all the entire execution of a GAPA program – to these practices. Currently, GAPA has a study group called Group of Study of Indicators, which analyzes quantitative and qualitative indicators. By the end of each year, this group prepares a report about the activities they have developed. After a given time, the financing agent asks for an external assessment and, for this purpose, hires a consultant to assess the work developed by GAPA. Therefore, it is a two-way assessment, at internal and external level.

In 1996, GAPA Bahia introduced into its management strategy, the elaboration of tri-annual strategic plans, annually updated. For this, they rely on the cooperation of an external consultant who, jointly with the institution team, analyzes the context interrelated to the epidemic, as well as the political and economic panorama. Such diagnoses serve as basis to the next 3-year period, and to outline strategic objectives. According to the respondent: “As important as providing a service to the community, is to provide it with quality, and the only way for reaching this quality is to plan, monitor, follow-up and assess”.

23) Specific Problems with Experiences

GAPA specific problems basically concern social conditions of target-population. As it is mainly oriented to population in need, it

understands that all conditions of individuals and communities are conditioned by social exclusion and low schooling capital. It assumes that such segments are less informed about the epidemic and social relationships, such as gender. This lack of information would contribute towards expanding the vulnerability margin to those individuals or communities and, therefore, they are in higher risk of infection. Hence, GAPA target-audience is subject to several kinds of vulnerability: “social exclusion, economic. . . ”

According to them, people focused are more concerned with other daily priorities that threaten their lives more than AIDS, such as: What they will have to eat at night; domestic violence and lack of basic sanitation. Therefore, they deal with a population that suffers serious limitations and have urgent needs. The major challenge posed to GAPA is to make them perceive that AIDS is another threat to their lives and, then, make them place the same relevance on this topic as they place on other needs.

According to the respondent, another challenge is to establish this issue as shared responsibility of the State and civil society: “AIDS is a topic that has not yet been duly undertaken by the State in its different spheres – municipal, federal and state. ”

Analyzing the institution background, one can observe that nowadays GAPA has a more varied audience in low-income communities. Now the challenge is much bigger than it was by the time of GAPA foundation, when it worked with more specific groups, such as gays and sex professionals.

Nevertheless, despite the problems identified, they mention many successful actions:

- The number of direct beneficiaries increases over the years: *“For example, we are in 28 cities in the State of Bahia, and other states are developing GAPA Bahia actions”;*
- Since the work with AIDS essentially entails behavior changes, although GAPA mainly focuses the low-income populations, it indirectly benefits other populations, leading the community to respond more positively to the AIDS epidemics, if compared to previous years: “The community is, somehow, more

engaged, more sensitive; our actions play a strong role in interfering on public opinion, influencing public opinion”.

24) Political Articulation

GAPA participates in some forums of political and mixed representation. They participate in the National Human Rights movement, belong to ABONG executive coordination, and participate in the PAD Collegiate – a process of articulation and dialogue with ecumenical agencies. GAPA holds biennial seat in the State Health Council and the Inter-institutional AIDS Commission, established in the State of Bahia. Furthermore, it participates in the Ministry of Health Sub-commission of Communication. The organization also participates in the Bahia State NGOs/AIDS Forum and the Permanent Assembly of Entities in Defense of Environment. It has participated in the National Committee of Vaccination, abandoned in the last administration, “for the lack of time and agenda”.

There is a concern about the issue of social control, monitoring public management quality in AIDS in Brazil at the three government spheres: “it intends to introduce people into forums of mixed representation, councils, etc”.

25) Partnerships

The major partnerships for carrying out political actions are: State STD and AIDS Coordination, Health Secretariats, Education Secretariat, Government Prosecutors Office, NGOs/AIDS, NGOs/Mixed, private institutions and other social movements.

It also has partnerships with social movements with other focuses than AIDS, other NGOs that, for example, are focused on human rights. There are partnerships with the state. In inland areas, they work in partnership with local governments, “as a way to officially introduce the topic of AIDS in municipalities”.

In the field of advocacy, it holds partnership with the Brazilian Bar – OAB, public prosecutor offices, Government prosecutors Office and law centers at universities.

The respondent considers that, now, GAPA Bahia could be converted into a center of excellence in HIV/AIDS, to the Brazilian Northeast region, and to the country. The remaining GAPA and GAPA Bahia are models for several organizations in the country and abroad: “We are even exporting our technology to other countries, such as Jamaica and Angola. So, we have converted this institution into a reference institution, a model institution”.

The features that make GAPA a unique organization are: the concern since 1992 on valuating, in the same intensity, the ultimate actions of its mission – for instance, develop educational programs for low-income women – and adopt social management as strategic action. “Since we started placing the same importance on management, program development or action, the organization trustworthiness increased. This peculiarity brought partners and credibility to GAPA”.

Another point mentioned is GAPA capacity of establishing strategic partnerships, expanding its universe, previously restricted to the AIDS movement, and relating the topic to other fields. Furthermore, it is now engaged to other forums and scenarios, and therefore bringing AIDS to the debate on human rights.

26) Incidence on Social Programs and Public Policies

Jointly with the government, the NGOs participated in governmental public policies concerning free access to medication, treatments and NGO capacity building.

According to GAPA leader, the NGO mission is to influence on public policies, in order to prepare, jointly with the State, more efficient AIDS-oriented public policies. Concerning the Legislative Power, GAPA is engaged in debates with city councilors and deputies, when the Federal Government budget is to be approved, in order to make amendments to allot resources for AIDS. Sometimes, it makes pressures, mainly when it perceives a precarious situation in the policy of drugs distribution.

It is worth mentioning that, thanks to the joint effort of civil society and government that resulted in public policies as the above-mentioned,

Brazil is international reference regarding universal access to anti-HIV treatment. Nonetheless, it should be clear that many people in many states, especially in the Northeast region, have no access to medications, even cheaper medications, to treat opportunistic infections.

The respondent highlights how GAPA reads the epidemic. Since a long time, GAPA understands that AIDS is not only a public health problem, but also a problem that affects the Brazilian development. It led GAPA/BA to become a reference institution.

27) The Organization Sustainability

It pursues diversifying the sources of financing, and does not perceive sustainability as possibility to self-maintenance. For Brazilian cultural and historic reasons, NGOs are not expected to become self-sustainable in short- or even medium-term: “The NGOs can only become sustainable if they work on the policy of diversifying sources of financing, reducing their dependence on a single source”.

The engagement in diversifying financial sources entails mobilizing resources locally raised. To negotiate the mobilization of locally raised resources, the NGO should be dedicated to marketing, providing greater visibility to the institution and to the cause. Then it would be capable of mobilizing its local resources, with the commitment of different civil society sectors in contributing, whether with financial resources or volunteer work. “GAPA has succeeded in mobilizing local resources, jumping from 0.3% of institutional budget on locally raised resources, to 32%. And it did not cease raising resources from foundations”.

The negative aspect emphasized is the State bureaucracy as a financing agent, with proceeding of the World Bank loans. “It is a bureaucratic relationship, which demands huge administrative and managerial efforts of the projects, and these projects support little administrative resources”. It should be observed the existence of a high level of administrative requirements.

Concerning the positive aspect, they claim that financing have allowed for strengthening all organizations. “The social response in Brazil became stronger upon the State support to NGOs, through financed projects”.

28) Interlocution with Governmental Instances in the Field of AIDS Epidemic

Brazil is a model, a reference in the aspect of developing joint actions: state and civil society. This experience is a model to other countries because, in fact, the AIDS movement has influenced the federal public policy, changing a little the history of AIDS in the country. This joint action, of partnership and, mainly, of perceiving the differentiated values of each player in this fight, set different but complementary roles. "I think it is extremely relevant not only for other peoples, other cultures, but for what is internally done in the country as reference to other causes".

According to them, the organizations still fail in undertaking the issue of sustainability as strategic and important to play their social role. Furthermore, some NGOs are dealing with sustainability because it is imposed by financing agents, by partners. The difficult in working with sustainability is because it is not an end topic, does not belong to the institution mission. They argue that working with sustainability means to develop activities that are not directly related to the target-audience. Many financing agents require the organizations to work with sustainability, but do not provide support to them, since they do not grant resources.

The State role in sustainability should be of promotion, incentive, supporting programs related to qualification and capacity building of organizations, besides granting resources.

The Federal Government has, somehow, done it along the last few years, when it carried out a national coordination program, endowed with strategy of information about the organization of sustainability and management topics, and then financed projects. The response to the AIDS epidemic in Brazil nowadays is a worthy response, thanks to the State and civil society. The civil society has contributed a lot to this response. What concerns us is that these social projects should be capable of remaining beyond the financial support granted by the State. This would be possible if they work more and more on sustainability. There is also the technical sustainability for establishing their institutions, setting strategic partnerships, partnerships with the State, partnership with social movement, with other NGOs and with financial society.

Concerning damages to autonomy, GAPA Bahia states that they have never felt restricted by financing agents in their political actions. Furthermore, they state that they have never had a relationship of dependency with international cooperation – the major source to GAPA.

However, they point out the new process brought about when the Ministry of Health started playing the role of financing agent to NGOs projects. GAPA reports a re-definition on priorities, based on the preferences of the Ministry, thus reducing the NGO political role, besides weakening the social activism power.

We could notice that, at national level, the activism in AIDS decreased when the State, the Ministry of Health, started sponsoring the NGOs. It is hard to have a more autonomous relationship of independence, pressure, and exercising activism when the major financing agent is the State.

It is worth mentioning that the work flows better with the federal government. “At the federal level there is a horizontal relationship, closer, of greater partnerships, because many experts now working to the federal government came for NGOs”.

B. 3. GGB - Grupo Gay da Bahia

- 1) Organization Name: GGB – Grupo Gay da Bahia**
- 2) City/State:** Salvador/Bahia.
- 3) Date of Foundation:** 28/02/1980.
- 4) Started Working with STD/AIDS in:**
1984 with no financed resources. In 1995, the Ministry of Health granted its first financial support to the Organization.
- 5) Kind of Organization**
Entity on homosexual emancipation – health and human rights.

6) Address/Phone:

ggb@ggb.org.br

Tel: (71) 322-25-52 / 321-18-48

7) Situation Concerning Headquarter

Premises were purchased and donated to GGB, for the time it exists. GGB President, Luís Mott, donated the premises and furniture. They do not pay rental, neither the Tax over Land Property [IPTU], which is paid by Luís Mott, but pay other fees, such as for electric power.

8) Where it Performs the Activities: ONG headquarter.

9) Fields of Action

The NGO works in the field of integral health promotion, human rights and establishment of favorable environments for gays, lesbians and transgender individuals.

10) Priority Field of Action: Gay movement.

11) Geographic Area of Work: National.

12) General Purposes

- Advocacy and promotion of health and human rights to homosexuals in the state of Bahia, and countrywide.
- Work on changing society view, by introducing new concepts on health and homosexuality in Brazil.
- Fight against homophobia;
- Disseminate information on homosexuality;
- Build awareness among the homosexual community;
- Fight against STD/AIDS.

13) Target-audience

Homosexuals, travesties, lesbians, family members and population in general.

14) Core Activities

- Human Rights;
- Prevention against STD/AIDS
- Capacity-building to leaderships in human rights and STD/AIDS;
- Legal assistance;
- Production of educational material.

15) Services Provided to Population

- Workshops on public services;
- Workshops on community mobilization;
- Workshops on safe sex;
- Distribution of condoms;
- Capacity-building to leaderships;
- Conferences on STD/AIDS
- Legal support (domestic and familiar violence; assets split; attendance at police stations).
- Psychological referral.

16) Works only with AIDS: No.

17) Advertises the Work Developed Through:

- Magazines, books, journals, videos, printed material, congresses, conferences, meetings and seminars.
- Distribution of material at beaches and malls. Deliver lectures at schools, corporations, and universities. They advertise the material through newspapers, textbooks, pamphlets, workshops and assemble stands wherever possible.

NGO Characterization and Background

18) Origin of the institution

GGB was founded in 1980, by a group of homosexuals concerned in advocating for human rights and citizenship for gays, lesbians and travesties. It was the first gay group in the Northeast region and, now, the oldest one working in Brazil. In 1982, GGB was registered as civil society, as a corporation. It was the first NGO of this kind to have register as corporation in the country.

19) Organization's Motivation Towards Working with STD/AIDS

In 1983 they started talking about AIDS, through the GGB Newsletter. However, in 1995, when the Ministry of Health granted financial support, they started working with STD/AIDS. What encouraged them to perform this kind of work was their perception of AIDS as a serious public health problem, and that the only way to find solutions would be to mobilize the whole society, mainly the most vulnerable groups that, at that time, were *and still are* the homosexuals.

20) Resources and Financing Sources

The financial resources of Grupo Gay da Bahia are granted by international cooperation agencies, agreements with public bodies and donations by individuals. However, the major source for resource intake is the Ministry of Health, through financed projects.

The strategy adopted by GGB to pursue financial support is the elaboration and execution of project. The institution also receives investments from the private initiative. Furthermore, it has a small shop, where they sell buttons, T-shirts, postal cards, collars, flags, pens, pencils, books, videos, etc.

21) Human Resources

The GGB trains monitors and multipliers in the communities, to distribute condoms, information material, and to organize meetings and debates in their districts. The GGB internal team undergoes information updating activities.

22) Work Methodology

GGB actions are aimed at prevention. They deliver lectures at schools, universities and corporations. They work with face-to-face interventions, phone services, printing information material, legal support, and referral of individuals involved in cases of violence and discrimination to police stations and public health services. The Group also delivers self-esteem workshops to the youth population.

The NGO employs meetings and questionnaires to assess the actions and activities it carries out; it prepares diagnosis about the number of beneficiaries, the quantity of material produced, condoms purchased and distributed, in addition to the actions implemented. During the meetings, they discuss the quality and development of the Group's actions. The assessment process is held on a monthly basis, after the meetings, workshops and discussion groups.

GGB highlights the way in which Brazilian society faces homosexuals as the major obstacle to its work. This perception influences on how the financing agencies select partnerships and projects. They also emphasize the vicious circle of discrimination that affects the esteem of homosexuals, and impairs their participation in collective actions for their rights and self-protection:

The homosexuals make up a population that is vulnerable to the AIDS epidemic. Because the Brazilian society does not have room for open communication for their free expression, there is great prejudice that prevents agencies from supporting the organization and fighting for the homosexuals' rights. They are vulnerable to urban violence, prejudice, and school violence and to infection by the HIV virus, because they don't have self-esteem or an environment of social acceptance.

23) Political Articulation

GGB has been a member of the International Gays and Lesbians Association (USA) since its foundation. It is also member of the *Associação para Saúde Integral da América Latina e Caribe* – ASICAL.

For many years, they have served as secretaries to the human rights field of the Brazilian Association of Gays, Lesbians and Travesties – ABGLT and currently have a seat in the ABGLT's Communication Secretariat.

The Institution also participates in the Bahia State Forum of NGOs/ AIDS (FOBONG).

24) Partnerships

The major partnerships of GGB towards carrying out political actions are with the State STD and AIDS Coordination, Municipal STD and AIDS Coordination, Government Prosecutors Office, Ministry of Justice, NGOs/AIDS, NGOs/mixed, Private Institutions and other segments of social movements.

The Group also mentions the partnership with the *Hospital das Clínicas*, which performs free and voluntary serum assays at GGB headquarters. Other partners are the CREAIDS, USAID, Municipal Health Secretariat, Local Government of Salvador, and the Emtursa.

25) Incidence on Social Programs and Public Policies

The NGO participated in the elaboration and implementation of governmental public policies referring to free access to medications, prevention devices, NGO capacity-building and advocacy in the fields of human rights and citizenship.

GGB has mainly played the role of inducing discussion and fomenting public policies, not only on AIDS, but mainly concerning human rights and quality of life of the homosexual population in the State of Bahia and Brazil, as well. The GGB pursues promoting these rights with councilmen and state representatives, by proposing both municipal and state laws. It also acts on enforcing the State duties, as the access to medication such as B-Vitamin Complex and Bactrim, which are important drugs for treating opportunistic diseases. Regarding the promotion of homosexual rights, the GGB claims punishment to perpetrators

and referral of crimes involving homosexuals to the Bahia State Secretariats of Public Safety and Human Rights. Currently, they are fighting for the inclusion of homosexual partners into the category of stable unions and entitlements to social security benefits.

The organization is part of the Municipal and State STD and AIDS Commissions, besides the Advisory Committee to the National STD and AIDS Programme. It also holds seat in major representative spheres, such as the National AIDS Commission of the Ministry of Health, the Committee to Homosexual Affairs in the Ministry of Health, and the National Council to Fight Discrimination, of the Ministry of Justice.

GGB does not participate directly in the Councils, but provides assistance to any institution that may submit proposals oriented to grant homosexuals social inclusion. It has already worked with the following Councils: Municipal Health Council, State Council, Social Assistance Council, and Council on Protection to Minors.

26) Organization Sustainability, in Mid and Long Terms

The GGB team is very concerned about the issue of sustainability, mainly because the NGO survives basically from the financial support of the Ministry of Health.

The situation is now worse, since the Ministry ceased financing some projects. This led many entities to management problems, and some even closed. This is a major concern for all, mainly for NGOs oriented to the homosexual's and sex professional's communities, because this cause, in general, doesn't touch people.

The GGB suggests that the State should assist the entities in seeking for sustainability alternatives. Furthermore, it must keep important programs of community mobilization and support to these organizations. "Some entities, for themselves, face hard difficulties in opening ways in civil society because of the cause they fight for. I wonder, what would happen if they were to ask money to any corporation?"

The NGO identifies as threats to the organized civil society sustainability, in the field of AIDS, the lack of resources from international, national and governmental agencies, thus leading several institutions to cease their works. Another threat would be the tributary charge on NGOs (charges, fees and taxes).

Many NGOs became technocratic institutions, in opposition to what they used to be when they were established, when they were strengthened. Maybe, they did that to become compliant to the political system in force, the issue of OSCIPS, and the issue of becoming compliant with the legislation. The leaders became technocrats, technicians in writing projects, technicians in rendering accounts and, somehow, that eagerness of social movement, that power of the social movement was left aside because of the requirement for a new logic, that of the political and legislative systems.

27) Interlocution with Governmental Spheres, in the Field of the AIDS Epidemic

The *Grupo Gay da Bahia* holds a very similar stance to that of APROSBA, because of the difficulty in raising resources to develop projects dealing with prostitution and male homosexuality. “In general, financing agencies and institutions prepare the programs, and the NGOs shall fit into such programs”. The only resources allotted to finance these programs are those granted by the Ministry of Health and, to a lesser extent, by USAID. The respondent emphasized: “Mac Arthur and Ford foundations, who have always supported the issue of AIDS, have never granted financial support to programs oriented to homosexuals”.

The institution emphasizes as positive points that influence the successful Brazilian experience, the decentralization and support through financial resources that are directly transferred to the institutions and, thus, avoid bureaucracy. Additionally, there is the model of partnership between the NGOs and the Government, which played a crucial role in reaching successful actions. The GGB also underlines the division of women’s groups, sex professionals, and homosexuals, which is important to build actions in any policy on the prevention against AIDS.

The *Grupo Gay da Bahia* understands that, since AIDS history is closely related to the homosexual movement, the National Program has positively contributed towards developing both fights.

Federal government resources employed on homosexual organizations have provided more visibility to them, thus expanding the sources for raising additional resources, at national and international levels. Countless entities were established, and there was a national debate not only about the issue of AIDS, but also on homosexuality. Furthermore, it allowed for the development of debates on self-esteem, health, conquest of inputs, human rights, printed material, advertising ideas, and led to more continuous debates in the media. Therefore, the gay movement owes its visibility to the discussion on AIDS. The State acknowledged the importance of homosexual NGOs – the Ministry of Health has even complimented the GGB for its efficacy and persistence in the issue of prevention against AIDS in Brazil. The dialogue between these institutions and the State was enhanced. The State started acknowledging and respecting these NGOs, besides perceiving homosexuals not only as vulnerable to AIDS, but also to homophobia, prejudice, and discrimination. It allowed for more resources allotted to this field, even if these resources were scarce.

In the field of interlocution between Organized Civil Society and governmental spheres in the fight for citizenship and human rights, the GGB reaffirms the important role played by the Ministry of Health in face of the homosexual population and fight against the epidemic. It observes that the transmigration of people from NGOs to the institutionalized political society cooperated towards a smooth dialogue: “There is the issue of people who were in the Ministry of Health, who knew the movement, some came from social movements and were sensitive to this issue”.

Currently, the NGOs have a relationship with other Ministries, and the Ministry of Health fomented it. Thus, the Ministry of Justice opened the debate and dialogue, financing some projects and, in the second issue of the National Human Rights Plan, it introduced short-, mid- and long-term issues for homosexuals. With the Ministry of Education, the formulation of education on transversal topics involves AIDS, human rights, sexuality at school, and it is a result of a campaign by the Ministry of Health, with pamphlets and posters specifically oriented at the education professional. Therefore, it opened the school doors for a work on prevention, and a special

chapter addressing sexual orientation. Therefore, it is a victory, and the merit belongs to the Ministry of Health.

In the GGB's opinion, the social movement – even being mainly supported by the Ministry of Health – does not lose its critical idea because, somehow, the Ministry itself has fomented the discussion. Therefore, although it receives governmental resources, it does not lose the notion of social behavior.

B. 4. GPM – Grupo Palavra de Mulher

1) Organization Name: GPM – Grupo Palavra de Mulher

2) City/State: Salvador/Bahia.

3) Date of Foundation: 21/10/1999.

4) Started Working with STD/AIDS in: 1999.

5) Kind of Organization: Advocacy on women's rights and health.

6) Address/Phone:

gpm. gpm@ig. com. br

Tel: (71) 321-67-14

7) Situation Concerning Headquarter

It has its own premises, purchased in partnership with the NGO GLB – they share the same physical space – and with resources granted by the organization leadership.

8) Where it Performs the Activities: ONG headquarter.

9) Field of Action: Women's movement.

10) Priority Field of Action: Prevention against STD/HIV/AIDS.

11) Geographic Area of Work: Municipal.

12) General purposes

- Foment actions on human rights to women, mainly concerning reproductive and sexual health. Promote human rights and policies on women's health.

13) Target-audience

Low-income women.

14) Core Activities

- Legal, psychological and medical referral;
- Lectures;
- Workshops on safe sex and preventive actions;
- Socio-cultural and leisure activities;
- Preparation and distribution of informative material;
- Promotion of courses and seminars;
- Workshops, group meetings;
- Home visits.

15) Ongoing programs and projects

Direito Positivo Project, for seropositive women.

16) Services Provided to Population

- Information services;
- Distribution of condoms;
- Educational lectures on women's health;
- Partnerships with hospitals and referral clinics.

17) Works only with AIDS: No.

18) Advertises the Work Developed Through:

- Pamphlets, folders, brochures, printed material and meetings.

NGO characterization and background

19) Origin of the institution.

Women's group aimed at carrying out activities in the fields of women's health, prevention against STD/AIDS and human rights.

20) Organization's Motivation Towards Working on STD/AIDS

They have worked on STD/AIDS since the NGO was founded, in 1999. They were motivated to do so because, until up that time, there was no specific work in this field aimed at women in Salvador. Furthermore, they were concerned about the lack of knowledge among women regarding STD/AIDS, and their poor power of negotiating the use of condoms with partners.

21) Resources and Sources of Financing

They emphasize that sponsorships are eventual for events and publications; international cooperation agencies; agreements with public bodies and donation received from individuals. The NGO used to be financed by the Latin American Networks of Women's Health, but now they have no source of financing.

The NGO adopted the strategy of donations by the organization leaderships and employment of projects financed by the Ministry of Health as a way for resources intake. The Entity also intends to organize a cooperative women's association.

22) Human Resources

In terms of human resources capacity building, the GPM provides and holds courses on human rights. The team attends human rights courses delivered by the Human Rights Foundation, besides those delivered by the Luís Eduardo Magalhães Foundation and *Voluntariado da Bahia*. Currently, the NGO is preparing a course on women's sexual and reproductive health.

23) Work Methodology

The NGO holds monthly group meetings to discuss weak and strong points in relation to the work performed. It also works on plans to adjust the demands required for the continuity of the actions in the following year.

Concerning difficulties related to the daily experience in the field of AIDS, the Institution emphasizes that the system of gender relationships rules the social relationships between the sexes, thus cooperating towards increasing women's vulnerability in face of STD/AIDS:

Women are vulnerable to STD/AIDS because they play the role of receptors, have no autonomy in the relationship, can't set a dialogue with the partner concerning the use of condoms, and even concerning their own lives. Another problem is the lack of accurate information and low self-esteem, which makes women vulnerable.

24) Political Articulation

The GPM is affiliated to the Feminist Health Network, National Network on Emergence Contraception, and to the CREAIDS Network. It is part of the Bahia State Forum of NGOs/AIDS (FOBONG), the Women's Forum of Salvador and the Human Rights Forum.

25) Partnerships

The major partnerships for carrying out political actions are set forth jointly with the State STD and AIDS Coordination, with the Ministry of Justice, with other Health programs and/or secretariats, with NGOs/AIDS, and with social movements.

26) Incidence on Social Programs and Public Policies

The NGO participated, jointly with the government, on the discussions about public governmental policies concerning access to preventive devices, NGO capacity building and advocacy for human rights and citizenship. The GPM is part of the State's Women's Council.

27) Organization Sustainability, in Mid and Long Terms

According to the GPM, the State role concerning the sustainability issue would be to induce and increase the establishment of partnerships, not only in the field of financing, but also concerning human resources capacity building and the employment of some professionals who work in specialized fields, and who could contribute towards resources intake. The NGO also states that the organized civil society institutions are playing the role of the State.

Some institutions have skilled individuals who take care of resources intake, leading to financial and technical sustainability. But most of them have no resources and, at any time, may close: I'd rather not answer this question, because I don't see any alternatives. What I notice is the lack of resources but I can't see any prompt solutions, I can't see any solution to this issue that affects most institutions.

28) Interlocution with Governmental Spheres, in the Field of the AIDS Epidemic

The GPM affirms that one of the consequences of STD/AIDS financing over the institutional agenda priorities is the difficulty in establishing a dialogue with the donor. The NGO has a project approved by the Ministry, by UNESCO or by UNODC. Furthermore, it points out that, if the financing organization's proposal does not fit into the institution's mission, the Organization refuses the financing.

As important issues in the success of Brazilian actions on the fight against AIDS, the NGO highlights the prevention policy

adopted in Brazil, besides the free distribution of medications. This is a result of a huge effort by the organized civil society.

The NGO believes that the relationship between the organized civil society and the Government happens solely on eventual works: “When the project ends, all relationships also end, and there is no continuity. The project ends, we cannot maintain the project, we have no human resources, and then the work is interrupted. Then, NGOs can hardly say anything to their users”.

Concerning the repercussion of governmental financing over the organization’s political actions, the GPM emphasizes that, if an institution targets its mission, it cannot lose autonomy because of governmental financing.

B. 5. CECUP – Centro de Educação e Cultura Popular

- 1) Organization Name: CECUP – Centro de Educação e Cultura Popular**
- 2) City/State: Salvador/Bahia.**
- 3) Date of Foundation: 04/03/1982.**
- 4) Started Working with STD/AIDS in: 1999 with researches and in April 2000 with actions.**
- 5) Kind of Organization: Promotion, advocacy and grant of rights.**
- 6) Address/Phone:**
cecup@terra. com. br
Tel: (71) 322-04-12

7) Situation Concerning Headquarter

Rented and maintained with resources from several projects, through agreements with public bodies and international cooperation.

8) Where it Performs the Activities: NGO headquarter.

9) Field of Action

Low-income population, mainly adolescents and youth.

10) Priority Field of Action

Human rights, children and adolescents' movements and prevention against STD/AIDS.

11) Geographic Area of Work: National, but works mainly in the State of Bahia.

12) General Purposes

Contribute towards the organization and development of communities with low-income populations, through the education process.

Rescue and appraise popular history, culture, knowledge and religion, mainly concerning the Afro-Brazilian population.

13) Target-audience

Diversified: blacks, women, children, adolescents and youth, family, educators in independent community schools and public schools: *However, our priority is always placed on people living in peripheral districts.*

14) Core Activities

It has three basic institutional programs. The *Política com Direitos Humanos* Program, the *Educação e Cultura* Program and the Etnia Program. *Política com Direitos Humanos* places priority on spaces of civil society, councils, and forums in public control spaces, councils and forums. *Educação e Cultura* works by providing advisory services to community-based schools, besides some public schools. *Etnia* focuses on the black movement, the issue of educators' qualification, and activists in issues of racism, discrimination, rescue and appraisal of Afro-Brazilian history, culture and religion.

They have STD/AIDS centers in districts with community-based schools, made up by educators and youth belonging to the communities. These groups work on dissemination, capacity building, and information, besides the distribution of condoms. The center opens every week to provide consultations and deliver lectures, and this is a continuous and permanent activity.

15) Services Provided to Population

Actions on STD/AIDS prevention, by holding seminars, publishing materials such as brochures and pamphlets, lectures, debates and establishment of community centers to adolescents, educators working on this issue at peripheral communities, including the distribution of condoms with guidance.

16) Works only with AIDS: No.

17) Advertises the Work Developed Through:

Journals, printed material, meetings, seminars, textbooks, pamphlets, debates and lectures.

NGO Background

18) Origin of the institution

CECUP was officially registered in 1982, but it was established in 1978, by a group of liberal professionals working in several areas, bound to trade unions and class entities.

In the times of military dictatorship, an articulation named Trabalho Conjunto dos Bairros, which involved the Districts Federation, the Association of Residents, the Engineering Club, the APLB, the Institute of Architects and trade unions arose in Bahia. In these communities, people were semi-illiterate or illiterate, thus leading to a demand on late literacy programs. There were some educators in these groups, who were developing a work on late literacy. Furthermore, there was the Bandeirantes movement, which also performed literacy works. Therefore, both groups joined – liberal professionals and the Bandeirantes movement – and started developing a work on literacy to the population living in Salvador's popular districts. This was the embryo that brought CECUP into life.

19) Organization's Motivation Towards Working on STD/AIDS

They have worked with research on STD/AIDS since 1999 and started developing actions in this field in 2000. When they developed a work with a young group in the periphery, they could notice the lack of information and education towards STD/AIDS prevention – *this was one of the motivating factors towards organizing a specific work in this field.* The research field started working on the issue of violence and STD/AIDS with a periphery group of youths, based on the demands observed during community-oriented works.

20) Resources and Financing Sources

CECUP sources of resources are the international cooperation agencies; agreements with public bodies and eventual sponsorships.

21) Human Resources

In order to consolidate its professional team, the NGO employs the criteria of hiring skilled personnel – good academic background and sociability skills – for the activities implemented by the Institution. The required actions on capacity building are performed through courses, seminars and qualification in services.

22) Work Methodology

The Institution follows-up its actions by holding systematic coordination meetings with all project coordinators, preparing reports, financial auditing and technical consultancy services to monitor and assess projects development.

As specific problems in developing the experience, CECUP highlights that, in addition to poverty, there is also the combination of lack of information and prejudices resulting from gender relationships.

The specific problems found among the NGO target-population are: lack of information, lack of sexual and reproductive education, prejudice, strong resistance by youth in using condoms, low level of negotiation by women in demanding the use of condoms.

It should be stressed that the major challenges posed to reducing risks, both individual and collective, of being infected with STD/AIDS among the population served by the NGO, are: Establishing prevention mechanisms, access to information and education actions with its audience.

Another challenge pointed out is the discontinuity of programs and projects, “because of bureaucracy and delayed transfer of resources”.

23) Political Articulation

The NGO is member of the NGOs/AIDS forum, the Bahia State Forum of NGOs and to ABONG. It is also part of the Human Rights Movement.

24) Partnerships

The main partnerships established to carry out the political actions are: the State STD and AIDS Coordination, Municipal STD and AIDS Coordination, Health Secretariat, Education Secretariat, Human Rights Secretariat, Government Prosecutors Office, Ministry of Justice, NGOs/AIDS, NGOs/mixed and other segments of social movements.

25) Incidence on Social Programs and Public Policies

The NGO participated in the discussion and elaboration of governmental public policies concerning human rights and citizenship.

The organization holds seat in the Inter-managerial Councils of Human Rights, Children and Adolescent, the Brazilian NGOs Association, the National NGOs Executive, the National Forum on Adolescents Rights, the State Council on Adolescents, the Municipal and State Council on Social Assistance, the Forum on Social Assistance. It is part of the Forum coordination and has representation in the State Council vice-presidency, the State Human Rights Forum, and participates in the National coordination of Black Entities.

26) The Organization Sustainability, in Medium- and Long-Term

The NGO is diversifying the sources of resources, orienting its efforts towards providing advisory services to junior enterprises of the Federal University of Bahia. It is negotiating the expansion of specialized publication services and consultancy to projects. Furthermore, it is supported by international and national cooperation agencies.

27) Interlocution with Governmental Spheres, in the Field of AIDS Epidemic

The NGO argues that, in the field of financing agencies, the allotment of resources to remedy actions is more praised than the allotment to preventive actions. In its opinion, the support to educative

campaigns, and preventive and educational works with population, should be prioritized because this would lead to reduced expenses with medication, and ambulatory and hospital services.

It also warns that STD and AIDS should be understood and worked in the light of universal right to health, in the field of Human Resources. Therefore, the NGOs should place priority on their participation in forums and councils, “the space to work and concretize public policies”.

As an important and positive component to achieve successful actions on STD/AIDS in Brazil, the NGO mentions the partnership work developed by the state and the organized civil society, “since by ourselves we would not solve social issues. It is essential to work in partnership as joint action, rather than outsourcing”.

A successful experience of the National STD and AIDS Programme was the distribution of medications; another was improved services in which the partnership between civil society and government is worthy of highlight.

We consider the partnership with the Ministry of Health, the World Bank and UNESCO as crucial. Social issues cannot be solved in an isolated manner and requires for joint efforts by several segments to establish public policies and, thus, develop actions. This becomes clear when we observe the developments achieved by the National STD and AIDS Programme, due to the partnership established between the social movement and the State.

Furthermore, concerning the relationship between the organized civil society and governmental spheres in the advocacy for citizenship and human rights, the NGO highlights that, at the national level, participation and dialogue flow smoothly. Nevertheless, at state and municipal level this does not happen.

The posture of the Federal Government is more open, there is a partnership with respect. This doesn't happen at state and municipal levels, where this relationship is poor, hard and still very authoritarian.

According to the NGO, the partnership with the government did not lead it to loose its autonomy in relation to the political

and technical agenda. This loss is something that should be observed based on the institution's capacity of imposing its mission, goals and work methodology with its audience.

The government grants financial support to CECUP, but it never gave up its line of work, a political proposal compliant to its principles.

B. 6. ABAREDA – Associação Baiana de Redução de Danos

1) Organization Name: ABAREDA – Associação Baiana de Redução de Danos.

2) City/State: Salvador/Bahia.

3) Date of Foundation: 08/2002.

4) Started Working with STD/AIDS in: 2002.

5) Kind of Organization: Association.

6) Address/Phone:

Phone: (71) 336-7943 / 336-86-73

E-mail: abareda@bol. com. br

7) Situation Concerning Headquarter

The Association of Residents of Ribeira assigned the working space. As counterpart obligation, the NGO pays electricity and water bills.

8) Where it Performs the Activities: ONG headquarter.

9) Field of Action: Damage Reduction.

10) Geographic Area of Work: State.

11) General Objective: Expand and advertise the actions developed by CETAD.

12) Target-audience: Users of injected drugs and crack cocaine.

13) Core Activities

Surveys on the profile of crack cocaine users; supply of pipes for use, preventing them from sharing and, thus, reducing exposure to diseases such as herpes, tuberculosis, hepatitis and AIDS; distribution of condoms.

They develop activities for male and female users of crack cocaine, oriented to STD/AIDS prevention, in addition to actions for women partners of users. The strategies to work on prevention are workshops on yoga and music, as a means to talk about STD/AIDS, drug and sex. *And, then, referring them to treatment.*

14) Services Provided to Population

- Workshops on yoga and music;
- Referral to drug use treatment;
- Access to medication for seropositive individuals.

15) Works only with AIDS: No.

NGO Characterization and Background

16) Origin of the institution

ABAREDA was established with the aim of expanding and disseminating the actions developed by CETAD/UFBA.

Since CETAD is governmental, they perceived the need for building a NGO, thus bringing the community and drug users closer to a civil society organization. Some people that worked for CETAD – like health agents and professionals from several fields – gathered for this purpose. Institutional strengthening came in August 2002, when they got resources to equip the NGO.

17) Motivation to work on STD/AIDS

They have worked on STD/AIDS since 2002. *What motivated them was the vulnerability of drug users.*

18) Resources and Financing Sources

ABAREDA source of resources is, basically, the Ministry of Health, through projects financing. The Association also receives contributions of its partners, who pay an annual fee amounting to R\$ 20.00.

ABAREDA considers increasing the number of members, and holding bingos and bazaars, as strategies to generate resources to maintain its activities.

19) Human Resources

Team capacity building is developed jointly with CETAD. Through this partnership, they provide courses on damage reduction, STD/AIDS, drugs and first AIDS in the event of overdose. All ABAREDA agents of damage reduction undertake the courses and capacity building programs, and then become multipliers.

20) Work Methodology

The Institution assesses actions performed through meetings and the General Assembly, held on regular basis, every six months.

During the meetings, they assess weak and strong points of the actions implemented, and the NGO financial status as well.

As specific problem related to the institution activities, they mention how drugs use brings vulnerability to chemical dependents, for STD/AIDS: “Vulnerability in relation to STD/AIDS affects most crack cocaine users, who change sex for drug, having sex for R\$ 1.00 to get crack cocaine and share the pipe”.

Services rendered to drug users in the scope of public health, and the discrimination against chemical dependents.

The importance placed to awareness building – not only concerning drug users, but mainly public in general – is increasing, taking into consideration the polemics on the model of damage reduction. “Repercussions and impacts of actions divide the public. Some support, understand, while others believe that supplying pipers is an incentive to the use of drugs”.

21) Political Articulation

ABAREDA is associated to the Brazilian Damage Reduction Network, the Latin American Damage Reduction Network – RELARD, the Brazilian Association of Damage Reduction Agents – ABORDA, the Ceará State Damage Reduction Association – ACERD; the Acre State Damage Reduction Network – REARD, the Association of Users of Alcohol and Drugs in General. Furthermore, it is associated to ABONG and, at the local level, participates in the Bahia State Forum of NGOs.

22) Partnerships

When it held the First Seminar on Damage Reduction in the State of Bahia, CREAIDS provided support and partnership, besides the Municipal Health Coordination, Municipal Council and Municipal Secretariat. The event provided for articulation and approximation between the state and local government.

23) The Organization Sustainability, in Mid and Long Terms

The organization is undergoing a sensitive moment, since it was recently founded and is no longer working within the CETAD's physical space. Therefore, it has faced difficulties in obtaining financing and support. The solution for its sustainability would be to prepare projects in the fields of STD/AIDS and drugs, while simultaneously involving damage reduction as a program in the Family Health Plan - PSF and Community-based Health Services Programme – PACS.

The NGO mentioned changes in government as threats to sustainability, since the problem surrounding the implementation of damage reduction in Brazil is still hardly discussed. In their turn, the institutions dealing with this topic are unknown and discriminated within the scope of some segments of financial support.

24) Interlocution with Governmental Spheres, in the Field of the AIDS Epidemic

The *Associação Baiana de Redução de Danos* highlights the distribution of medications, improved assistance services and partnership established between the organized civil society and the government as factors that contributed to the success of the National STD and AIDS Programme.

According to them, it brought about a relationship between drug users and institutions with which they work, such as the *Hospital das Clínicas* (reference in STD/AIDS) and CETAD (reference in treatment to drug users). When ABAREDA advertises the work performed, showing the possibility of treatment, the users seek for doctors and the NGO refers them to assistance, and this started happening after the establishment of partnership with health institutions.

C. THE FEDERAL DISTRICT

C. 1. ESTRUTURAÇÃO – Grupo Homossexual de Brasília

- 1) **Organization Name:** ESTRUTURAÇÃO – Grupo Homossexual de Brasília
- 2) **City/State:** Brasília/DF.
- 3) **Date of Foundation:** 09/01/1994.
- 4) **Started Working with STD/AIDS in:** 1996.
- 5) **Kind of Organization:** Advocacy and services provision.
- 6) **Address:**
estruturacao@df. mailbr. com. br
- 7) **Situation Concerning Headquarters:** The space is rented.
- 8) **Where it Performs the Activities:** NGO headquarter.
- 9) **Field of Action:** HIV/AIDS; gay movement.
- 10) **Priority Field of action**
Gay movement, lesbian movement and movement of male sex professionals.
- 11) **Geographic Area of Work:** State.

12) General Purposes

- Promote and fight for improvement to the quality of life of gays, lesbians and travesties in the Federal District.
- Advocacy and promotion of human rights to homosexuals, social control, proposal of public policies, services provision and integral health.

13) Target-audience: Men who have sex with men, lesbians and travesties.

14) Core Activities

- Meetings open to gay and lesbian audiences in the Federal District;
- Exhibitions of videos on gay and lesbian topics;
- Proposals and monitoring of public policies towards the exercise of homosexual citizenship;
- Actions on STD/AIDS prevention;
- Assistance to seropositive individuals belonging to the MSM and WSW population.

15) Ongoing Programs and Projects

They have three projects financed by the National STD and AIDS Program.

16) Services Provided to Population

- Participation in seminars;
- Educational lectures in schools;
- Participation in campaigns on the prevention against STD/AIDS;
- Distribution of condoms;

17) Works only with AIDS: No.

18) Advertises the Work Developed Through:

- Bi-monthly Newsletter, printed material, congresses, conferences, meetings and seminars.

NGO Background

19) Origin of the institution

A small group of gays and lesbians in the Federal District who were concerned about the discrimination and prejudice of civil society against homosexuals created it.

20) Organization's Motivation Towards Working with STD/ AIDS

They have worked on STD/AIDS in a systematic way since 1996. The respondent informed that their motivation to develop this sort of work was, first of all, their willingness in working with more efficacy on this issue for homosexuals, because they feel that this population remains very vulnerable, not only to STD/AIDS, *but to discrimination, prejudice and non – understanding about their roles as citizens.*

Therefore, they consider that prevention cannot be separated from assistance to and self – esteem of homosexual. The issue of AIDS, in the daily life of *Estruturação*, is very important but, at the same time, is very sensitive because they do not want to work with beneficiaries out of an integral perspective:

AIDS must be worked under an inter – disciplinary approach. It should deal with violence, citizenship, and not only with AIDS itself. So, I believe that homosexual movement should be alert, and have the capacity of building sensitiveness among managers, whether at the national or local level. And we have difficulties, since homosexuals are a population vulnerable to the HIV/AIDS epidemic.

21) Resources and Sources of Financing

The major financial sources that support the *Grupo Estruturação* come from donations of individuals and sponsorships. To assist in affording the major expenses, coordinators and assistants donate a share of their earnings. Furthermore, they rely on donations made by NGO volunteers. The sales of key holders, necklaces and T – shirts with the drawing or the colors of the rainbow, the symbol of gay and lesbian movement, has also contributed towards generating income to *Estruturação*. The institution also intends to adopt social marketing of condoms as a strategy for resource intake: (. . .) “we keep on inventing, if we want to become visible, we must always be creative, inventive, but this is also a very pleasant duty”.

22) Human Resources

Concerning human resources, the *Grupo Estruturação* also employs creativity to solve the lack of financial resources to qualify its volunteer team: it established partnership with local NGOs/AIDS – GAPA/DF – to develop capacity building actions for both NGOs. This capacity building took place in two moments: first, the NGOs/AIDS prepared *Estruturação* volunteers as regards the several elements involved in facing the AIDS epidemic. In a second stage, team provided training to GAPA/DF concerning the specificities related to homosexuality.

Up to now, maintaining a volunteer staff has been a very sensitive issue as it faces, among other difficulties, the problem of making volunteers “incorporate this commitment, making investments in sustaining the volunteer system”.

Still in the field of human resources, it established partnership with STD and AIDS Management in the Federal District, in the sense of assembling a database to follow – up projects developed by *Estruturação*. This follow – up intends to develop a critical view on the format of capacity building activities, taking more accurate definition on the profile of volunteers to be incorporated into actions performed by the Group into consideration. They could notice the need for clearer profiles for volunteers and the projects where they were to work. It should take into consideration the fact that populations assisted by

actions developed by *Estruturação* are different from one another and, therefore, require for different approaches. Nevertheless, baseline principles for the work remain the same for all populations, i. e., citizenship, self – esteem strengthening, distribution of condoms.

Travesties have no defined sexual orientation, the issue of identity and, therefore, to work with this population you need more mature, experienced, expansive, and cheerful volunteers, who are less circumspect. Engagement is the issue in capacity building to volunteers. It is quite a chronic problem.

Currently, the *Estruturação*, jointly with GAPA/DF, the *Grupo Pela Vida/RJ*, and *Grupo Arco – Íris/RJ* are participating in capacity – building actions to allow them to develop and implement Project *Body*.

The Project is a partnership to provide in – home follow – up care to HIV carriers in the Federal District, in the field covered by these actions. I can't say anything on behalf of the project, but what we notice here in Brazil is that Project *Body* Rio de Janeiro is being developed by two NGOs. One works on the human rights of homosexuals and the other on assistance by the *Grupo Pela Vida*. I think they want, within the reality of each one, to bring this model. The Coordination is not the financing agent, and it is important in the field of stability. The financing agent is from Holland – a NGO working on human rights to homosexuals.

23) Work Methodology

The assessments are made during the weekly meetings of the Board of Directors. They check the actions development and make permanent monitoring.

24) Partnership

It tries to enhance its partnerships to carry out political actions. “First of all, the natural partnerships”, working in the NGOs/AIDS Forum and with organizations that make it up, whether organizations like Support Shelters or mixed NGOs, or even those working on prevention and/or assistance. On the other hand, they keep dialogues with the State STD and AIDS Coordination, Health Secretariat, Ministry of Justice, National STD and AIDS Programme, private institutions and other social movements.

This trend of establishing partnerships is not employed solely to seek for solutions to the problems of team capacity building; it is also considered as a qualitative jump towards political legitimacy of *Estruturação* at several spheres. In this sense, it has already established partnerships with the academic sector: the University of Brasilia (UnB), the organization of the Seminar on Social Policies for the Homosexual Population in the Federal District. Recently, they opened space at UnB Colleges of Education and Law; with social movement – it is a member of the Brazilian Association of Gays and Travesties and to the Gay Parade Association (ABGLT). Additionally, it is member of the National Forum of Human Rights Entities, and founding member of the NGO/AIDS Forum in the Federal District. Furthermore, it pursues enhancing the permanent dialogue with other local NGOs – as, for instance, the articulation with GAPA/DF – to monitor STD/AIDS policies in the Federal District. Following the same lines, the respondent mentioned the interlocution with the Damage Reduction Program, “Since it would be useless working only on STD/AIDS among travesties, since they also join experiences in drugs”.

The group also works jointly with the Human Rights Commission of the Brazilian Federal Chamber, which is supporting the implementation of Project Body in the Federal District.

Aiming at providing visibility to works developed by the group, another outstanding partnership was established with Mr. Brain – an advertisement agency that developed *Estruturação*'s campaign on STD/AIDS during Carnival. “Our functional image, the image of our association, the Parade promoted by *Estruturação*, was prepared by Mr. Brain, with no costs to us. So, we have high-quality services, which somehow break this link with the State”.

25) Incidence on Social Programs and Public Policies

The NGO participates in the Federal District Health Council, the Forum on Children and Adolescents, the Inter – managerial Council, with the Human Rights Commission of the Legislative Chamber, the

Gay Parade Association, the National Human Rights Forum, the Brazilian Association of Gays and Travesties, besides being members of the National Forum of Human Rights Entities.

Jointly with the government, it participated in the elaboration of public policies concerning free access to treatment, NGO capacity building, especially as regards human rights and citizenship.

26) The Organization Sustainability, in Mid and Long Term

Sustainability is a major concern to the organization. Homosexuals' human rights acknowledgement requires for support by local government, since it is hard to obtain financing exclusively for advocacy on this issue.

Sometimes the government team is more resistant to these issues of the human rights of homosexuals. It is more conservative, with strong religious fundamentalism. On the other hand, we are concerned about making the Coordination understand and be sensitive to the fact that judgment on the moral value of these actions goes far beyond, and we are not sure if our local health managers will perceive it.

It is worth mentioning that this NGO financial stability is a constant challenge. The major threat concerns the sources of financing, especially the lack of resources that may lead to demobilization and discontinuity of implemented actions. Brazil is a country that carries out assertive measures in the fight against the HIV epidemic and "if there was a successful initial investment, it would be necessary to continue it and, therefore, it is an endless process".

Concerning the results of governmental financing, particularly the support from agreements set forth with the World Bank (AIDS I and AIDS II) to fight HIV/AIDS, the NGO feels favorable conditions to keep different roles, i. e., the government does not exercise control just because they grant financial resources. "I don't believe that NGOs loose autonomy, I have never heard of it, nor have I perceived this sort of guidance, this state influence".

The *Grupo Estruturação* claims to be the first gay entity that launched a textbook approaching the conscious vote of the homosexual, financed by NGO resources, because it did not want to have its credibility with the target-audience damaged. The textbook was launched in the communication means, and intended to reach many homosexuals who do not participate in the Group.

All beneficiaries refer to the creation of *Grupo Estruturação* as an inflexion point in their lives and that brought about improvements in the quality of life and acceptance of their homosexuality. The work on prevention against STD/AIDS is considered positive; all of them acknowledge the projects developed and want to work directly on them.

27) Interlocution with Governmental Spheres, in the Field of the AIDS Epidemic

The NGO understands that HIV/AIDS have minimally assisted in concretizing a way of thinking about public health policies, which used to be ruled by the 1988 Sanitation Reform and the Unified Health System (SUS). It allowed for employing principles on decentralization, popular participation and dialogue between the state and civil society. It should be recorded that the success of Brazilian actions is a milestone, but it demands further developments.

For Brazil, I would highlight this guideline towards working, articulating with civil society. To listen to civil society. To create spaces where these demands by society are heard and met, whenever possible, converting them into political claims: “So we, as an organized civil society, want to have this intention of listening to our basis and converting it into political tools, complying with the law that you may pursue”.

Although the Group claimed the inexistence of institutional autonomy loss, when financed by governmental resources, they report the interference on the priorities of daily agenda. However, it should be taken into consideration that this organization is a reference group in advocacy for homosexuals’ human rights, and they have more influence over their target-audience due to financial and technical limitations.

The articulation between State and the civil society shall be of partnership, where the State should assign some duties to civil society.

However, the State should not assign the duties inherent to it, like financing, enforcing and encouraging the actions developed in the NGOs. The Ministry of Health Coordination, regardless the government in power, sustains the program, because it relies on the civil society support. The more support to a program, project or service has from civil society, the less it will be left at the mercy of a given government. Concerning the Ministry of Justice, the human rights issue did not happen. “We have noticed that the National Coordination provided more tools, means and took social steps towards allowing us to work on homosexual’s citizenry. If a program is successful, it is because of civil society mobilization”.

At the regional level, specifically for the Federal District, the NGO believes that the interlocution with government happened in different ways, since at the local level a moralist understanding on the relationships between people of the same sex remains. This kind of concept is opposite to baseline assumptions towards controlling the epidemics, where full exercise of rights and citizenship reinforce the actions on health promotion and prevention against diseases acquired through sexual practices, as is the HIV/AIDS: “it brought some improvements to local management, but we still want more”.

The Group reinforces that such political ambiances demand greater commitment from NGOs towards capacity building, developing partnerships and social mobilization, since civil society should be better organized at the local level.

C. 2. GAPA/DF – Grupo de Apoio e Prevenção à AIDS do Distrito Federal

- 1) Organization Name: GAPA/DF – Grupo de Apoio e Prevenção à AIDS do Distrito Federal**
- 2) City/State: Brasília/DF.**
- 3) Date of Foundation: 17/09/1991.**

- 4) **Started Working with STD/AIDS in:** 1991.
- 5) **Kind of Organization:** Non – profit civil society of private law.
- 6) **Address/Phone:**
gapadf@zaz. com. br / gapadf@terra. com. br
Phone: (61) 326 – 70 – 00 / 328 – 36 – 68
- 7) **Situation Concerning Headquarter**
It does not have its own premises. Since 1996 the space is assigned through an agreement with the Social Action Secretariat of the Government of the Federal District. The agreement is about to be renewed for an additional 5 – year period. They pay only for electricity and telephone bills.
- 8) **Where it Performs the Activities:** ONG headquarter.
- 9) **Field of action**
Male and female sex professionals and movement of children and adolescents. Behavioral intervention and assistance to people living with HIV/AIDS.
- 10) **Priority Field of Action:** Prevention against STD/HIV/AIDS.
- 11) **Geographic Area of Work:** State.
- 12) **General Purposes**
GAPA/DF develops works mainly oriented to prevention. The projects developed aim at providing

guidance and information to the Federal District population and surroundings on ways of prevention, adoption of safer sexual practices and correct use of condoms. Fight against discrimination and behaviors that damage human rights of HIV/AIDS carriers. Fight for the establishment of an efficient public health policy concerning HIV/AIDS in the Federal District.

13) Target-audience

Seropositive individuals and family members, women, children and adolescents in conflict with the law, confined in the Center of Specialized Juvenile Services – CAJE, and sex professionals.

14) Core Activities

Works on STD/AIDS prevention among populations living in the Federal District and surrounding regions.

15) Ongoing Programs and Projects

GAPA/DF develops two projects on direct assistance to seropositive individuals: legal and psychological assistance.

16) Services Provided to Population

- Dial – AIDS;
- Legal and psychological assistance;
- Educational lectures on HIV/AIDS;
- Library specialized on HIV/STD/AIDS;
- Hospital visits.

17) Works only with AIDS: Yes.

18) Advertises the Work Developed Through:

Magazines, congresses, meetings and seminars.

NGO Background

19) Origin of the institution

In 1989, a group of friends gathered to try to provide information to the population about the risks of contamination from AIDS. The work started with small interventions held at gas stations, with no established objective and audience. In 1991, they decided to structure the institution, asked GAPA the authorization for employing the name, and defined their area and way of working in the Federal District. Then, they founded the NGO GAPA/DF. They prepared their statute based on the statute of GAPA/São Paulo.

20) Financial Resources

The major sources of resource intake to GAPA in the Federal District are donations by individuals and corporations. Furthermore, the institution relies on eventual sponsorships, additionally to some resources granted by international cooperation agencies and agreements with public bodies. They also charge for services provided, such as lectures and training to community – based health agents. The institution employs, as strategy to pursue financial support, the sale of invitations to events, such as parties promoted by the organization. Additionally, it has projects financed by Caritas, and eventual and advertising campaigns prepared by the team.

21) Human Resources

In terms of capacity building to the team and volunteers that seek for GAPA/DF, it believed, in principle, that training could be held according to the volunteers' demand, based on their selected field of work. Facts that not necessarily corresponded to the Institution demands towards making ongoing projects effective; i.e., “volunteers used to come to GAPA, got acquaint and selected the project where they would work”. Currently, they believe that capacity building should be oriented to areas needing personnel.

22) Work Methodology

There is a special concern in regard to the work methodology. The major concern is focused on the NGO planning process, mainly due to the work that is mostly performed by volunteers. It demands for thinking about a planning that may fill in the gaps existing in actions, in order to introduce the volunteer staff into the fulfillment of projects activity agenda. In this sense, the Institution points out the acceptance by HIV/AIDS carriers towards individuals who do not have the virus or the disease as a problem. Typically, the non – condition of individuals living with HIV/AIDS experienced by volunteers becomes a constraint to the users seeking for the NGO.

One of the barriers we found is related to the acceptance of volunteers who are not HIV/AIDS carriers: I come to talk with them, the first thing they want to know is if I have AIDS. And if I say that I don't, the person becomes closed, and will talk only to another person with AIDS.

23) Political Articulation and Social Control

GAPA/DF is a member of GAPA Network that, in its turn, is associated to REGLA. They are also part of the Permanent Forum of Civil Society Organizations working with AIDS in the Federal District. The Organization's major partnerships are with the District STD and AIDS Coordination, Secretariats of the Ministry of Health, other NGOs/AIDS and mixed NGOs, in addition to private institutions. The Institution frequently attends meetings of the Federal District Forum/AIDS. It sends representatives to all national meetings of NGO/AIDS (ENONG), to GAPAS Network and to EDUCAIDS.

GAPA/DF participated in the discussions, elaboration and implementation of public governmental policies and programs concerning access to preventive devices, besides capacity building to health professionals. Currently, it is part of the Inter – institutional AIDS Commission in the Federal District, representing the segment of local NGOs/AIDS.

24) Organization Sustainability, in Mid and Long Terms

The organization sustainability is a very complex issue for its members, since it brings a lot of uncertainties. These uncertainties are bound to difficulties and, to some extent, to expectations created by the Federal Government concerning its cooperation to the civil society towards developing works in the field of AIDS. That is so because the National Coordination initially became the “major financing agent, leading NGOs to great development due to the AIDS movement and, out of the blue, reduced the resources”. On the other hand, the institution understands that the State is not responsible for the financial, technical or political sustainability of the NGOs, and they “must learn to do it by themselves, to try to survive and leave the dependence they created in relation to the National Coordination”.

25) Threats and Strong Points Concerning Sustainability of Civil Society Action in the Field of Fighting HIV/AIDS

The institution identified strengths to sustainability, concerning the emergence of new leaderships and activism. The NGO also considers the expansion of fields of action as a positive change: “greater investments in organization; work not only with AIDS issue itself, but with collective health, reproductive health, women’s health, homosexual health and children and elderly health.” It acknowledges that this maturity results from the AIDS movement.

Among the threats to the NGO’s work, it highlights the lack of relationships between civil society and political society, since this sort of debate would assist the establishment of strategies that could refrain or even abolish the dependence on the State’s financial resources, through the diversification of contacts with other financing agencies. The NGO also pointed out difficulty related to the cultural/social context, due to huge obstacles faced in the duty of building sensitiveness among the community in general, because of the remaining social reactions that think AIDS as something that happens only to others.

26) Interlocution with Governmental Spheres

GAPA/DF highlights the following as components that have contributed to the successful Brazilian experience in the epidemic control: The conquering of free medication; government initiative on financial resources transfer to NGOs, to allow them to develop actions in this field; and the joint action between government and NGOs.

Although acknowledging the merits of the National AIDS Program, the NGO reports strong implications caused by the government financing to fight AIDS in Brazil. That was stronger over the role played by NGOs, in the context of fulfilling their political agenda, and on how they implement their actions. In this regard, comes about the common saying that most NGOs remain working because of financing granted by the World Bank and, without this source, half of them would have closed their doors, not only in the Federal District, but all over Brazil. GAPA/DF highlights that such financing operations have influenced the NGO agenda.

In our latest project, when we were negotiating the agreement renewal, we excluded some areas and included others, which were in higher need. The financing was not released while we didn't reinsert the area we had previously excluded. In the end, you have to cut other areas, because you won't have volunteers to perform all duties.

The Institution also observes that the National Coordination used to make direct transfers to the NGOs, and now this duty was assigned to State management and coordination units. This causes further delays thus jeopardizing the continuity of end actions among populations served by government – financed projects.

According to the NGO, concerning the relationship between civil society and government, dialogue and interlocution were gradually ceasing, giving place to services provision, and reducing the participation of NGOs/AIDS and social movements in national actions proposals. The efforts towards broader participation in the elaboration of programs and actions did not necessarily come about, and the relationship with state was changed, becoming limited to provision of services, despite the perceived protagonist role played by civil society.

Most NGOs financed by the National Coordination easily survive. But we, who have decided to learn to live without the Coordination, are suffering.

GAPA/DF does not perceive any major loss of autonomy because of financing granted by the National AIDS Project. However, they fear losing this autonomy if they are converted into Civil Society Organization of Public Interest – OSCIP. “We fear losing our voice in government, or that any other financing agency comes, impairs everything and closes the doors in general”.

C. 3. ARCO – ÍRIS – Associação Brasileira de Combate à AIDS

- 1) Organization Name: GRUPO ARCO – ÍRIS – Associação Brasileira de Combate à AIDS.**
- 2) City/State:** Brasília/DF.
- 3) Date of Foundation:** 18/12/1990.
- 4) Started Working with STD/AIDS in:** 1990.
- 5) Kind of Organization:** Association.
- 6) Address/Phone:**
Abcagrupoarco – iris@zaz. com. br
Phone: (61) 361 – 95 – 11
- 7) Situation Concerning Headquarters:** it has two rooms purchased with their own resources.
- 8) Where it Performs the Activities:** NGO Headquarter.

9) Field of Action: Gay movement and women's movement.

10) Priority Field of Action: HIV/AIDS.

11) Geographic Area of Work: State.

12) General Purposes

- Support and strengthen HIV/AIDS carriers and family members through psychosocial support, guidance and several services, besides the participation in specific groups and projects;
- Contribute with educational actions to prevent STD/HIV/AIDS;
- Participation in social control rooms.

13) Target-audience: seropositive individuals and family members, as well as the population in general.

14) Core Activities

Actions on prevention and education to HIV/AIDS carriers and the public in general, mainly among low-income populations.

Capacity building and lectures. In the more assistance field, they distribute basic food baskets, condoms and make hospital and home visits. They provide advisory services to some organizations or movements that want to be institutionalized.

15) Ongoing Programs and Projects

Currently, Arco-Íris is developing four financed projects: three by the National Programme and one by DKT do

Brasil. One of these projects aims at purchasing basic food baskets, while the remaining ones are focused on people with HIV/AIDS. Another objective is to provide information and improve information quality for people affected by the epidemic in the Federal District and surroundings. They have a project oriented to self-help, aimed at establishing contact and exchanging experiences.

16) Services Provided to Population

- Information on STD/HIV/AIDS;
- Lectures on STD/HIV/AIDS;
- Workshop on safe sex;
- Several services;
- Counseling prior to and after anti-HIV testing;
- Several referrals to the services network in the Federal District and surroundings;
- Hold events on HIV/AIDS.

17) Works only with AIDS: Yes.

18) Works advertised through:

Lectures in schools, corporations and community, besides promotion of health exhibitions.

NGO Background

19) Origin of the institution

The institution results from the demand by health professionals and HIV/AIDS carriers, who sought for space out of health services that could allow for assistance and support to seropositive individuals in the Federal District.

20) Organization's Motivation Towards Working with STD/ AIDS

The NGO was established with the purpose of working with STD/AIDS, *to improve and strengthen people living with HIV/AIDS, besides the concretization of a policy on AIDS*. Currently, they work on broader public health, but with priority focus on AIDS.

21) Resources and Financing Sources

The National STD and AIDS Programme provide the main source of resources for Grupo Arco – Íris/DF to execute its actions, through financed projects. They are also financed by the DKT do Brasil to execute projects on social marketing of condoms, in addition to donations made by individuals and to payment for holding events.

The project on social marketing of condoms, financed by DKT do Brasil, aggregates activities on prevention to other objectives, i. e., to build a network for trading low-price condoms, mainly in the Federal District surroundings, comprising seven cities.

As strategy for resources intake, the group adopts financed projects on institutional management; furthermore, they promote workshops on production and income generation as an alternative to raising resources for the Institution and users.

22) Human Resources

The NGO develops continuous capacity building oriented to its internal audience (professionals and volunteers), towards qualifying those who work with self-help groups. It also intends to provide a clearer view on public policies, like the rights and mechanisms of social insertion.

Concerning external audience, the group develops timely actions, such as capacity building for Commission on Prevention against Labor – related Accidents; proper and required information on safe sex practices, thus contributing towards changing the community behavior. It offers free handicraft courses to the NGO users.

Furthermore, it qualifies teachers in AIDS-related issues, besides qualifying health agents, better fitting their language to the development of actions.

23) Work Methodology

To concretize its actions, the NGO considers it succeeded in building a dynamic of methodological working where users – even those external to the Institution – take advantage of its actions. It also succeeded in defining the specificities of each action developed, because they used to face overlapping problems, mainly in the field of assistance. Concerning prevention, three axes are outstanding: *lato sensu* assistance, prevention and social control.

According to the respondent, increasingly occupying spaces of social control is a crucial action. They understand that the construction of more inclusive public policies also depends on the organization. Therefore, the NGO relies on the participation of some members at regional spheres of social control, “since right is built upon participation”.

The Grupo Arco-Íris built spaces for assessment, which work in a complementary and continuous way. They hold strategic meetings to assess actions, jointly with the technical team and, sometimes, with users. Furthermore, they employ assessments with partners.

Every year they assess the performance during the period of collective vacation and, based on this assessment, they plan the following year. During the assessment, they identify weak points, successes and challenges: “It assists the structural thinking about the continuity of actions performed by Arco – Íris”.

According to the Group, these meetings have allowed them to: View ways for optimizing financial resources; have a view on the whole set to improve planning, abandoning the individual treatment to each timely project. The projects coordination has promoted more technical debates on indicators, construction, continuous assessment of actions and cooperation among projects, since they are closely related one to another. The institutional policy has gathered

the actions on prevention: “we understood that projects are mainly focused on assistance and on the relationship of participation in social control”.

The coordination of Grupo Arco-Íris also remarks the visible effects and changes on the lives of its users. They notice that people believe in the NGO work, understanding that their participation in the group was crucial to improve their quality of life and to win rights. The co-existence with other carriers is considered one of the main gains, because it provides sustainability to face all sorts of difficulties, from practical issues such as dealing with the disease, to emotional and personal problems.

Nevertheless, the NGO reports specific problems related to the experience with users. In this sense, the Institution mentions significant tensions in the field of adherence to medication: “The lack of understanding by those individuals who should adhere”; safe sex and self-care; incapacity of the health service in dealing with HIV/AIDS-related issues; and the difficulty of population, mainly the youth, in having access to information and free condoms.

24) Incidence on Social Policies and Public Policies

The Grupo Arco – Íris is a member of the National Network of People living with HIV/AIDS (RNP+ – Brazil). It is part of the National Programme of the Strategic Project Cidadã Positiva, oriented to qualify female HIV carriers, to activism and strengthening leaderships.

At the Latin American level, it had been associated to the Latin American Movement of Women with AIDS and to the Redla. At the local level, it participates in the Secretariat of the Federal District AIDS Forum, in partnership with GAPA.

It mentions four Municipal Secretariats as outstanding partnerships to carry out political actions, namely: Assistance, Education, Labor and Health, additionally to local corporations.

The NGO participated in public policies on free access do medication, free access to treatment, access to prevention devices, NGO capacity building and in the issues of human rights and citizenship.

It is part of the Health Council of Cruzeiro, and holds seat in the Federal District Pathologies Forum. Furthermore, it participates in the Inter-institutional Commission of AIDS in the Federal District, and holds seat in the Managerial Council of Day Hospital. It also integrates the Advisory Committee of Women to the National STD and AIDS Programme.

Three representatives of Arco-Íris attended the Regional Meeting of NGOs (ERONG), held in 2002, where it influenced over the appointment of representatives to the region in the CNAIDS.

Additionally to ENONG, the Group has participated in health conferences; meetings of women with AIDS; congresses on prevention against STD; NGOs meetings, from ERONG to ENONG. It participated in the meeting of the National Network of People Living with HIV/AIDS – RNP+ – Brazil, besides attending the Seminar on Policies of Medication and Meetings of the Federal District Health Councilors.

25) The Organization Sustainability, in Medium and Long Term.

Sustainability strategies are planned on annual basis, since these actions usually come from 1 – year projects, and they never know if the approved budget will be the same as the proposed. However, every year the NGO undertakes the commitment of granting its works, i. e., its sustainability.

The Group states to be highly dependent on the National STD and AIDS Programme. This leads them to think about the relevance of diversifying their sources of finance for raising resources, even with international NGOs and/or international organizations.

The NGO sustainability is also based on workshops on handicraft production, comprising production of resin-made watch, CDs, plaster paintings, wood boxes and production of accessories such as purses, household goods and handmade candles. However, they are aware about the need of improving their sustainability in medium-time, granting the quality level, besides finding strategies to products flowing.

The NGO motto has always been the work with people living with HIV, and the line of financing allowed for this orientation and the possibility of building several responses to an epidemic situation in the Federal District and surroundings. “Since 1994, we rely on financing granted by loan agreements. Furthermore, we succeed in building responses and now we have clearer ideas, even about our priority focus of action”.

Since the establishment of the group, its main financing agent has been the National AIDS Programme. Through projects financed by the National Coordination, they could purchase furniture, goods and equipment. Therefore, the Group considers positive the governmental support to institutions that started working in the field of AIDS.

On the other hand, they believe that such financing brought some degree of dependence, and some managerial areas of Arco-Íris are inefficient, mainly concerning the Institution planning in medium and long terms.

According to the NGO, it worked for a long time focused on annual projects, rather than on the diversification of sources of financing or with more engaged people. “Currently, a serious issue that jeopardizes Arco-Íris working – as happens with many other NGOs – is this early concern about the need for diversifying its source of resources and financing”.

Furthermore, it delayed in intensifying the dialogue with state and municipal public power. However, this interlocution is easier and more constant for NGOs/AIDS and for Arco-Íris, particularly.

According to the NGO, few organizations were not threatened by the end of the National STD and AIDS Programme financing. This governmental sphere is trying to build room for debating sustainability, supporting some publications, prizes, production of materials. However, the NGO feels “the need for a baseline moment”. Another difficulty pointed out is the lack of stronger and more consistent actions towards allowing for the interlocution with other ministries developing public policies actions transversal to AIDS. That would allow for gathering efforts towards building collective actions and co-accountability.

26) Threats and Strong Points Concerning Sustainability of Civil Society Action in the Field of Fight Against HIV/AIDS

A strong point identified by the NGO concerns the development of actions in the field of HIV/AIDS, the construction, over the years, “of a serious organization that works with competence”. According to the Group, the effective participation in national and international spaces allows for the insertion into other spheres, and may lead to increased possibilities of knowledge and political articulation. For example, the incorporation of a more comprehensive speech about public policy, by the movement on AIDS, has allowed for broader dialogues with other movements and NGOs. It is worth “to seek for other segments and important actors to gather powers, open broader range of participation – whether with women’s movements, or with the issue of other pathologies, or even with social control issues or other NGO”.

Concerning weak points, the respondent highlighted the NGO work in relation to the assignment of teams to projects, which jeopardizes the execution and success of works performed by the institution. Another factor mentioned concerns the lack of diversified sources of resources, because the NGO depends on the National STD and AIDS Programme, and some projects are financed only for one year. This has hindered the execution and the maintenance of the NGO structure, because it is hard to think in long-term success. According to them, to some extent the government participates in this stage, both concerning the NGO weakness and its sustainability.

The National STD/AIDS failed in converting the decentralization process into a gradual one. Currently, we only have one line of financing, valid until December 2003, while next year the amount to be transferred to civil society, through fund-to-fund transfer, accounts for 1/3 (one third) of Arco-Íris budget. If we sum up the three projects currently supported by the National STD/AIDS Coordination in 2003, it means that altogether they account for the amount allotted to the whole civil society in the Federal District for 2004.

According to the NGO, one could observe that, in the Federal District, some organizations are evidencing their incapacity in

obtaining other sources of financing and, even if they remain developing some actions, they would be drastically reduced and have direct impact over what the civil society has built over the years.

27) Interlocution with Governmental Spheres, in the Field of AIDS Epidemic

The NGO points out that the major success of Brazilian actions on fight against AIDS was the active participation of organized civil society, since early stages of the Government Programme. It comprises assistance, prevention and human rights, jointly with a strong activism by this civil society. It is worth mentioning that Brazilian program place priority on each of these components, thus building more efficient guidelines:

You think on assistance, while you speak about research. You think on treatment and you think on production, breach of patents. Brazilian view is broader, it is not restricted to a governmental agenda. It comprises agendas by civil society, universities and many other players, thus allowing for mutual dialogue and joint work.

For Grupo Arco-Íris, the major challenge that Brazil faces is the need for implementing and carrying out the Brazilian Unified Health System (SUS). Furthermore, it highlights the major role that civil society plays, jointly to the importance of leadership renewal and steady surveillance:

Civil society in Brazil has always enjoyed, with more or less facility, room as the player responsible for efficacy in response, even if the Brazilian government doesn't say so. Even if the merit is all given to Brazilian government, we as organized civil society know that we are harvesting together, because it also depended on us. I believe there are too many failures and I think there is some appropriation, but there is room enough for all of us in this continuous and permanent process of building. We must be watchful and know that anything we build may ruin at any time.

So, there is need for always relying on new activists, new leaderships, to be in the agenda and that other public policies may employ this model of constitution and interlocution between government and civil society, consolidated with AIDS.

The group understanding was achieved in the field of AIDS, a community participation that would not be so plentiful in other fields of social life. Furthermore, the NGO stresses the importance of networks and international relationships established, as social responsibility to be shared by all, i. e., avoiding the exclusive assignment to the Government of the duty of structuring the mobilization of several actions in prevention, care to carriers and fight against prejudices and the epidemic. The following testimony clearly states the perception on the relevance of Brazilian model to other experiences, cooperating with other countries.

This model should be an example for other Brazilian policies, since community and organized society participation isn't so strong in other very important policies. Today we also have the capacity, as organized civil society, of establishing lines of cooperation with organized civil society in other developing countries. We understand that this responsibility is not exclusive to the Brazilian government.

We now have know-how and methodology learnt along these years of fight, and we may help strengthening and building transparency in this relationship of powers correlation with other countries, mainly Africa and Latin America. We have competencies, skill and willingness to disclose our best knowledge, and to show to other countries that Brazilian response worked. Each country has autonomy, and must want the participation of all to build their response.

C. 4. CFEMEA – Centro Feminista de Estudos e Assessoria

- 1) Organization Name: CFEMEA – Centro Feminista de Estudos e Assessoria**
- 2) City/State: Brasilia/DF.**
- 3) Date of Foundation: 07/1989**
- 4) Started Working with STD/AIDS in: 07/1989, with more emphasis as of January 2001.**

- 5) **Kind of Organization:** Civil Society, non-governmental, feminist, of public nature.
- 6) **Address/Phone:**
Telephone: 328 – 16 – 64
- 7) **Situation Concerning Headquarters:** CFEMEA works in rented premises.
- 8) **Where it Performs the Activities:** NGO Headquarter
- 9) **Field of Action**
The major feature of this organization is its advocacy work with the Legislative Power.
- 10) **Priority Field of Action**
Women’s movement; Human Rights Movement and National Congress.
- 11) **Geographic Area of Work:** National and Regional.
- 12) **General Purposes**
Fight for full citizenship to women, for equitable and sympathetic gender relationships, and for fair and democratic society and state.
- 13) **Target-audience**
The NGO focus is on the National Congress: deputies, senators, besides women’s movements and human rights movements. Currently, through their publication named *Fêmea*, they reach all mayors, state deputies, and

councilwomen. Furthermore, they reach the public of universities, individuals enrolled in CFEMEA who are interested in the NGO studies and topics.

14) Core Activities

The NGO coordinates the political debate about the Social Security Reform, within the scope of women's movements. They also attend public hearings on Brazilian Pluri-Annual Plan, mainly those related to the National Women Secretariat.

CFEMEA actions are oriented by the Program *Direitos para a Mulher na Lei e na Vida*, which comprises four major projects, detailed below.

15) Ongoing Programs and Projects

1) Advocacy in the legislative – monitoring of Bills concerning women; 2) budget and women's rights – they discuss and propose budgetary amendments; it is now starting a project to monitor this budget. It takes gender debates to the Congress, through seminars, public hearings, developing work with the commissions and women representatives. It works in articulation with the Brazilian Women's Movement, both directly with organizations and through networks of Brazilian Women's Articulation; 3) political communication: this project comprises the monthly CFEMEA newsletter, freely distributed all over the country, dealing with current debates on the movement and the Congress. The project on press office embraces publications in the field of communications; 4) the project on institutional development, intended to support activities, involves upgrading to the NGO staff, its resources and capacity building.

16) Services Provided to Population

Center of documentation and informative campaigns for 1,500 radio broadcasters that are mainly community-based.

17) Works only with AIDS: No.

18) Advertises the Work Developed Through:

CFEMEA newsletter, books, journals, videos, printed material, congresses, conferences, meetings and seminars.

NGO Background

19) Origin of the institution

CFEMEA founders used to participate in the National Council of Women's rights, and used to advocate, at the National Congress, for women's rights.

When the Constitution was enacted, the Council was extinguished. They returned to their origin institutions, but left a gap, since women's movement was used to having someone in Brasilia to take care of their interests in the National Congress. Because of this gap caused by the Council and the Constitution, which should be ruled, they decided to establish the CFEMEA. The NGO was aimed at monitoring bills submitted to the National Congress, concerning women's rights. That was in 1989.

20) Organization's Motivation Towards Working with STD/AIDS

They started working on STD/AIDS at the end of 1989, and were strengthened in January 2001, because of the spread of AIDS among women, thus converting it into a thematic related to women. *Many bills dealing with AIDS were submitted to the Brazilian Congress and we perceived we could not remain aside from this process. We could not fail in serving, in following-up these projects.*

Among the organizations surveyed in the Federal District, the *Centro Feminista de Estudos e Assessoria* – CFEMEA is the only founded in the 1980's, and the only one belonging to the women's movement. In this regard, the NGO emerged with the mission of fighting for full citizenry to women, for equitable gender and sympathetic relationships, and for a fair and democratic society and state.

It places focus on the National Congress and, therefore, acts directly on representatives and senators, i. e. , the Legislative Power – and this is a feature of the institution. Nevertheless, the organization was established by women who used to participate, at that time, in the National Council of Women's rights and who, during the Constituent Assembly, were involved in the advocacy for women's rights, at the National Congress level.

At the end of 1989, it started working with STD/AIDS, and this work was strengthened in January 2001. The decision of entering into this field was due to the increasing epidemic among women, which led this topic to become an important debate in the feminist agenda. At that time, the first bills oriented to the epidemic were submitted to the National Congress.

21) Resources and Financing Sources

Financial resources are mainly granted by multilateral institutions (United Nations, international cooperation agencies and agreements with public bodies, UNFPA, UNIFEM, UNICEF, Ford Foundation, MacArthur foundation, the North-American NGO International Women's Health Coalition (IWHC), the Fund for Gender Equality by the Canadian Operation, OXFAM and also the Ministry of Health).

It has several financed projects, such as the ones with the Ford and the MacArthur Foundation, which allow them to afford with rental and maintenance expenses. These are institutional projects on advocacy, but allow them to employ the resources on their premise maintenance.

CFEMEA employs, as resources intake strategy, the constant submission of projects to agencies that finance initiatives oriented to the defense of women's rights. The articulation with these agencies is

normally made by the collegiate, in a joint work. However, the NGO feels the need of seeking for new sources of financing. In this regard, the institution started dialogues with national businesses, like the Boticário – the first experience of the NGO with financing by a national corporation – which provided partial support to the National Conference on the Brazilian Women, held by CFEMEA in 2002.

22) Human Resources

In opposition to the remaining organizations surveyed in the Federal District, CFEMEA does not hold formal courses. However, it believes that qualifying its staff is a core duty towards improving the actions it implements. For that, the NGO provides its team the possibility of constant participation in seminars and meetings.

23) Methodologies Used to Implement the NGO's Actions/ Projects

The *Centro Feminista de Estudos e Assessoria's* actions are oriented to advocacy at the National Congress level. Therefore, they monitor bills regarding Reproductive Rights, Sexual Rights, Violence Against Women, among others. The project aimed at following-up bills related to women and AIDS is inserted in the field of Reproductive Rights and Sexual Rights, taking into consideration CFEMEA's thematic structure.

In the field of institutional assessment, the organization prepares reports on monitoring the women-oriented public policies. Furthermore, they hold weekly meetings with the technical team, with the help of a representative of the administration team. These meetings aim at sustaining the constant flow of information on the NGO dynamic, besides planning the weekly activities.

Additionally, they perform strategic 4-year plans that are revised on an annual basis. In this strategic planning, the NGO is supported by consultants assigned by WILDES and the British Airport Foundation.

They is a constant presence in meetings with all councils, partners and financing agents, aiming at reflecting about CFEMEA, concerning its financial and political sustainability.

24) Incidence on Social Policies and Public Policies

At the local level, the institution is associated to the Federal District Women's Forum and to the NGO/AIDS/DF Forum. It is represented at the Regional/DF unit of the National Feminist Network on Health, Reproductive Rights and Sexual Rights, besides being an alternate of the Inter-institutional AIDS Commission of the Federal District Government.

At the national level, it is affiliated to the Inter-Networks Forum; to the National Feminist Network on Health, Reproductive Rights and Sexual Rights; to the Brazilian Association of NGOs (ABONG). Furthermore, it has representatives in the Executive Coordination of the Brazilian Women Executive Coordination and in the National Committee of the Global Social Forum. At the international level, they are members of the Mercosur Feminist Articulation, and of the International Committee of the Global Social Forum.

The major partnerships for carrying out political actions are held with NGOs/AIDS, NGOs/mixed and with programs and/or secretariats of the Ministry of Health. They have several political articulations that support CFEMEA actions in the National Congress, mainly the National Feminist Network on Health, Reproductive Rights and Sexual Rights.

CFEMEA participation in the debate and implementation of public policies and government programs on the fight against HIV and the AIDS epidemic is through the Federal District NGO/AIDS Forum. The NGO represents the women's movement in the local Inter – institutional AIDS Commission. It doesn't have any articulation with the Federal District government, except for the participation in said Commission.

25) Organization Sustainability, in Mid and Long Terms

According to the NGO, it should increasingly pursue national resources because at the international levels the flow of cooperation agencies resources to other countries and continents is high, as so happens with the MacArthur Foundation. On the other hand, the cessation of some financing grants, jointly with changes in the field of international cooperation, has motivated the interest in establishing new financial partnerships, at the national level.

Nevertheless, it is worth mentioning that, despite the need for financial resources to continue with CFEMEA actions, the team clearly states that the NGO political capital was built along its history and according the NGO's line of action is socially respected, and is not subject to negotiations. A solution presented would be to set work groups with NGOs that have plenty of experience to discuss the issue of financial sustainability:

We are concerned because our current team depends on these resources. We have lots of work to do that depends on these resources.

It is a new experience for us, and we have to go for it. So, we want to have this relationship with the private initiative and, at the same time, we have several principles that we just can't give up.

26) Interlocution with Governmental Spheres, in the Field of the AIDS Epidemic

CFEMEA works on the follow-up and monitoring of AIDS projects at the National Congress and therefore work in a very specific field. So in principle, financing granted particularly to this activity does not suffer any governmental interference in this agenda. However, based on meetings held with the AIDS II legal advisory unit, they observe tenuous implications to the women's movement agenda.

There is a constant concern about AIDS III Programme implementation because projects will be locally financed, i. e. , in the states. In this regard, there is a not so positive expectation in relation to this new kind of procedure with financial supports. CFEMEA believes it may come to face serious problems concerning the participation in AIDS III, due to the transfer of resources to the Federal District Government, since the NGO develops works at the national level.

It cannot be felt like something transferred by the Federal District Government. We will have serious problems in placing ourselves if we want to participate in AIDS III. At the end, the Federal District Government will claim it doesn't have obligation to monitor laws for the whole country.

Concerning Brazilian bi-lateral actions on the fight against AIDS, the NGO underlines the conjunction of two factors: one, the mobilization of part of the organized civil society towards finding a response to the epidemic; the other one concerns government, with its political intentions and financial resources. The Brazilian Programme has decisive visibility worldwide, and this has to do with the partnership between civil society and the government.

It was a moment that I believe we cannot repeat. People were mobilized towards effectively carrying out the AIDS movement.

It was neither a governmental issue nor a governmental decision. It was the pressure of civil society that had the insight to find the way.

According to the NGO, the AIDS movement awoke people's consciousness about their rights, the right to know the procedures and treatments, to citizenship, to access to health, "It was good under the feminist view, because several women were empowered concerning their citizenship".

According to the Organization, there is a very significant acknowledgement on the relationship established between the civil society and governmental levels in the field of fighting the AIDS epidemic, whether in prevention or assistance. This acknowledgement could be noticed through requests to CFEMEA, by universities or other civil society organizations. In fact, civil society organizations' contribution towards the set of responses to the epidemic deserves its merits. Undoubtedly, this interlocution characterizes the Brazilian differential.

Nevertheless, this dialogue will only achieve the desired success if the particularities of each society sector are respected. Civil society should keep its independence in relation to government. There is an alliance between state and civil society towards fighting AIDS, but it cannot mean any damage to identity, the roles cannot be mistaken. Therefore, the NGOs must have their own spaces

and cooperate with government, but should maintain its potential of criticism: “We want to help and contribute for its success, but we cannot close our eyes and accept everything and avoid criticizing when we have to criticize. Otherwise, it becomes senseless, civil society and state are mistaken one for another”.

The NGO claims that full autonomy is yet to come, because the party that transfers money has the final say in decisions. Furthermore, the NGOs still have great financial dependence on the Ministry of Health.

D. RIO DE JANEIRO

D. 1. Associação Carioca de Redução de Danos

- 1) Organization Name: Associação Carioca de Redução de Danos.**
- 2) City/State: Rio de Janeiro.**
- 3) Date of Foundation: 1999.**
- 4) Started Working with STD/AIDS in: 1999.**
- 5) Kind of Organization: Social Movement on Advocacy.**
- 6) Address/Phone:**
Praia de Botafogo, 316 – room 920.
ZIP code 22. 250 – 040
Tel: (021)551 – 5400
Fax: (021) 589 – 4309
Email: sbnepad@uerj. br

7) Situation Concerning Headquarters

It does not have its own headquarters, and occupies a space lent by the Integrated Plan on Marginality – PIM, in institutional partnership with five other organizations.

8) Field of action

They work on capacity building and the implementation of new programs on damage reduction.

9) Priority Field of action

Develop policies and services in the field of damage reduction among drug users.

10) Geographic Area of Work

State and District or District Group (twenty municipalities in Rio de Janeiro).

11) General Purposes

Develop advocacy for policies on damage reduction, besides sustaining actions developed in municipalities.

12) Target-audience

Drug users belonging to the twenty municipalities in Rio de Janeiro. Managers and NGOs responsible for these actions in the municipalities.

13) Core Activities

- Capacity building and advocacy for policies on Damage Reduction among health and education managers.
- Provide sustainability to works performed by municipalities.
- *Chá da Cidadania*: discussion group with the participation of a diversified audience and inclusion of issues related to health and human rights.

- Meeting for protagonists: they discuss topics related to the rights of drug users, pursuing the users' identity.
- Forum on Damage Reduction in Rio de Janeiro.

14) Ongoing Programs and Projects

- *Chá da Cidadania*;
- Program on vaccination against hepatitis B;
- Project on Institutional Development.

15) Works only with AIDS: No.

16) Advertises the Work Developed Through:

International Congresses, visitation to foreign agencies and technicians.

NGO Background

17) Origin of the institution

The Associação Carioca started as a social movement in 1999. They were concerned about the sustainability of actions on damage reduction, since the projects were very dependent on universities, state secretariats, and did not have the features of a non-governmental organization. At the time, eight other state associations that shared the same purposes were established. Therefore, the Carioca emerges in the scope of the Damage Reduction Programme by NEPAD/ UERJ – the first program in the State of Rio de Janeiro. For a long time, they have worked in the university. On one hand it was a benefit, but on the other hand they missed their autonomy. As of 1992, they started their integration with other AIDS movements in Brazil, opening the possibility of partnerships with similar features: *now, we are building a poll of institutions within the PIM, where we work in partnership with many other NGOs.*

18) Organization's Motivation Towards Working with STD/AIDS

Since its foundation in 1999, the NGO has had the following motto: *motivation was almost the history itself*. In fact, the process already existed, through projects on damage reduction that worked on STD/AIDS.

19) Resources and Financing Sources

The financial resources that subsidize actions performed by the *Associação Carioca de Redução de Danos* are mostly granted through projects financed by the Ministry of Health. To some extent, it is also sponsored by international cooperation agencies, besides donations by individuals.

As a strategy for resources intake, the association adopts actions and projects on institutional enhancement, holding partnerships with ABIA. However, as a mid-term strategy, the NGO is trying to establish a sort of contribution granted by the Organization's beneficiaries.

20) Human Resources

The association adopts the strategy of qualifying damage reducing agents and even intends to institutionalize this category in the Brazilian Unified Health System – SUS. When beginners start working in the NGO, they undertake an internship stage where their profile and potential towards engaging in the topic are observed.

21) Work Methodology

Damage-reducing agents are trained through text discussions, and also interventions and problem solving approaches.

At every stage of renewal or execution of a new project, the NGO assesses its priorities. The projects are elaborated according to the demand, and are adjusted to existing resources. All staff members and service providers participate in the planning.

Since it works with drug users, the NGO is concerned about different vulnerability factors: there is not a grant of rights, and they are in extremely deprived socioeconomic conditions.

The major difficulty in developing its actions concerns the discrimination perception, marginal image and the place with no citizenship assigned to chemically dependent individuals in society, thus negatively affecting their self-esteem.

Along almost ten years of work, we now have access to the network; we now know how to do it. Time taught us how to bring users closer to us, and introduce them into another place. For us, if that is not for the society, it should be for us.

Another problem is the difficulty in effectively performing actions on prevention, since users are afraid of bearing syringes. It is necessary to build sensitiveness among the public security field, towards facing users as individuals who must prevent. Besides syringes, drug users in Rio de Janeiro's peripheral areas or municipalities have never had access to condoms, health services, and syringe exchanges. During the stage of action development, throughout the NGO's existence, it could be seen that some municipalities that used to provide only assistance services started developing prevention actions with Damage Reduction. This is an innovation in the behavior and actions of these municipalities. Another innovation was to successfully show public managers how worthy the investment on Damage Reduction is. "We could notice that this project is more and more renewed, more people want to set partnerships to promote damage reduction".

The association outlined some focal points concerning inter-sectorial works; qualification to health, education and public security professionals; and the establishment of partnerships with services on treatment to drug users.

Since its field of action is prevention, and users have difficulties in engaging into other services that do not deal with the issue of drugs, the Association becomes an interface with assistance services, such as basic food baskets, purchases of transportation tickets, insertion into groups of mutual assistance and adherence to medication.

22) Political Articulation

The *Associação Carioca de Redução de Danos* is part of the NGO/AIDS Forum in Rio de Janeiro and the ABORDA – Brazilian Network on Damage Reduction. At the international level, they are members of the Latin American Network named VELARTE.

23) Partnerships

The association has partnerships with the State STD and AIDS Coordination, Municipal STD and AIDS Coordination, Health Secretariats, Education Secretariat, NGOs/AIDS, NGOs/mixed and other branches of the social movement. “It is very interesting to introduce Damage Reduction into the NGO/AIDS forum. I think we have a different history than the movement as a whole. I think we are always trying to discuss these alternatives”.

The major partners in the municipalization projects are several municipal secretariats. At the state level, there is a significant partnership with the State Health Secretariat and the State STD and AIDS Coordination. “We have jointly held the first seminar on damage reduction. They are an extremely important interlocutor for us – when they discuss damage reduction they use us as reference”.

At the federal level the NGO holds a partnership relationship with the Ministry of Health: “we disclose our difficulties, make suggestions and propose efficient alternatives for our policy. The relationship with the Ministry of Health is a worthy way for us”.

Still at the national level, the partnership with the Specialized Center on Training to Alcohol and Drug Addiction – CEAD is outstanding. Furthermore, the Department of Human Rights of the Rio de Janeiro State University is an official partner of the NGO.

24) Incidence on Social Programs and Public Policies

The NGO participates in discussions on human rights and citizenship. It participates in the State STD and AIDS Commissions and AIDS Commission, and holds a seat in the Health Council. It is inserted in some non-formalized political debates, such as the discussion on a new policy on drugs, held in the Brazilian House of Representatives.

25) Organization Sustainability, in Mid and Long Terms

Currently, it is bound to financing by the Ministry of Health, because it is not acquainted to other ways of resource intake. They maintain their daily infrastructure – related expenses through a partnership established with five institutions (PIM), sharing the same physical space. This sort of cooperation endowed the institutions with stronger political power and, at the same time, allowed them to share expenses.

When an institution is short of money, it doesn't pay; when another is short of money, it doesn't pay. It is very good to know that in a given moment they will need to, so we have to share institutional quotas, i. e., each organization member of the partnership received for projects pays a monthly quota to sustain the space and the organization. So, nowadays the association's expenses are paid for by donations from its members and the partnership. I think that is how the process is sustained now.

In short – term, the NGO intends to formalize some documentation required for it to become eligible for other financing sources. It claims that civil society is little mobilized, and due to daily duties, long – term survival is jeopardized.

Concerning the sources of threat to sustainability, the association underlines the instability of government on what should be priority, and the lack of new initiatives to support and strengthen the movement. Another threat is the possibility of losing resources. On the other hand, it should take into consideration the state support in some fronts, such as political articulation issues. Nevertheless, the state has not yet promoted debates on the issue of sustainability.

26) Interlocution with Governmental Spheres, in the Field of the AIDS Epidemic

Within the framework of implications resulting from governmental financing to the priorities set forth in the *Associação Carioca de Redução de Danos'* agenda, the NGO states that, in principle, the priority actions make up a complex picture to be analyzed. Some

NGOs succeeded in winning space. Now they are in such a stage of internal development that allows for establishing other partnerships and other sources of financing and, therefore, are more capable of articulating and executing their duties. Nevertheless, the most articulated NGOs keep strong relationships with the Ministry of Health, which is the most substantial source of resources to works on AIDS. “They talk about damage reduction as a priority. I think that we are priority because we are extremely disorganized as a movement, as possibility of finding other sources of financing”.

In the field of partnership with government, the *Associação* reports that, despite the excellent relationship with the governmental spheres, sometimes public managers should recall the role of civil society, always paying attention to bases and, therefore, articulating movements in benefit of the target-audience.

We have to keep it in mind. We must know the right time to claim, and claim, and be supportive whenever possible. We must work in partnership, whenever possible. For example, the insertion of damage reduction in prisons. Regardless of the Ministry of Health’s articulation, the civil society must make pressure, must [do it], it is our role, and it is our place. We are defending users, people served.

The association also points out the existence of competent bodies in HIV/AIDS, such as the Health Secretariat, the STD and AIDS Coordination, and the Rio de Janeiro State University – UERJ. However, the state remains unskilled in some areas, as for the example as the Law on Damage Reduction that was vetoed.

According to them, the Brazilian Program’s success relies on the integration, solidarity and partnerships achieved in the field of AIDS. These actions are considered humanist, rather than just sanitarian: “it makes the difference between Brazilian actions and actions developed elsewhere”.

Concerning interlocution between civil society and government, the association believes that the Rio de Janeiro AIDS Forum allows for a fight for rights. Nevertheless, the institutions are somehow

accommodated in this process, with intercrop periods where, without enough resources, they lose the beneficiaries' access and go back to the starting point.

The association discusses drug policies with Rio de Janeiro CEAD and perceives that: “on one hand, the Body is favorable to the establishment of public policies in this field, and on the other hand give opinions contrary to such policies.”

The *Associação Carioca* also observes the huge fight for the proceeding and enactment of the State Law on Damage Reduction by Rio de Janeiro House of Representatives. The Institution had to make articulations with several political representatives to grant rights previously set forth in the constitution but that, in practice, are not enforced.

In the arena of these disputes, the association identifies the social movement integration as a strong point. The movements are increasingly consolidated, and the interface between homosexual and prostitution movements is significantly set: “when we integrate and work jointly, we have stronger powers of pressure and actual analysis of situations”.

Nevertheless, the association feels a sort of constraint when implementing its actions, resulting from governmental financing. However, they believe that new financial partnerships would allow for overcoming this problem.

D. 2. PELA VIDDA/RJ – Grupo PELA VIDDA/ Rio de Janeiro

- 1) Organization Name: GPV/RJ – Grupo PELA VIDDA/ Rio de Janeiro**
- 2) City/State: Rio de Janeiro/RJ.**
- 3) Date of Foundation: 24/05/1989.**
- 4) Started Working with STD/AIDS in: 1989.**

5) Kind of Organization: non-profit civil society.

6) Address/Phone:

gpvrj@pelavidda. org. br

Tel: (21) 2518 – 39 – 93

7) Situation Concerning Headquarters:

The building belongs to the Federal Government, but may be used for an undetermined period of time. The NGO pays for its operational expenses such as electricity and telephone bills, condominium fees, and fire prevention fee.

8) Where it Performs the Activities: NGO headquarters.

9) Field of Action: HIV/AIDS.

10) Priority Field of Action: HIV/AIDS.

11) Geographic Area of Work: State.

12) General Purposes

Promote appraisal, integration and dignity to people living with HIV/AIDS, encouraging them to exercise their citizenship. The NGO works in several areas, because it holds a broad mission. Another objective is to change the beliefs of people who seek for the institution, converting them into protagonists rather than victims: *people who can only receive, having nothing to give.*

13) Target-audience

People directly affected by HIV/AIDS, and also their family members and population in general.

14) Core Activities

- Sociability activities: basically oriented to integration, with no formal commitment;
- Capacity building workshops: basically administrative meetings;
- Reception workshops: first contact with new people coming to the organization;
- Legal services;
- *Chá das Travestis*: Closed event;
- Arts workshop;
- Youth meeting: *Encontro Mercado* project;
- Political activism: With government and civil society.

PELA VIDDA works basically on four different fields of action. One is prevention, through a specific project of lectures at corporations, telephone – and Internet-based information service – the so-called Dial-AIDS –, and distribution of condoms. Another field of action comprises activities on sociability, self-help with different audiences. Another powerful action is the political activism, held not only at formal representations besides government or inside the civil society, but also through participation in international events. The last field of action concerns assistance: free legal assistance to people facing AIDS-related problems, and the project on home care to people in advanced stage of AIDS.

15) Ongoing Programs and Projects

Buddy Brazil: home care to carriers in more advanced stage of HIV/AIDS;

Viva Voç Project : prevention;

Encontro Mercado Project: youth meeting.

16) Services Provided to Population

- Free legal assistance;
- Distribution of condoms;
- Lectures;
- Workshops on prevention;
- Workshops on capacity building;
- Sociability groups;
- Dial-AIDS (telephone and Internet).
- Home care for carriers in advanced stages of the disease;
- Self-help meetings: differentiated audience (women, travesties, youth and men.)

17) Works only with AIDS: Yes.

18) Advertises the Work Developed Through:

Newsletters, brochures, books, folders, posters, journals, videos, congresses, conferences, meetings and seminars.

NGO Background

19) Origin of the institution

The Grupo PELA VIDDA was established in early 1989, as a consequence of the mobilization actions undertaken by Herbert Daniel, who acquired AIDS at the end of 1988. Herbert Daniel decided to call some people engaged in or

with some interest on the AIDS epidemic in Rio de Janeiro, because he felt the need for a space for integration. During its first meetings, held in ABIA facilities, few people used to discuss Daniel's ideas on solidarity, civil death, and about living with HIV and AIDS: *So, the PELA VIDDA was basically established for the purpose of becoming the space for people to exchange their experiences, besides having voice to provide some sort of response to the epidemic.*

20) Organization's Motivation Towards Working with STD/AIDS

The NGO has worked on DST/HIV/AIDS since its foundation. The reason was the need for room for the integration of people living with HIV and AIDS.

21) Resources and Financing Sources

The resources of Grupo PELA VIDDA/RJ are granted by international cooperation agencies (80%) and the Ministry of Health (20%). To a lesser scale, it also receives eventual sponsorships and donations made by individuals and corporations. It is also financed by the European Union.

When the group was founded, the epidemic was hardly known. The international interest – through financing agencies and governments of other countries – in investing in AIDS actions in Brazil was proportional to the knowledge on the epidemic. It was favorable to the group because it allowed for it to survive, over time, with a broad range of financing agents, allowing for plurality in its work agenda and diversification on the origin of financial resources:

We have always succeeded in renewing financed projects. Our major institutional financing agent remains a Dutch agency that has been financing PELA VIDDA for ten years. The financing agreements are renewed every three years. When the 3-year period is about to end, we prepare a new proposal for its extension.

22) Human Resources

The NGO has a line of capacity building to volunteers assigned to specific projects, such as: Viva Voz, Dial AIDS and home care. These volunteers must be in tune with novelties, as in terms of treatment for example. In opposite, volunteers participating in daily duties should know the institution and the context wherein it is inserted more deeply. Now, PELA VIDDA is starting a new line of capacity building where users receive information on what effectively exists, in terms of activities, and get to know what is necessary for the NGO to continue developing its actions. Therefore, the beneficiary has the opportunity of participating in the construction of some strategies aimed at reverting some hard situations.

Many come here or go to a Health Unit, get their medicines every month, and don't have the slightest idea about the previous work involved in that means. When medications lack, and PELA VIDDA must denounce, the users don't know what it means, the work involved. They go to health units exclusively to have their needs met.

It is crucial to take this new line of capacity building in face of the panorama of expected changes in financing mechanisms.

We will no longer receive resources directly from the Ministry of Health, through biddings. The resources for NGOs are now transferred Fund to Fund. Municipalities and states will have to establish their annual goals to carry out their works, activities, and the NGO work must be integrated to this goal planning, because the states and municipalities will now be responsible for transferring resources. The Ministry of Health remains only with projects considered as strategic, such as, for example, the project on National Meeting, projects on network establishment. Furthermore, the methodology for transferring resources to NGOs will also change. And for it to effectively happen, we need to occupy formal spaces for resources approval, i. e., the district, municipal and state Health Councils. And to have civil society represented in these councils and to grant its participation, not only privileging AIDS-related issues, the representation should be of collective interest. And to allow these people to occupy those spaces, they must be trained. And this training is more oriented to this sort of participation. They must understand what the Brazilian Unified

Health System – SUS is, what this decentralization policy is, how this Fund-to-Fund transfers of resources from the National Health Fund will take place. Finally, it is a more specific capacity-building, something new that we are trying. This is one of the challenges.

23) Work Methodology

The NGO has a coordinator who works based on a diagnosis prepared about their activities. Sometimes, the board of directors must provide information, identify any need of reformulation in activities, or emphasize given aspects. However, the beneficiaries are usually invited to plan the best working of actions and activities developed by PELA VIDDA/RJ.

The NGO highlights some constant problems concerning aspects of STD/AIDS prevention, mainly in the field of vulnerability. This context should take the social context of the different audiences of PELA VIDDA/RJ into consideration, since this aspect deviates individuals from the possibility of exercising their citizenship.

The NGO points out another issue: the invisibility of AIDS, with direct impacts over preventive actions, because people believe that this issue has already been solved. Furthermore, it stresses the problems related to adhesion to medication and its side effects:

Unlike twenty years ago, you no longer have TV campaigns emphasizing the issue of AIDS. Then, we have the access to antiretroviral drugs, which reduced the death rates. Currently, we are in a situation of invisibility, because no one talks about the issue, and it seems to be banal. People have the wrong idea that, if they get infected, the Ministry of Health distributes medication. However, there are many other issues involved. First of all, we don't know for how long the Ministry of Health will have money to purchase so much medication. Currently, it can provide these medications because of the domestic production, which makes drugs cheaper. Another aspect is the difficulty in using these medications. At the same time that drugs inhibit the virus replication, they make the immunological system stronger, additionally to several serious side effects. They make people develop other pathologies. I had never had diabetes, and became diabetic and insulin-dependent last year because of the continuous use of one such medication. And this is not broadly informed. So, people have this distorted view that 'if I get infected I have access to medication, so there is no problem'.

The NGO observes improvements in the quality of life of HIV carriers, since the group provides information, promotes meetings and provides legal assistance. Furthermore, its target-audience has access to medication, tests and treatment. However, they acknowledge that the group still lacks methodologies and tools to assess the beneficiaries' behavioral changes:

The return is very subjective. In some activities we have it, despite the degree of subjectivity, but we fail in better quantification. In general, it is about what we feel about people; it is to observe how people return to PELA VIDDA, how they engage in a given project, how they want to become volunteers. This is the kind of return we have. Another return is when we are requested to go to corporations, schools. The PELAVIDDA is also reference to communication means. This is also an impact assessment.

24) Political Articulation

The group is not formally associated to any network. The links with networks are personal rather than institutional. Some people working in PELA VIDDA/RJ participate in the National Network of Seropositive Individuals (RNP+) and in the Global Network of Seropositive Individuals (GNP). The NGO is member of the NGO/ AIDS Forum in Rio de Janeiro.

25) Partnerships

The major partnerships are with the State STD and AIDS Coordination, the Municipal STD and AIDS Coordination, Programs Coordination, Government Prosecutors Office, the Ministry of Justice, NGOs/AIDS, NGOs/mixed and Private Institutions.

26) Incidence on Social Programs and Public Policies

The group participates in the discussion on free access to medication, treatment, NGO capacity building and Human Rights and Citizenship.

Concerning political representations at the level of state government and Ministry of Health, it holds seat at the State AIDS Commission of the State Health Secretariat, the National Committee

on Anti-HIV Vaccinations, the Theme Group On Nights, which also belongs to the National Programme.

At the local level, it participates in the Municipal Health Council, Municipal STD and AIDS Council, District Health Council (central region), the Community-based Forum on AIDS. Furthermore, it has community-based participation in the Project on Anti-HIV Vaccination Research, the so-called Project Praça XI, and in the Hospital São Francisco de Assis.

27) Organization Sustainability, in Mid and Long Terms

According to the NGO, it enjoys a relatively stable and safe situation, since it relies on diversified sources of resources. It knows that, even if one financing agent suspends its investments on AIDS, the PELA VIDDA/RJ will not stop its work. This situation is quite different with other NGOs that work with one single financing agent. “If the financing agent changes its agenda, or a World Bank loan expires, and the Ministry of Health ceases its investments in civil society, the NGO loses its ground is not capable of seeking for local resources”.

At the same time, they report difficulties similar to those of other NGOs, basically concerning the constant seeking for resources intake. The PELA VIDDA/RJ always works in the perspective of a tripod comprised of the three levels of sustainability: financial, technical and political. Here, the key word is “partnership”.

I would say that the key word is partnership, not only for the issue of financial resources – we are used to thinking only about financial sustainability, and forget about technical and political sustainability. I may have a terrific international financing agent, but I cannot keep good relationships with the community, they don't acknowledge me, no governmental programs support me, i. e. , I don't have political articulation. Therefore, I won't know the best employment to such resources. At the same time, if my institution doesn't have skilled technicians to develop the project, something similar will happen, I have resources and they will be misused.

As civil society is strength, the PELA VIDDA/RJ highlights the acknowledgement (at national and international level) of the social movement of AIDS in Brazil, which preceded the governmental response.

Among threats, the NGO mentions the issues of sustainability, the epidemic's invisibility and the view of some international agencies that Brazil already has universal access to health, provides medication, the National Programme is structured and, therefore, does not need further investments of international capital.

This is one of the major risks to sustainability: To prove that AIDS remains priority in Brazil. Another threat mentioned is the centralization of financial resources: The NGOs work specifically with a resource provider and, therefore, in the event of changes in government or in the agenda of an international agent, they may endanger all actions developed over time because the NGO was not concerned in diversifying its sources for resource intake.

28) Interlocution with Governmental Spheres, in the Field of the AIDS Epidemic

The PELA VIDDA/RJ argues that, despite clearly understanding the notion of autonomy and institutional identity, there is the need for being in tune with the priorities of a financing agent in a given moment and, thus, trying to adjust the NGO and target-audience demands in the same agenda: "It does not mean that we are going to change our work agenda to try to guarantee our resources".

According to the group, the major successes are: universal access to medication, through domestic production of drugs, the implementation of a legislation that grants rights to the HIV/AIDS carriers, and the civil society organization towards pursuing legitimate rooms for claiming.

Concerning the interlocution between civil society and government, the NGO believes that, initially, it was a distressing and, to some extent, profitable relationship. According to them, the dialogue will be improved when the NGOs start participating in planning, instead of just supporting or signing a campaign. Here, tension is an expression, or a way for maintaining autonomy and criticism.

PELA VIDDA/RJ clearly knows to which extent it may criticize and when it may become allied to government. In fact, whenever necessary, we point out the errors with no constraint. We are dealing with policies, instead of people. We regret that the Ministry of Health and governments feel hurt, but we won't stop our criticisms, whenever they are applicable. So, it is a necessary tension, sometimes a hard one.

AIDS-related policies are executed to a maximum extent in the states of Rio de Janeiro and São Paulo, taking limited financial and human resources, additionally to the bureaucracy of the government apparatus into consideration.

Usually, the State Programme fails in execute what is planned because its administrative apparatus is obsolete, bureaucratic, and doesn't have the required agility to release resources and, sometimes, the state must reimburse the Ministry of Health because it fails in executing the resources. Rio de Janeiro and São Paulo have a partnership, other than that with the Ministry of Health, because of their physical proximity. So, we can maintain a dialogue with the state that, sometimes, is impossible to do with the National Coordination. So, in my opinion, there is a lot to do, but what has been done is what could have been done in face of financial and human resources limitations.

The NGO argues that, initially, AIDS was understood as a health issue, rather than one of human rights, even because when the World Bank opened the possibility of a loan to actions on AIDS, it placed emphasis on the issue of health, on treatment to individuals. In this regard, the NGO believes that, in thinking the aspect of human rights over, there is the possibility of embracing other topics, *like an umbrella*. The Ministry of Health and the National STD and AIDS Programme have always adopted the human rights view. It has guided some actions, and the government finances projects on legal advisory – as for example the fact that the PELA VIDDA legal project is partially financed by the National Programme – because they understand that human rights are crucial to face the epidemic. “We were all going in the same direction, i. e. , of favoring and facilitating the access to people's rights”. In the field of rights, the group employs the strategy of setting partnerships with the State Government Prosecutors Office, with the Federal Government Prosecutors Office, with the Public Defenders Office and the Brazilian Bar.

We hold partnership with the Regional Labor Bureau, and when a person comes to PELA VIDDA legal advisory, experiencing a situation of dismissal because of prejudice, we don't sue the corporation, but refer the individual to the Regional Labor Bureau. The Bureau then contacts the corporation and tries to solve the situation. We have reached these faster and more effective responses through partnerships.

In the perception of the NGO representative, the World Bank financing led the NGOs to establish a relationship of dependency with the Ministry of Health. This relationship is harmful to the NGOs' identity: "Sometimes we notice that a NGO cannot even have a critical thought about the government, about the actions of the Ministry of Health, because the dependency relationship is so strong that it [the NGO] does not even ponder the possibility of opposing to any issues in these spaces". According to them, at the same time that this financing was important, because it allowed for developing several efficient actions in response to the AIDS epidemic, on the other hand it established this dependence. This relationship entailed financial and political consequences, since the NGO cannot keep a distance and clearly understands its autonomy in the arena of negotiations with government. "Sometimes, it is extremely harmful. Most NGOs, not only in Rio and São Paulo, survive mainly with financing by the Ministry of Health".

D. 3. ABIA – Associação Brasileira Interdisciplinar de AIDS

- 1) Organization Name: ABIA – Associação Brasileira Interdisciplinar de AIDS.**
- 2) City/State: Rio de Janeiro/RJ.**
- 3) Date of Foundation: 1986.**
- 4) Started Working with STD/AIDS in: 1986.**

- 5) **Kind of Organization:** Association.
- 6) **Address/Phone**
abia@abiaids. org. br
Phone: (21) 2223 – 10 – 40 / 2224 – 16 – 54
- 7) **Situation Concerning Headquarters:** Rented.
- 8) **Where it Performs the Activities:** in several spaces:
headquarters, community.
- 9) **Field of Action:** Gay movement and women’s movement.
- 10) **Priority Field of Action:** Prevention against STD/HIV/AIDS.
- 11) **Geographic Area of Work:** The city and the state of Rio de Janeiro, and at the national level.
- 12) **General Purposes**
Promote the development of social and scientific activities aimed at the prevention and fight against AIDS, such as studies, researches and socioeconomic projects, social-political studies, database assemblage, data management and interpretation, preparation and dissemination of reports, newsletters and publications, whether by the organization or through third parties, and development of other activities related to this organizational objective.
To reach these purposes, it establishes contacts, agreements and program exchanges with entities, organizations, public or private bodies and national and foreign foundations and societies.

13) Target-audience

Seropositive population: women, serodiscordant couples (heterosexuals and homosexuals), men who have sex with other men, gay communities, health professionals at the municipal and state levels, and the population in general.

The ABIA traditionally works with male homosexual populations, but it is open to the female populations. However, since there are other NGOs developing works oriented to the female population, ABIA places priority on male homosexual groups. Another target-audience is people in treatment – HIV/AIDS carriers – and people working on treatment – health field professionals. Additionally to these specific audiences, it provides services to the general public comprised of researchers and students that look to the organization for information and researches.

14) Core Activities

- Support groups to individuals living with HIV/AIDS, project on adhesion to the treatment and qualification of leaderships in Health Councils;
- Debate and room for research – partnership with the University of Columbia and the Rio de Janeiro Federal University (institute of psychiatry / mental health) for researchers in the technical field;
- Publications specially addressed to monitoring public health policies concerning sexuality, HIV/AIDS and reproductive health. For that, the NGO promotes debates and seminars;
- Information on HIV/AIDS and distribution of condoms to young students (high schools and universities);
- “*Entendendo os tratamentos*” workshop to assist individuals in understanding the treatment, and the “*Homens que fazem sexo com homens*” workshop for youth, about men who have sex with men;

- The entity also provides services, in its Center of Documentation and Resources, to students and researchers of different academic backgrounds, and also to the public in general;
- It issues informative materials on HIV/AIDS epidemics on a regular basis.

The activities are projects focused on specific audiences: people living with HIV/AIDS, youth, and prostitutes. Another project develops works with both heterosexual and homosexual serodiscordant couples. In the field of social research, it carries out activities with users of mental health services and HIV/AIDS carriers who are psychiatric patients. Another major activity of ABIA is in the field of publications.

15) Ongoing Programs and Projects

They have projects in the field of treatment and support to treatment that they refer to as “adhesion. ” However, these are support groups to people living with AIDS, and who are undergoing treatment. This project comprises with municipal and state health professionals, who discuss the issue of treatment.

Another project, in partnership with the University of Columbia and the Rio de Janeiro Federal University (Psychiatry Institute), focuses on the issue of HIV/AIDS among users of mental health services.

16) Services Provided to Population

- “*Entendendo os tratamentos*” Workshop;
- Theater and video workshop to MSM youth;
- Workshops on manual works, informatics;
- Workshop for serodiscordant couples;
- Service: ABIA Documentation and Resources Center.

17) Works only with AIDS: Yes.

18) Advertises the Work Developed Through:

- Newsletters, brochures, folders, manuals, magazines, videos and scientific publications;
- Books, journals;
- Congresses, conferences, meetings and seminars.

NGO Background

19) Origin of the institution

The history of ABIA dates back to the 1980's, and follows the paths of its two founders, the anthropologist Herbert de Souza (Betinho) and doctor Walter Almeida who, since their early stages, were committed to the HIV/AIDS epidemic.

The original idea of establishing what would further become known as ABIA arose in 1985, when Walter Almeida traveled to the USA to seek for further information on AIDS. At that time, Almeida used to attend scientific conferences on AIDS in the USA, and intended to establish a Brazilian Interdisciplinary Foundation on AIDS: *In Brazil, the disease was changing from an abstract concern to a devastating reality among hemophiliacs in Rio de Janeiro. This concern with hemophiliacs assisted in inserting AIDS into Betinho's political agenda.*

As of 1985, Betinho invited several doctors, researchers and representatives of social movements to the NGO IBASE – which he founded and headed – to discuss issues related to AIDS. In 1986, these meetings were expanded and started attracting renowned Brazilian individuals, opinion-makers; people involved with social movements and leaders of NGOs acknowledged in the field of citizenship, like the

lawyer Nilo Batista, Bishop Dom Mauro Morelli and the anthropologist Rubem César Fernandes.

In 1986, the nucleus analyzed several organizational structures for the group they intended to establish. Finally, on 10 April 1987, the entity registered its bylaws. *However, those who participated in the process of building it agree that, for practical purposes, ABIA started to exist at the end of 1986.*

Therefore, the *Associação Brasileira Interdisciplinar de AIDS* – ABIA, was founded in 1986 by a group of activists, such as Betinho, Herbert de Souza, Herbert Daniel and other activists and health professionals who wanted to fight against the AIDS epidemic. Initially, it was a composition of activists and people from the gay movement in Rio de Janeiro.

A prevailing philosophy at that time, even because of Betinho's leadership, was to establish a solidarity network for advocating for the rights of those living with AIDS. ABIA was engaged in the fight for blood quality: *it happened when Brazil still had blood banks.* After the fight for blood quality, the advocacy for rights to people living with AIDS, rights to service, hospital services, right to medications prevailed: *At that time, Brazilian government didn't even have the issue of AZT.* At the same time, they worked with corporations, to avoid dismissal of seropositive individuals. Even after the National AIDS Programme establishment, they continued developing actions of advocacy for the rights of diseased people, and for services quality, humanization in services provided to seropositive individuals.

20) Organization's Motivation Towards Working with STD/AIDS

ABIA was founded to work with HIV/AIDS.

21) Resources and Financing Sources

The sources of resources of the *Associação Brasileira Interdisciplinar de AIDS* are granted by International Cooperation Agencies (Ford

Foundation, MacArthur Foundation and EED), agreements with public bodies and donations made by individuals. As resource intake strategy, the NGO tries to diversify sources, and keep continuous work: “You can’t wait for a project to end and then negotiate another with the same financing agent, or with different partners. You must have a broad range of activities, rather than work on one single activity”.

22) Human Resources

Since ABIA professionals are graduated or technicians, capacity building is oriented to specific areas, such as in the use of a given software of data analysis for research, English classes, computer science in general, and other specific areas, depending on the participants’ field of interest and work. They also employ participation in seminars, conferences and congresses as capacity building tools.

23) Work Methodology

ABIA prepares a 3-year strategic plan, which is annually reviewed. Along the years, the NGO develops activities of interest: “We keep them as leading actions in the institution. There are others that depend on some projects: opportunities that arise in relevant fields, which may vary along the year”.

The board of directors and the general coordination participate in this planning process: “the process and strategic planning used to be prepared through external consultancy services. Since last year, this work has been made jointly with all participants of ABIA and external consultants”.

Through debates and seminars, they discuss the developments and work on suggestions for improvement: “Not only criticizing, but performing joint analysis. This is how we try to work”.

According to the NGO, there are several problems in implementing their actions. The biggest difficulty would be to keep people attending to and participating in preventive activities, because the population that is most vulnerable to the epidemics is becoming

poorer and poorer. Thus, the activities are developed directly in the community, granting the attendance of participants that would not participate because they lack financial resources to subsidize transportation/displacement to the activity site.

Another problem is the prejudice, discrimination, physical and psychological harassment, exclusion of the homosexuals' families from the school, community and church environments and events.

The challenge that ABIA faces in the field of reducing individual and collective risks of HIV infection among its beneficiary population is: better elaboration on the prevention issue, providing and discussing prevention alternatives, within the context of people's lives.

According to ABIA, a solution for these difficulties would be to insert these people into an environment where they feel safe, where they can talk about and work on their self-esteem, their sexual and reproductive rights, their access to services, prevention devices, prevention alternatives, human rights and, therefore, retrieve their citizenship.

The pioneer work is defined by its capacity of joining all players – as government, universities, services, and target-population, people living with AIDS – in the same forum of debate.

There is no specific assessment on the impact of NGO actions on all beneficiary populations but, on the other hand, concerning male homosexuals group – the NGO's target-population over the years – there is a survey that points to improvements in prevention indicators, both concerning the increased use of condoms and reduced number of sexual partners.

The institution considers results as positive. Concerning general investments in AIDS, it mentions the attraction of new participants to the NGO's activities. The target-audience reports positive changes and recovery of citizenship after attending the group and workshops.

Furthermore, the NGO mentions the relevance of their work as an example, since several universities, financing bodies and international institutions seek for them.

Universities, financing bodies, international institutions and international academic institutions approach ABIA for internship programs or studies. The documentation center is another thermometer. The federal government and international and national agencies acknowledge the existence, role and importance of ABIA works in Brazil.

24) Political Articulation

The *Associação Brasileira Interdisciplinar de AIDS* is affiliated to ABONG; to *Rede Brasil* (responsible for the articulation with multi-lateral institutions); to *Rede de Monitoramento Presidente Amigo da Criança*, under the leadership of Abrinq; to Brazilian Network of Peoples Integration (Rebrip).

25) Partnerships

In order to develop its actions, the NGO holds partnerships with the State STD and AIDS Coordination, the Municipal STD and AIDS Coordination, Health Secretariats, Human Rights Secretariats, Government Prosecutors Office, Ministry of Justice, Other Programs and/or Secretariats of the Ministry of Health, NGOs/AIDS, NGOs/Mixed, Private Institutions and other segments of social movements.

26) Incidence on Social Programs and Public Policies

It participates in the discussion on free access to medications and treatment. It participates in the State STD and AIDS Commissions, and in the Advisory Committee to the National STD and AIDS Programme. It holds seat in the AIDS Commission (at the state level). It provides training to health professionals at the municipal level.

The institution highlights that this field of public policies and governmental programs to fight the epidemic is the *leading wagon of ABIA*. According to them, they prepare suggestions and recommendations through several publications and the debate among several participants – government, universities, services, target-population and people living with AIDS.

The first battle was the issue of blood control, then the fight for the rights of people of not being dismissed from work because they were HIV/AIDS carriers, to have access to treatment and to medications, the issue of patents. For example, the two last seminars held by ABIA in this specific field were: HIV/AIDS and development, and HIV and the Brazilian Unified Health System – SUS, to discuss with the Ministry of Health, Rio de Janeiro AIDS Coordination, health professionals, SUS users and universities working on and researching this field.

The idea is to discuss all issues, making recommendations to be attentive, to work on a way to improve the introduction of the HIV topic into public policies, discuss financing and improvement of services within the scope of SUS.

Furthermore, ABIA performs monitoring and assessment activities that also ground recommendations towards developing the National STD and AIDS Programme. It also articulates with the committee on the MSM population, and the committee of labor to female population (federal level). A way for disseminating and taking its recommendations to several audiences, particularly government and civil society, are the publications and seminars, besides documents in networks. It circulates informative material at the NGOs/AIDS forum, Rede Brasil and Abrinq Foundation.

27) The Organization Sustainability, in Mid and Long Terms

The NGO divides this topic in two levels: concerning financial sustainability, it states the impossibility of estimates beyond a 3-year period, due to economic instability.

In long-term, impossible in Brazil – not even private corporations have sustainability. The institution feels ease for three years, no problems, but every year it starts new projects, seeks for new partnerships or continue existing partnerships, always renewing and seeking for new partnerships.

Concerning political sustainability, they believe it is important to maintain credibility with beneficiary population and the field where they work.

I think institutions should be concerned not only about financial resources, but also about participating in Forums. It is important to inform people on

what the institution does and intends to deserve this credibility; this is political sustainability. When you submit a project or a possibility of partnership with another NGO or a governmental institution or an international institution, you have political support in the field you want to work.

In the field of institutional strength, the NGO underlines the consolidated structure of specialized services – network of services (testing centers, laboratories, and specialized ambulatory and skilled professionals): “I don’t believe that any other program of fight against any epidemic, in such a short-time, succeeded in implementing a services network with this level of quality”.

However, the challenge is to continue and improve the quality of this service network, assembled and consolidated, ranging from professional qualification to physical structure to develop these services. The NGO also states that problems are related to the fact that: “current structure results for a 15-year work, and its improvement and continuity depends on a continuous and permanent movement”.

Concerning threats, the NGO believes to be undergoing a critical moment, since the introduction of AIDS into SUS scope and the consequent decentralization of the actions by the National STD and AIDS Programme will be transferred to states and municipalities. This would mean discontinuity of actions. Therefore, this moment demands, at the governmental and civil society level, enhanced structures and networks.

28) Interlocution with Governmental Spheres, in the Field of the AIDS Epidemic

In the field of implications by governmental financing over ABIA priority agenda, the NGO stresses as negative point the delay in transferring resources, resulting from bureaucracy:

The State apparatus is very hard, it is stubborn. Even if the Ministry of Health resource is directly made available to AIDS, this flow of resources to the final user or final service has never been natural, through natural ways. Difficulties have always existed, the money is retained somewhere. You provide capacity building to civil society or health professionals and,

then, you don't have money to afford it. It was foreseen, planned, came for Brasilia to the state, and there it remained – it was not released for payments to be made. This is a serious problem. Now, with the transfer of resources addressed to specific projects of the NGOs, which will also pass through this fund, even if this money is “certified” to prevention, allotted to NGOs to develop this work, we doubt they will succeed in employing this resource. Because if the money that goes to health units or to training health professionals doesn't happen, how will this money to NGOs happen?

On the other hand, the institution highlights as success in the Brazilian actions on the fight against AIDS the assemblage of an infrastructure network of services, inclusively in comparison to other developing countries. ABIA also underlines the victory in free distribution of medications, and the partnership work developed by government and civil society as core components in the Brazilian success: “Something you just don't see anywhere else in the world. Even in countries that have NGOs, there is no such partnership, this kind of partnership of complementary work and social control, like we have in Brazil”.

They work with financing agents or projects that, for themselves, are sources of financing. The NGO emphasizes that they select fields of work that provide “freedom to speak, think and write whatever you want, think and believe”. Under this light, they believe their autonomy is not endangered and, up to now, they have not had any problems with financing agencies. However, they report the existence of NGOs that depend on resources and projects of the Ministry of Health to continue their actions, and even to survive.

D. 4. DAVIDA

- 1) Organization Name: DAVIDA – Prostituição, Direitos Civis, Saúde (Rede).**
- 2) City/State: Rio de Janeiro/RJ.**
- 3) Date of Foundation: 15/07/1992.**

- 4) **Started Working with STD/AIDS in:** 1989, previously to the NGO's foundation.
- 5) **Kind of Organization:** Social movement.
- 6) **Address/Phone**
davida@davida. org. br
Tel: (21) 2224 – 35 – 32 / 2242 – 37 – 13
- 7) **Field of Action**
National consultancy and advisory services on STD/AIDS; human rights, prevention against HIV/AIDS, movement of children and adolescents.
- 8) **Priority Field of Action:** Male and female sex professionals.
- 9) **Geographic Area of Work:** National.
- 10) **General Purposes**
The association aims at building opportunities to enhance the citizenship of sex professionals, organizing the category to fight for basic rights, such as health.
Another focus is social mobilization, articulation with other social movements of civil society.
Also outstanding is the promotion of self-esteem and citizenship to marginalized communities, mainly sex professionals and their clients, in addition to adolescents. For that, they hold several activities in the field of organization, education, income generation, professional qualification, health, culture and communication. AIDS prevention is inserted into this work of sex workers in

assuming the importance and dignity of their work.

Another objective is to change the Brazilian law on prostitution, including among their rights:

- Reduce the category's vulnerabilities, mainly in the fields of legal rights, health and security;
- Grant a protagonist role and social visibility to sex professionals;
- Denounce and challenge the stigma, prejudice and discrimination that affect sex professionals;
- Qualify the category leaders;
- Assist in the establishment of sex professional's associations;
- Exercise social control and promote public policies to the category;
- Fight for legal recognition of the profession;
- Fight for improving working conditions and quality of life of sex professionals;
- Provide consultancy to governmental bodies, other civil society organizations and private initiative in issues related to prostitution.

11) Target-audience: Sex professionals, children and adolescents.

12) Core Activities

- Provide support and advisory services in the establishment of associations of prostitutes all over the country; provide technical support to legally instituted associations; and, promote meetings;
- Promote capacity building courses to NGOs working with sex professionals all over the country;
- Prevention against STD/AIDS;
- Support sex professional associations in the elaboration and development of projects on STD/AIDS prevention;

- Documentation Center specialized in prostitution;
- Vocational courses to children and youth for the carnival (sewing, metal works, joinery, ornaments, sculptures, rhythms).

13) Ongoing Programs and Projects

- Provides advisory services to the *Cidadania nas Ruas* project;
- *AIDS Nem Pensar. . . Sou DAVIDA* Project, on prevention oriented to sex professionals;
- *Esquina na Noite* Project, responsible for capacity – building project in the Southeast region;
- *Carnaval de Negócios para Jovens* Project: educational project with children and adolescents (sewing, metal works, joinery, ornaments, sculpture, rhythms).
- *Previna na Prostituição* Project on prevention against STD/AIDS,

14) Services Provided to Population

- Distribution of condoms;
- Thematic workshops;
- Vocation courses oriented to labor market (youth);
- Access to the institution's library and documentation.

15) Works only with AIDS: No.

16) Advertises the Work Developed Through:

- *Beijo da Rua* newsletter (monthly publication addressed to sex professionals all over Brazil);
- Journals, videos, printed material, press;
- Congresses, conferences, meetings and seminars.

NGO Background

17) Origin of the Institution

Non-profit, non-governmental entity founded in 1992 to continue actions started in 1986 by another NGO. Its foundation results from the need to articulate the Brazilian Network of Sex Professionals, established in 1989, and systemizes information in the fields of education, youth capacity and its building, and organization of the sex professionals' movement.

In fact, the network has been effectively operational since 1989 and became official in 1992. The need for establishing the network results from the reduced number of associations, and its establishment would contribute towards increasing the number of associations.

They divided the duties by region:

The North Region would be in Belém de Pará, since it already had an association. Northeast Region would be in Ceará and Southeast Region with us. The South Region, with Rio Grande do Sul. At that time, we didn't have anything in the Midwest. Two, three years ago, they assembled a network; the Midwest is hard. But this regional thing works on the daily life of people; we also noticed that in the more political history, more of national politics, people don't follow it, so the DAVIDA started coordinating all these regions, at the national level.

18) Organization's Motivation Towards Working with STD/ AIDS

AIDS prevention is part of the female sex workers efforts towards taking on the importance and dignity of their work.

19) Resources and Financing Sources

International cooperation agencies; agreements with public bodies; corporation's donations; and, timely sponsorships.

20) Political Articulation

The NGO is part of the Rio de Janeiro NGOs/AIDS Forum and heads the National Association of Sex Professionals.

Currently, the Network's political agenda is very focused on the issue of law: Our major purpose is to change the Brazilian law on prostitution. So, that is our agenda, and takes much of our time. As of the solution of this issue, a new historic moment starts, our agenda is completely changed, and we will start working on advocacy.

In relation to the organized civil society movement, the institution believes it should be inserted into issues arising in the social movement in general, mainly with the women's movement, and the black movement as well.

The first experience in the relationship between the Network and governmental spheres is with the National STD and AIDS Programme. This relationship opened several opportunities for interlocution with other governmental bodies: The Ministry of Justice, in the rights commission; and the Ministry of Labor. Some associations that work with youth and children belong to the Network, and it is well articulated to the State Education Secretariat.

21) Partnerships

The major partnerships are with the State STD and AIDS Coordination, Municipal STD and AIDS Coordination, Health Secretariat, Human Rights Secretariat, Ministry of Justice, Other Programs and/or Secretariat of the Ministry of Health (Culture Secretariat); NGOs/AIDS, NGOs/mixed; Private Institutions (*Bradesco* Foundation) and other segments of social movements.

22) Incidence on Social Programs and Public Policies

Jointly with the government, the NGO participated in public policies related to access to early diagnosis, access to prevention devices, NGO capacity building, human rights and citizenship. Currently, it participates in the formulation of policies, and holds

seat in several committees. Furthermore, it attended all discussions on projects financed by the World Bank.

It is part of the Health Council, State Commissions STD and AIDS Commissions, and the Advisory Committee to the National STD and AIDS Programme.

23) Sustainability of Program Actions Within the NGO Work Plan

The NGOs acknowledges increased efforts by the National Programme and the NGOs and some forums towards qualifying the organizations to sustainability, since the NGOs are still unprepared: “I am afraid of thinking about what will happen when the loan ends. There are *seven hundred* something NGOs/AIDS in Brazil. What will happen with all of them! Many of such NGOs survive with the coordination’s money”.

The NGO emphasizes the great efforts required to keep on track. The end of the World Bank resources and the decentralization process, i. e. , the Fund-to-Fund transfer, will pose a challenge to governmental financing, mainly in the field of AIDS:

There is a whole process of building up these NGOs for them to understand their sustainability. There is the technical, the political – crucial to reach financial. If you have lots of NGOs that just render services, with no political view on their role and without any technical team, which don’t think about this technical thing, how will you reach the money? So, this is a long process. We have seven hundred something NGOs but, out of them, there are five, six, that manage the technical, political and financial aspects. The challenge posed for us, as movement, is to assist these NGOs to find tools and, at the same time, remain standing up all along this process.

The NGO pursues developing its political and technical sustainability through the articulation / partnership with other NGOs and networks, aiming at developing its financial sustainability.

Concerning the threat to the sustainability of their activities, the *DAVIDA* mentions the lack of assessment on the NGOs actions, because they still have difficulties in making them. There is one single assessment on the financial aspect. Another threat would be the financial dependence on the National STD and AIDS Programme.

Concerning strong points, the institution refers to the discussion with government, the National Programme and their accessibility as the major positive points, in addition to the change in the population's view as regards sex professionals.

They also emphasize the establishment of networks on advocacy of human rights to sex professionals, strengthening of NGOs networks through the NGOs/AIDS Forum.

24) Interlocution with Governmental Spheres, in the Field of the AIDS Epidemic

The *DAVIDA* observes that the relationship between the National Programme and the social movement opened ways to contact other governmental bodies. However, there is a huge confusion concerning the role played by each of them. The civil society believes to be a service provider and sees the government as the major facilitator of resources. On the other hand, sometimes the government treats the Civil Society Organizations – OSC as civil society, sometimes as service provider, taking over their agendas.

The government believes we are service providers and some of us also believe that. This is the most serious problem in the government / civil society relationship, because we aren't service providers. I think this is a big mistake. Another issue is when the National Coordination misunderstands the agenda: The agenda is ours, and the NC thinks it belongs to them. Things must be clear, because some movements also make confusion on this. For example, last year, when I was attending a meeting of the advisory committee, sex professionals, the agenda was on the table and the last point was the national meeting of sex professionals. I said: "I am sorry, but this is not your agenda. I won't discuss it here in Brasilia. It is the movement's agenda. "But a friend got angry at me: "Let it be, otherwise we don't get any financing to the meeting". People mistake the roles on both sides.

Concerning positive points, the NGO believes that the relationship between government and civil society, as of the establishment of the National STD and AIDS Programme, is outstanding. Another crucial issue is the quantity of actions that have been and are still being

developed, leading to the epidemic refraining. It also stresses the development of several projects that led the NGOs and the National Programme to a broader view on the issue of AIDS, thinking it not only as a disease, but also as a problem that involves self-esteem, organization and health promotion.

E. SÃO PAULO

E. 1. CFL/SP – Coletivo Feminista Lésbicas de São Paulo

- 1) **Organization Name:** CFL/SP – Coletivo Feminista Lésbicas de São Paulo
- 2) **City/State:** São Paulo.
- 3) **Date of Foundation:** 31/03/1990.
- 4) **Started Working with STD/AIDS in:** 1996.
- 5) **Kind of Organization**
They have decided that the organization way would be a collective, and its leaders would work as coordinators, decentralizing the roles of presidents and the rigorous format of a group, since collective is a more open and self-managerial organization.
- 6) **Address/Phone**
cfl@canbras. net
(11)3104 – 8379
- 7) **Situation Concerning Headquarters:** temporary, *waiting for the financing of a project.*

- 8) Where it Performs the Activities:** At NGO headquarters and in prisons.
- 9) Field of Action**
HIV/AIDS, women's movement and other social movement (human rights to prisoners).
- 10) Priority Field of Action:** Gay/Lesbians movement.
- 11) Geographic Area of Work:** Municipal.
- 12) General Purposes:** Provide political visibility and respect to lesbians.
- 13) Target-audience:** Women, lesbians and confined populations.
- 14) Core Activities**
- Holding meetings and seminars;
 - Prevention against HIV/STD/AIDS among women;
 - Training;
 - Publications;
 - Lectures
 - Researches.
- 15) Services Provided to Population**
- Free legal orientation to lesbians who are victims of violence;
 - Guidance to students.
- 16) Works only with AIDS**
No. It also works with human rights to lesbians and women in general.

17) Advertises the Work Developed Through:

- Dissemination of research on female prisoners;
- Brochures, printed material;
- Congresses, conferences, meetings and seminars.

NGO Background

18) Origin of the institution

In early 1990, São Paulo missed an organization of feminist lesbians directly and simultaneously working with the movement of feminists, Gays, Lesbians, Bisexuals and Transgender – GLBT, in São Paulo. So, thirty lesbians got together and decided to assemble a group comprised of lesbians, to develop actions and works under a feminist perspective. It would be an association of lesbians, aiming at providing visibility to its members.

19) Organization's Motivation Towards Working with STD/AIDS

The work with STD/AIDS started in 1995/96, in the framework of a prison-based work developed with women. Initially, they worked on a research on prevention concerning the sexuality of confined women. The theater group developed this work. However, they are no longer working. The proposal of working on STD/AIDS resulted from a proposal by a member who works in the prison system, and the organization embraced the idea: *We were the first group to enter a prison system to develop a work with women. There was the GAPA, but GAPA only distributed condoms, in front of the door, on the sidewalks, at surroundings. Now there are several groups developing the work in the system.*

The *Coletivo Feminista Lésbico*⁴⁸ was founded in 1990, aiming at providing political visibility and advocating for human rights of lesbians. Early in that year, São Paulo missed an organization of feminist lesbians directly and simultaneously working locally with the movement of feminists, Gays, Lesbians, Bisexuals and Transgender – GLBT. São Paulo missed a collective of lesbians that could work under the feminist perspective, therefore filling in that gap. Up to now, the NGO headquarters are temporary (rented).

The institution started working with STD/AIDS in 1995, encouraged by the challenge of working on STD/AIDS prevention among women living in prison systems. A member of the Collective, who worked in the prison system, proposed this intervention.

The NGO's working organization is the minimum: It is made up by a board of directors, coordination, a treasury section and a secretary. The duties of the NGO members are not defined; they are distributed according to projects under implementation.

20) Resources and Financing Sources

The *Coletivo Lésbico* resources are granted through agreements with public bodies. The NGO employs projects application as strategy for financial intake. “The projects let us survive. Projects are our source. There is no other source, because donations are rare (individual). Corporations’ donations are through corporations and projects”.

⁴⁸ This NGO ceased working in 2003, few months after the interview. Few months later, it restarted working, because they had an approved project, through international financing. This project allowed them to start developing a work in the field of education, which they consider as very relevant.

21) Human Resources

The *Coletivo Feminista* has four members, among employees and service providers. Furthermore, it relies on the cooperation of fifteen volunteers.

The entity does not carry out capacity building activities, because they try to hire skilled professionals to meet the organization's demands. Due to the entity work in the field of STD/AIDS prevention in female prisons, they had to hire specific advisory services to provide guidance and training in this new activity.

22) Work Methodology

To assess the activities developed, the *Coletivo* sets focal groups with people involved in the projects developed. Concerning the work with confined women, the major difficulties concern the population working in the penitentiaries, because of their prejudice, rather than that of prisoners. The institution considers this as an innovative experience in the field of NGOs' action, since it provides visibility to the dilemmas experienced by women deprived of liberty, mainly concerning prevention.

In general, lesbian women do not have heterosexual intercourses and are not drug users, therefore they don't believe they are vulnerable and may contract the HIV.

23) Political Articulation and Incidence on Social Policies and Public Policies.

The *Coletivo Feminista Lésbico* is not affiliated to any specific network/articulation. It only participates in the National Feminist Network on Health, Reproductive Rights and Sexual Rights, at the national level. At the local level, the NGO participates in São Paulo NGOs/AIDS Forum.

As main partners to carry out political actions, the NGO mentions the state and municipal STD and AIDS coordination in São Paulo, besides the coordination of other programs and/or secretariats of the Ministry of Health. They also maintain dialogues with NGOs/mixed and other social movements.

24) Organization Sustainability in Mid and Long Terms.

The Organization has no expectation on self-sustainability, since they basically work on project implementation. Currently, the *Coletivo* is implementing a project to build sensitiveness among teachers, addressed to sexual orientation, in the school context.

The education field is something very important, and we have always wanted to develop something in this field, to deal with the education issue, because intervention on the educational system means interventions on our work. Interfere with society. The society is corporative and the educational system is what matters. We have always felt this need. Education involves everything, so the educational system – which respects citizenship, sexual diversity – is something that meets our desire of granting respect to lesbians. I think this is how we see things.

The *Coletivo Feminista Lésbico* mentions the work with people committed to the NGO objectives and field of action as one of its strong points. Concerning threats, they mention the lack of resources to develop the activities.

25) Interlocution with Governmental Spheres, in the Field of the AIDS Epidemic

According to the CFL leader, the link between civil society and government was positive, and allowed for the development of activities. However, the NGO emphasizes that such locution is asymmetrical, in terms of power, and, therefore, the link is negative to the organized civil society, mainly concerning autonomy. “The government expects people to assemble the project according to the government expectation. . . it is very far from autonomy”.

Furthermore, the NGO highlights that the organized civil society organizations are responsible for demarking their political room, in the sense that projects should have direct connection with the reality of the NGO’s beneficiary population.

Moreover, they feel that NGOs keep with government a relationship of service providers, thus reflecting the Public Power’s attempt towards tutoring, inclusively the NGOs policies. On the other hand, they say that it is hard to work under a perspective that

goes beyond service provision, oriented by cultural and structural changes, towards getting financing:

To be following-up meeting demands. Move things on, grant citizenship, respond to the demand and targeting not only the incoming demand, but also social class changes. I think we should try.

Concerning the impact of governmental financing over their political actions, the *Coletivo Feminista Lésbico* claims damages to the autonomy. “The problem is to loose autonomy, because you become committed. You loose your autonomy. You become committed, additionally to the relationships to be established, like: Financing, estimates, power relationships”.

E. 2. ALIVI – Associação Aliança pela Vida

1) Organization Name: ALIVI – Associação Aliança pela Vida

2) City/State: São Paulo.

3) Date of Foundation: 05/03/1989.

4) Started Working with STD/AIDS in: 1987/88.

5) Kind of Organization

The *Associação Aliança pela Vida* is a philanthropic, non-governmental organization, established to provide support to HIV/AIDS carriers in need.

6) Address/Phone

e-mail: pccrepal@uol. com. br

Phone: (11) 3106-09-75

7) Situation Concerning Headquarters: Own.

8) Where it Performs the Activities: In homes, on the streets and at its headquarters.

9) Field of Action

STD/HIV/AIDS prevention; assistance to HIV carriers and/or people living with AIDS.

10) Geographic Area of Work: National.

11) General Purposes

The *Associação Aliança pela Vida*'s objectives are:

- To render solidarity to seropositive individuals, especially women and children, sheltering them in their units, mainly those suffering from other social problems and who are homeless. The association allows this population to share a community life, receive health care, food, clothes, notions of personal hygiene, school for children, leisure, etc;
- To provide beneficiaries means and conditions to leave the institution and be reintegrated to society as fast as possible;
- To develop and expand the scope of the project on income generation and sustainability (Hydroponics, Bakery, Food Processing), in benefit of needy communities;
- To develop and expand the educational project *Raízes e Asas*, for the Institution's youth, providing vocational courses to youth over age twelve;
- To make its work known beyond the spheres related to AIDS and STDs.
- To treat and provide social support to HIV/AIDS carriers, who are poor and abandoned, in their homes;

- To develop activities on information, education and communication, oriented to prevent and fight AIDS;
- To advocate for social rights of HIV/AIDS carriers.

12) Target-audience: Homeless HIV/AIDS carriers.

13) Core Activities

Besides providing shelter to people, the NGO started developing a work oriented to adhesion to treatment, which is an essential requirement for permanence in the institution. The individual must adhere to treatment. The work is developed with the support of nurse assistants, who administer medications and provide guidance.

The same happens with children. They are re-educated, referred to first level schools.

Provide dental care, psychological services and referral to doctors. The idea is to *discipline* the beneficiaries on therapy-related issues and, in a second stage, the NGO prepares them to *return to their lives in the world*.

The NGO develops several workshops, with the intension of providing new professions to these people. They deliver courses on horticulture, bakery and computers. *The idea is to reintegrate them into society. I mean, to provide the initial structure; people become stronger, improve their self-esteem, their human condition and then return to society.*

14) Services provided to the population

- The NGO has semi-ambulatory units that provide care to people in almost terminal condition, and shelter to children victimized by social discrimination against AIDS;
- Free legal assistance;

- Provides housing, medical assistance and treatment, besides developing educational and vocational projects, aiming at the social reintegration of these citizens (courses on horticulture, bakery, computer).

For that, ALIVI has a pool of thirteen shelters or support houses, distributed among four units: **Terra da Promessa** (Mairiporã/SP), **Casa da Paz**, **Estrela da Esperança** and **Casa Pequeno Príncipe Tim**. The first affiliated unit is being implemented in São Paulo north region and is named **Raízes e Asas**.

These efforts intend to improve the outlife of HIV/AIDS carriers, by providing them proper food, medications, hygiene, leisure and spiritual treatment, to delay the emergence of opportunistic diseases and reduce the rate of hospitalizations;

- Nursing care, administering medications and guidance;
- Referral of children to first level schools: *currently, our children attend private schools, subsidized by the institution.*
- Dental care, psychological care, referral to doctors.

15) Ongoing Programs and Projects

The *Associação Aliança pela Vida*, in cooperation with its partners, develop several projects. It started developing them aiming at the social reintegration of its patients. All projects are basically oriented to meet the needs of the assisted people and, whenever possible, benefit the needy communities in the region.

The *Geração de Renda e Sustentabilidade* project comprises five projects: Hydroponics (with the major objective of generating professional qualification, job and income for AIDS carriers living in the *Terra da Promessa*); Bakery; Food Processing; Earthworm breeding (aiming at producing earthworms and humus for trading); and Gardening and

Landscaping (to qualify youths, children to seropositive parents, to introduce them into the labor market).

This project was created as a way to promote social integration to AIDS virus carriers sheltered by ALIVI. It is mainly oriented to provide professional qualification to the institution residents in activities that allow for income generation, providing them a feasible alternative for self-maintenance, in an immediate and permanent way, besides contributing towards allowing them to live a more worthy life.

It intends to maintain the sheltered beneficiaries working while they live in the Institution and, even when they have conditions to retake their lives outside, they may keep a link, as aggregated, and may continue participating actively in the project, thus keeping their income.

Furthermore, it develops projects with the following partners:

Stern Der Hoffnung – This NGO, the name of which in English means Hope Star, has offices in Paderborn, Germany and in Villars-Sur-Glâne (Friburg), Switzerland. It has financed most of ALIVI's permanent expenses, since its foundation.

Missionzentrale Der Franziskaner – This organization centralizes the works by Franciscans all over the world, and provides support to ALIVI operational infrastructure.

Deutsches Caritas – Verband – Supports ALIVI in its operational infrastructure.

Miserior Hilfswerke – NGO bound to the Catholic Church. It supports social activities worldwide and, for ALIVI, provides operational infrastructure support.

Community-based Association “O Amor é Nossa União” – This institution has long contributed with ALIVI in its several demands.

Religious Community João XXIII – For many years, this NGO has worked as partner to ALIVI in its several needs.

Tortuga Zootecnia Ltda – Provided financial cooperation to purchase three **ALIVI** units, as follows: Casa da Paz (full support), Casa Pequeno Príncipe Tim (partial support) and Casa Raízes e Asas (partial support). Every year it provides school material to **ALIVI** children.

Brazilian Association of Education and Culture – ABEC/ Nucleus of Social Action Marista – Assigned, in “commodatum” regimen and for undetermined time, the house for the Unit Estrela da Esperança. It also provides financial support to **ALIVI**, and donated part of the resources employed in the purchase of the Unit Raízes e Asas.

Inter-American Development Bank – IADB – Project UNESCO BRA914/59 – Ministry of Health – These partners support nine financing projects approved through AIDS I and II, some of which have already been executed, some are under execution and some were approved and are in the contracting stage. Among these projects, one is oriented to income generation for people living with AIDS.

NGO “Capacitação Solidária” – At the *Terra da Promessa* Unit, it carried out the “*Caminhos da Serra – Ecoturismo e Monitoramento Ambiental*” project involving thirty youths, in the same age group, of which sixteen were employed in the region labor market immediately after finishing the course.

Faculdades Integradas Cantareira – FIC – Provide technical support, professional qualification and timely assistance to the project on income generation executed at the *Terra da Promessa* Unit, named Hydroponics.

NGO “Amar é Viver” Support Group – GAAVER – ALIVI cooperates with GAAVER in social assistance to seventy families, in the peripheral area of São Paulo’s northern region. These are families of people living or co-existing with the virus of AIDS.

Ícone Educação Infantil e Ensino Fundamental – This institution provides support to the “*Raízes e Asas*” project providing a 50% subsidy to monthly school fees for sixteen children currently attending classes there.

Projeto Comunitário, with the Research Institute Emílio Ribas – Provides weekly home assistance to patients in the *Casa da Paz* and *Estrela da Esperança* Units. It is a voluntary work developed by a multi-disciplinary medical team.

16) Works only with AIDS: Yes.

17) Advertises the Work Developed Through:

Videos, congresses, conferences, meetings, seminars and through partnerships with governmental institutions and others, such as *Emílio Ribas* and *Caritas* in São Paulo, by referring patients.

NGO Background

18) Origin of the institution

ALIVI was established in 1989, upon the initiative by a Swiss nurse, Ms. Maria Elisabeth Eicher, known as Lisete. Lisete was hired by Caritas International, in Germany, and developed a work on home care to patients in bed and the elderly, participating in a multi-disciplinary team. This experience called the attention of Brazilian Franciscan Friars who, headed by the Cardinal Archbishop of São Paulo at that time, D. Paulo E. Arns, were attending an international congress where Lisete and her husband were also participating in Germany – more specifically in Munich. Lisete reported to the Brazilians her experiences in home care to diseased people, and they became very interested.

They visualized an opportunity of rendering services to AIDS patients in São Paulo, since the ambulatory and hospital structure in that city could not meet the demand, not to mention the huge social difficulties faced by the patients.

In 1988, Lisete arrived in São Paulo, upon invitation made by the Franciscans. She soon noticed that the local reality in relation to AIDS was quite different than the reality she knew, i. e. , the profile of the victims of the disease in Brazil was very different than that for German patients, for example. Here, social issues were associated to the disease. AIDS victims were mostly needy people, with no social and family infrastructure to support them. In fact, most of them lived on the streets.

In this context, Lisete proposed to build a support house, basically to provide the social infrastructure to HIV/AIDS carriers and thereafter, if possible, provide them treatment. Then, on 5 March 1989, *ALIVI – Associação Aliança pela Vida* was founded.

The first unit of ALIVI was the *Terra da Promessa*, in a land plot purchased with the support of International Non-Governmental Organizations such as STERN DER HOFFNUNG; DEUTSCHES CARITAS – VERBAND; MISSIONZENTRALE DER FRANZISKANER (the organization that centralizes the work of Franciscans all over the world) and MISERIOR HILFSWERKE (bound to the Catholic Church and supporting social actions worldwide). Furthermore, many individuals, corporations and national parishes contributed in this effort. *Terra da Promessa* shelters women with AIDS, who have no financial or family support, and who need housing and conditions for a worthy and normal life. Their children, whether carriers or not, are also sheltered.

In 1993, the *Casa da Paz* was built to assist weak patients, who needed intensive specialized monitoring 24 hours a day, seven days a week. The house has twelve beds and the patients are assisted by a multi-disciplinary team (nurse, nurse assistant, doctor, physical therapists, nutritionists and social assistant) at the entity's premises, through the project on community service, of the Infectology Institute Emílio Ribas.

The third unit of ALIVI is *Estrela da Esperança*, founded in 1995, named after the German NGO that, up to this date, is the major cooperation agency to ALIVI. With nine beds, it takes care of patients in bed, suffering from neurological sequels of drugs or other diseases originated by AIDS.

In 2000, the *Casa Pequeno Príncipe Tim* was founded, aimed at sheltering exclusively children victims of AIDS, HIV/AIDS carriers or not. Some are orphans to parents that died from the disease. Others are children to mothers/fathers who, because of the disease, lost their prerogative of parents. Previously to this unit, when a mother living in the *Terra da Promessa* died, her children were sent to the S. O. S. Criança. Now, they are housed in the **Casa Pequeno Príncipe Tim**, where they may enjoy the whole infrastructure built to allow their best development, granting basic rights to housing, education and health. Since this Unit houses only children aged between 0 and 12, a new support house is being implemented. It will be an affiliated unit to house adolescents aged between 12 and 18. It will be called *Raízes e Asas* and intends to provide social support, including housing, educational support until high school and, probably, vocational courses to fifteen youths.

19) Organization's Motivation Towards Working with STD/AIDS

When the NGO was founded, infrastructure in the HIV field was very poor. The NGO was established basically aiming at providing this social infrastructure to HIV/AIDS carriers and thereafter, whenever possible, provide treatment.

The *Associação Aliança Pela Vida* was founded in 1989, and its target-audience is made up of homeless HIV/AIDS carriers. Therefore, the institution comes to life with the following objectives: (i) provide solidarity to seropositive individuals, especially women and children, housing them in its units, mainly those suffering other social problems, and who are homeless. The association allows this population to share a community life, receive health care, food, clothes, notions of personal hygiene, school for children, leisure, etc; (ii) Provide to beneficiaries means and conditions to leave the institution and be reintegrated to society; (iii) Treat and provide social support to HIV/AIDS carriers, who are poor and abandoned, at their homes; (iv) Develop activities on information, education and communication, oriented to prevent and fight AIDS; and (v) Advocate for social rights of HIV/AIDS carriers.

It has its own headquarters, and its organizational structure is made up by a chairperson, vice – chairperson, first treasurer, second treasurer, first secretary, second secretary, fiscal council (three members and three alternates), first executive director and second executive director. It holds assemblies at every two or three years, with the intention of renewing or improving the institutional statute. The assemblies reelect the board of directors, or elect a new one. The coordinators of several departments have autonomy to develop their own projects.

20) Resources and Sources of Financing

The NGO resources are granted through partnership signed with the Ministry of Health/National STD and AIDS Programme. It receives cooperation from Germany and Switzerland, promoted by Maria Elisabeth Eicher, of the NGO STERN DER HOFFNUNG,

which finances about sixty percent of ALIVI monthly expenses. Therefore, it is the major partner in implementing and developing several projects. The institution is also financed by the following international NGOs: DEUTSCHES CARITAS – VERBAND; MISSIONZENTRALE DER FRANZISKANER (the organization that centralizes all Franciscan works in the world), and MISERIOR HILFSWERKE (bound to the Catholic Church, and supports social activities worldwide.)

Other sources of resources are donations made by individuals, corporations (enterprises and national parishes), in addition to agreements with public bodies and other International Cooperation Agencies.

The costs, salaries and charges, expenses with vehicle maintenance, fuel, are paid by Europe, through an organization named Stern Der Roffnung, with headquarter in the cities of Baderbonn, in Germany and Friburgo, in Switzerland. They send monthly resources to maintain the institution. For expenses with water, electricity, telephone, maintenance of houses, we employ collections through telemarketing: asking São Paulo communities for resources over the phone. So, we work with outsourced offices, which collect resources in exchange for small profits. We also receive 50% discount on the water (by SABESP) and electricity (by Eletropaulo) bills and we are exempt from employer's contributions to INSS.

21) Human Resources

The NGO has 43 staff members and 12 members of the board, working as volunteers. In order to provide better services to its clients, the NGO qualified its collaborators. For that, it relied on the cooperation of countless volunteers and huge community support: the *Capacitação Solidária* NGO carried out, in the *Terra da Promessa* Unit, the *Caminhos da Serra – Ecoturismo e Monitoramento Ambiental* project – a course to thirty young individuals, in the same age group, of which sixteen were employed in the region labor market immediately after finishing the course; the *Faculdades Integradas Cantareira (FIC)* provide technical support, professional qualification and timely advisory services to the project on income generation at *Terra da Promessa*, named Hydroponics.

The institution does not have internal structure to hold trainings and, therefore, it hires individuals who used, for instance, to work in health services:

For example, a person who worked as nurse assistant in the Emilio Ribas is a good candidate to any eventual job opening, because this person is already skilled, to some extent. What we do along the professional life of these people is to encourage them to participate in upgrading activities. So, when Emilio Ribas promotes seminars, in the event of any extra-curricular activity related to any state body, we try to send our staff to participate. This is for those directly linked to the issue of AIDS, the nurse officials, nurses, etc.

The general services professionals – cooks, clerks – are recruited based on the curriculum analysis: “Some of our staff members have worked here since the NGO was founded. So, these are people that over time, regardless of their activities in the institution, are somehow qualified”.

22) Work Methodology

The NGO meets once a year to assess the teamwork and provide guidance to works. In terms of problems, they identify as specific issues of the experience with their target-audience: (i) lack of information of population, regardless of their social class; (ii) condescending attitude towards their sexual life, mainly among the youth; (iii) communication means failure in disseminating full information on preventive devices; and (iv) difficulty in adhering to the treatment. Nevertheless, the entity considers its role in the AIDS field as very important, since it promotes a different environment to homeless carriers.

It is an impact for the rest of their lives. A person who passes through ALIVI is changed forever. We show them, or try to show them, another reality of life. If the person accepts it or not, that is another thing. But we rest assure that this person now knows another reality of life. And it has surely changed this person forever. Even, for example, those who leave the institution because they can't live in community. These are people that don't accept and don't want the rules we have here. So, they return to the streets. But they never loose the link with what they got here.

The institution is also aware about the impact over the family members of the carriers assisted. The family members – father, mother, brothers, sisters, cousins – when they get acquainted with the NGO they change their attitudes, mainly those concerning their posture as regards the reactions of prejudice against the carriers and the disease. This impact can also be noticed in schools, in relation to children.

Most of these people, in a way or another, come to get acquainted with the institution. These people that live here, our audience, have surely lived with several relatives. So, the family members have some history about these people. So they come to the institution, become stable, start changing their attitudes. The relatives notice the difference. Suddenly they decide to visit, to know the institution, and discover that the person has really changed his posture. Another example is the school our children attend – it is a private school, where ALIVI pays a part (school costs, monthly tuition) and the other part is a partnership with the school, which granted a 50% scholarship. When we started doing it, on the first day of class, the news that there were children with AIDS attending class was quickly spread. And that is not true; most of our children don't have AIDS, although some of them do. The principal was scared – “oh, my god! I will loose the other students!” – and most parents wanted to transfer their children to other schools. There was a movement like: either they stay, or we stay. So, we went to the school and proposed a lecture, a meeting with parents to explain how the disease is transmitted. And now the school tells us: “look, we don't know what we would be without you”. The parents changed, the students changed. Now, the children live together, come and go, have friends in this school, are building a social nucleus out of the institution, are breaking the ghetto of the institution, because they are attending classes in a good school, and are establishing friendship with these people, with these students. So, we are changing the lives of many people.

23) Political Articulation

ALIVI is affiliated to São Paulo NGOs/AIDS Forum and, to implement its actions and activities, it holds partnerships with UNESCO, Private Cooperation Agencies, NGOs/Mixed, other NGOs/AIDS and Programs or Secretariats of the Ministry of Health.

Although the institution reported in another tools of this Research (structured questionnaire) its participation in the discussion on governmental policies and programs against AIDS, the respondent said that such participation never happened. On the opposite, local

managers have never consulted the NGO about these policies: “We were never heard (. . .) there isn’t room for the suggestion on public policies. We could be called to cooperate, give opinion, but we aren’t”.

The entity participates in the Municipal and State Health Council, the Advisory Committee to the National STD and AIDS Programme, and the Inter – managers Council. They have attended the ERONG (2001) and the ENONG (1999 and 2001).

24) Organization Sustainability in Mid and Long Terms

According to the NGO, most institutions working specifically on HIV/AIDS have grounded their sustainability perspectives on resources from financial agreements signed with the National STD and AIDS Programme (AIDS I and AIDS II). However, they emphasize that agreements like this, from agreements established with Multilateral Financial Institutions – here, the World Bank – have fixed time to implement programs, and these cannot become the resources responsible for the continuity of actions. In this regard, ALIVI calls attention to the dispersion concerning the debate on strategies to sustain the work developed by civil society organizations, both in prevention and assistance. Currently, upon the end of AIDS II agreement and the expected changes on AIDS III, there is a great gap in the discussion on quality, or even on the continuity of these works, because of the decentralization of resources and the establishment of different kinds of relationship within the scope of the Brazilian Unified Health System – SUS. These changes have not yet been duly understood by the government or by civil society, and bring concerns in relation to the performance of the Brazilian responses to the epidemic. Furthermore – the NGOs adds – the decentralization of AIDS-related actions to SUS and the fund-to-fund policy not necessarily have impact on NGOs sustainability.

I mean, they had too much time to think it over, they sit over AIDS II, thinking it would be endless, and discovered that it is not so. Now, since AIDS II finished, everybody is pursuing some sort of sustainability. So, the word now is sustainability. I believe that many NGOs shall disappear when AIDS II ends. The Ministry gave a chance in 2003, so they would have something remaining from AIDS II. We shall

receive something by the end of this year to sustain the programs we have for a while, but this will come to an end. So, everybody is thinking about this program of fund-to-fund resources. I didn't understand this fund-to-fund, because I don't know how transfers will be done. First, let everything happen, because neither the government, nor the state, organizations, state agencies know exactly how things will be done. They are still discussing among them, and then they will call the NGOs and say: Your share is this – if there is any share to NGOs. I am very sorry, because it is really a pity to talk about zero hunger in Brazil – the first thing that the state should do is to call the existing organizations and say: 'you are our number one partners; you are already in the front line'.

According to the NGO, the partnership with state is unilateral: "theirs when they need us, but when we need them, we are never attended". Only the CRTA provides assistance when we need disposable material, some extra medication of general use, for example, an aspirin, first aid articles, for dressing: "Except for that, the State doesn't give us anything. They never sought us to assist in maintaining vacancies, current expenses, expenses with meals, clothes, apportionment".

Some projects are under implementation, aiming at increasing the institution's sustainability resources, using a mix of opportunities to gather resources. For example, the implementation of a bakery that, at the same time provides job and income to people, and simultaneously promotes a sort of training in the professions of bakers, confectioners, baker's assistant and confectioner's assistant. The net revenue of this initiative will be employed to assist the institution.

Similarly, there are activities on hydroponics, i. e. , the cultivation of vegetables employing the hydroponics method, in water, at specially assembled banks. This project is supported with UNESCO resources, and training to involved personnel is delivered in partnership with the *Faculdade Cantareira*. Profits and revenues are reverted, partially to the residents' income generation, partially to the institution.

The NGO ALIVI also develops, in partnership with Stern der Hoffnung – Germany and Switzerland – a project on the implementation of production and bottling of mineral water from a water mine in the property.

In fact, we have prospected the source and it was classified as mineral water. So, we are assembling a small plant and shall bottle this water and trade it in market, as any other company in this industry. And the net operational revenue will also be reverted to the institution.

25) Interlocution with Governmental Spheres, in the Field of AIDS Epidemic

Among positive impacts, the NGO highlights that the governmental financing led NGOs to become more professional, investing in project formulation and rendering of accounts. On the other hand, as negative impact, they point out the dependence of several NGOs on the National Programme support.

Concerning the success of the Brazilian actions, the NGO ALIVI highlights, first of all, the universalization of antiretroviral drugs, upon pressure of the civil society. The second outstanding fact is the partnership established between the National STD and AIDS Programme and the NGOs, through AIDS II.

As negative impacts, the NGO mentions that the only institutions financed are those that have already received foreign support. However, as positive impact it mentions the social return to the NGO activities.

Financing is the state's major duty, because it is my money returning to me, it is the money I pay as taxes returning to me, when we see the society organized, filling in a gap that the state didn't. Or that I am in a partnership with the state to improve my quality of life... So, there is no problem, and it will not make me loose my political independence.

According to them, for lack of political maturity sometimes when people are to sign an agreement, they do not notice that it is an agreement, a technical cooperation between two parties: The government and the organized civil society. They cannot loose their political identity; neither must cease their political criticism because they receive financial support, because they have a project financed by the National Coordination. It is quite the opposite, they say.

The NGO considers it as a partnership that worked well and, therefore, should remain among the Brazilian responses to the epidemic. The governmental institutions should know the NGOs

better, besides developing proposal-based initiatives in the field of baseline actions. The NGO acknowledges the merits due to the Municipal STD and AIDS Coordination, which restructured the Regional Service Centers. However, the governmental institutions forget that the NGOs have their own views, their ideology.

The organization develops projects in the field of human rights, in partnership with UNESCO. It develops a project on free legal services to people with AIDS, in several fields – civil, criminal, labor – with resources of AIDS II.

According to them, there is no damage to autonomy, because each NGO has the ability of proposing activities to better fight the epidemic, the National STD and AIDS Coordination does not impose any action or guideline.

ALIVI received about fifteen timely supports by AIDS I and II, and no one has ever decided what we should do. They just want us to inform where we intend to apply the resource and, at the end of the project, they want us to render accounts through bureaucratic reports, proving the expenses. Thus, this is not losing autonomy; it is to be disciplined in what you have proposed. Ultimately, no one obliged you to propose that. This is not losing autonomy; rather, I had huge autonomy to propose things and they accepted. What would be a loss of autonomy, as some leaders say, would be to seek for the institution and they oblige you to do something you don't want to do. This doesn't exist, it never happened. The Ministry, in this aspect, is very democratic.

E. 3. APTA – Associação de Prevenção e Tratamento da AIDS

- 1) Organization Name: APTA – Associação de Prevenção e Tratamento da AIDS.**
- 2) City/State: São Paulo.**
- 3) Date of Foundation: 21/12/1992.**

4) Started Working with STD/AIDS in:

Since 21/12/1992, that was the motto for establishing the NGO.

5) Kind of Organization: NGO

6) Address/Phone:

Phone: (11) 3266-33-45

E-mail: aptasp@ig. com. br

7) Situation Concerning Headquarters

Rented. The NGO aims to purchase a room and is saving for that.

8) Where it Performs the Activities: rooms rented in the community.

9) Field of Action

Prevention and treatment of STD/HIV/AIDS and Movement of Children and Adolescents.

10) Priority Field of Action

Prevention in HIV/AIDS;

Preventive programs at schools.

11) Geographic Area of Work: National.

12) General Purpose

Reduce vulnerability to HIV and AIDS;

Advocacy for basic rights.

13) Target-audience

Children and adolescents; parents and family members of HIV carrier children; female sex professionals and travesties *in the end of the line*, population in general.

14) Core Activities

- Self-help support group – family members and parents of HIV carrier children;
- Preventive education, assisting the schools in implementing program.

15) Ongoing Programs and Projects

Partnership with *Hospital Emilio Ribas* and the *Instituto da Criança*. Partnership with the Education Secretariat: APTA Teen – adolescents who discuss the actions; preventive works, in the shape of counseling sex professionals and travesties – the NGO plans to develop a program on complementary income generation to this population; and prevention among women (mothers and adolescent daughters).

16) Services Provided to Population

Support group to parents and relatives of seropositive children and adolescents;
Psychological and counseling services;
Courses and training to teachers and school networks;
Counseling, prevention and preparation for the anti-HIV test.

17) Works only with AIDS: No.

18) Advertises the Work Developed Through:

Books, videos, congresses, and conferences.

NGO Background

19) Origin of the institution

Health and education professionals, all public civil servants, who used to work in the field of HIV/AIDS, concerned about prevention and other models of work in this field, such as research. These professionals gathered and founded the Institution, which became specialized in the field of research and education, mainly on the issue of preventive programs at schools.

20) Resources and Financing Sources

Timely sponsorships, such as events (EDUCAIDS), publications. Donations made by individuals, agreements with public bodies.

As resources intake strategy, the NGO employs projects. Furthermore, each professional involved in the implementation of any project approved through APTA, donates ten percent of his or her fees to the institution. Additionally, there are some agreements and timely sponsorships (UNICEF, Family Health Programme in Imbu, for example). There are no agreements with the international cooperation.

21) Human Resources

The strategy for recruiting human resources is based on curriculum selection. After the selection, the potential volunteers come to the institution for an interview (the Reception Day). The volunteers that decide to work on some activity carried out by APTA should undergo training.

22) Work Methodology

The NGO makes annual planning to outline the potential projects to be implemented, besides discussing the financing to each of them.

Concerning assessments, APTA holds bi-monthly meetings to discuss aspects related to the NGO performance, particularly projects

implementation. Sometimes, they call experts to assess specific projects.

To the organization, planning is a continuous process, since it always assesses its activities, readjusting priorities and goals, according to the reality of the moment each project is experiencing. At the end of each year, they perform a general balance, checking positive and negative aspects of the experience.

The NGO is seeking for innovative initiatives. When the survey was performed, the Institution was developing the APTA Teen project, focused on young leaderships.

23) Political Articulation

At the local level, it is affiliated to the NGOs/AIDS Forum. At the national level, it is member to the Networks of People Involved with AIDS and Seropositive Women, besides being member to the ABONG.

At the regional level, the entity intends to become affiliated to LACCASO – Latin American and the Caribbean Council on NGOs/AIDS, and at the international level, it participates in a network established in Berlin, for people and NGOs working on preventive education.

The NGO usually attends the Regional and National Meetings of NGOs/AIDS.

24) Partnerships

To develop its actions, APTA's major partners are, effectively, the State and Municipal STD and AIDS Coordination, the Health, Education and Human Rights Secretariats, Program Coordination, Government Prosecutors Office, NGOs/AIDS, NGO/mixed, Private Institutions and other social movements.

Furthermore, it holds partnerships based on exchange of services, such as training to staff members of a given business, in exchange for reduced prices. "For example, we will hold the EDUCAIDS at Hotel Intercontinental, so we offer training to staff members and the hotel, as counterpart, grants us 50% of discount over regular fees. So, we exchange a lot of work for things we need".

25) Incidence on Social Programs and Public Policies

It participates in the formulation of governmental public policies on access to early diagnosis, medication, treatment, preventive devices, NGO capacity building in Human Rights and citizenship, as well as on the provision of HIV tests during pre-natal care. It is part of the Health Councils, the Advisory Committee to the National STD and AIDS Programme and the Inter-managers Councils. It represented the movement of fight against AIDS in UNAIDS Theme Group, for four years.

26) Organization Sustainability, in Mid and Long Terms

The issue of political and financial sustainability has concerned the NGO for some years. Therefore, it holds a great event every year, the EDUCAIDS, and converts the registration fees into resources to sustain the entity. “The issue of sustainability is linked to the consciousness about public policies, rights, citizenship. I think that many people imagine that sustainability means money: How much will I have. This is a mistake”.

According to the institution, some factors that threaten the sustainability of both NGOs and the movement against AIDS are: Loss of many leaders; few NGOs develop works on qualification of their staff; difficulty in finding professionals with time and availability to work; the lack of understanding about the analysis on context, identity, differentiation between the state’s and the civil society’s role, difficulty in financing projects, and the vulgarization of AIDS and violence.

As strong points, the NGO identifies the fact of existing people who worked in social movements and now are formulating official public policies, besides the universalization of medication distribution in Brazil.

27) Interlocution with Governmental Spheres, in the Field of AIDS Epidemic

According to APTA, Brazilian actions on the fight against AIDS are successful because of the universalization of distribution of

medication, additionally to the civil society initiative supported by the government and international agencies. The EDUCAID events are also mentioned, because they cooperate towards providing visibility to AIDS-related actions, due to media coverage.

The NGO also believes that roles are now extremely mistaken. Nevertheless, the movement has enough political maturity so as to allow for the joint work by the government and civil society in outlining public policies.

Concerning the relationship between civil society and governmental spheres on the fight for citizenship and human rights, the NGO believes there is a true relationship of partnership. It also claims that NGOs/AIDS should hold seat in the ministerial groups of work on the fight against exploitation of children.

According to them, the NGOs/Aids' loss of autonomy due to the National STD and AIDS Programme financing to political actions is relative, as follows:

I think that those who loose autonomy in fact never had it. An entity that looses autonomy because it is financed, in fact never had autonomy, because it doesn't know what it is, what it is doing.

It is important to have a north, an institutional mission to understand how the financing may contribute towards achieving the institutional goals, instead of inverting this relationship.

E.4. PELA VIDDA – Pela Valorização Integração e Dignidade do Doente de AIDS

- 1) Organization Name: GRUPO PELA VIDDA – Pela Valorização Integração e Dignidade do Doente de AIDS.**
- 2) City/State: São Paulo.**
- 3) Date of Foundation: August 1989.**

4) Started Working with STD/AIDS in: 1989.

5) Kind of Organization

It is a non-governmental organization, a private institution with public purposes, non-profit, performing volunteer actions, basically in the field of solidarity. Organization of services provision, advocacy and prevention.

6) Address/Phone:

gpvsp@uol. com. br

Phone: (11) 3656-45-01

7) Situation Concerning Headquarters: Own.

8) Where it Performs the Activities: At headquarters.

9) Field of Action: Sex professionals and gay movement.

10) Priority Field of Action

Prevention against STD/HIV/AIDS; assistance to HIV carriers and/or people living with AIDS; Human Rights; Male Sex Professionals; Activism and Communication.

11) Geographic Area of Work: National and municipal.

12) General Purposes

- Fight marginalization, clandestinity and solitude faced by seropositive individuals. Fight against discriminations, advocating for their civil rights, whenever applicable.
- Critically follow-up initiatives in public and private health concerning the fight against AIDS epidemic.

- Promote information and prevention against infection by the virus, placing attention on the infected people's need for information.
- Build open spaces to people living or co-existing with AIDS, where they may exchange experiences.
- Always encourage the full social integration of HIV carriers, diseased or not, and advocate for their full citizenship.
- Make the discussion on AIDS more accessible, converting it into a tool for activism and challenge, through the advocacy for HIV carriers' rights; production of information (publications and Internet); prevention oriented to vulnerable populations and political activism.

13) Target-audience

Seropositive individuals and family members; male homosexuals; sex professionals and population in general.

14) Core Activities

- 'Chá positivo'– sociability meetings;
- Project on prevention oriented to homosexuals;
- 'Mil estrelas' – work on professional qualification to travesties;
- Distribution of informative material;
- Distribution of preservatives to the projects' target-audience;
- Legal assistance;
- Sociability and self-help groups, oriented to seropositive individuals, their friends, family members, partners.

15) Ongoing Programs and Projects

- Project *GAYS*
- Project Profissionais da Noite do Sexo Masculino e Travestis, oriented to male night professionals and travesties;

- Project Chá Positivo;
- Project Assistência Jurídica, oriented to provide legal assistance;
- Project Home Page.

16) Works only with AIDS: Yes.

17) Advertises the Work Developed Through:

- Pela Vidda booklets;
- Informative materials distributed in projects;
- Journals, publications.

NGO Background

18) Origin of the Institution

Pela Vida emerged in 1989 in Rio de Janeiro. It was founded by Herbert Daniel, with the participation of Betinho and many other people. Some months later, the São Paulo nucleus was founded. Initially, the Grupo Pela Vidda/São Paulo relied on the cooperation of Jorge Beloque, Jacks, Buchara, jointly with Pedro de Souza, Julio Gaspar – two journalists – and other persons. In the beginning, the organization worked in a space in the GAPA. The group aims at advocating for the individual's civil rights, political activism, provide visibility to the rights of people living with HIV/AIDS. The NGO is dedicated to provide visibility to information, translating medical and technical information into a more accessible language, converting it into an additional tool to the challenging activism. They are also engaged in prevention among homosexuals, sex professionals, whores and travesties; prevention and service provision to people living with HIV/AIDS; and, moreover,

in the issue of sociability and self – help. Here, sociability is not addressed exclusively to seropositive individuals, but also to their friends, family members, and partners.

19) Organization's Motivation Towards Working with STD/AIDS

The issue of advocacy of HIV/AIDS carriers' rights.

20) Resources and Financing Sources

The resources of Grupo PELA VIDDA are granted by individuals' donations, timely sponsorships and agreements with public institutions. It relies on formal financing by UNESCO and UNODC, through the National STD and AIDS Programme, additionally to Private International Cooperation Agencies, as the Ford Foundation.

Many times the group could not rely on governmental financing, sometimes for their own difficulties, sometimes because financing was not available, or even because they decided to waive the government financing to their activities.

Sometimes, they needed financing to carry out activities in a more organized way, to issue publications, to perform broader project on prevention among homosexuals. So they established partnership with ABIA and PELA VIDDA/Rio de Janeiro, under the sponsorship of Ford Foundation.

The NGO does not cease its activities because of the lack of resources. In moments like that, it employs the strategy of building awareness among its members, and apportions the expenses among them. Furthermore, it promotes parties, lunches, to sustain the activities and its headquarters.

21) Human Resources

The Grupo PELA VIDDA in São Paulo decided for the non-professionalizing of the NGO.

We have already had a PELA VIDDA with more intellectualized, academic staff, people with university degree. It was gradually changed. Now, I think the profile trends more to people with leadership capacity, which

can gather volunteers or agents, then to people with qualification to execute something. I would say that, now, the staff is more duty-based, is made up by more operational leaderships. They want to put things in place and the projects on the streets, with quality.

22) Work Methodology

The Grupo PELA VIDDA/SP does not have human resources to assess the implemented actions. The NGO lacks activists and volunteers more skilled in dealing with projects and public in general.

We urge for assessment on what is done, of knowing. You spend ten years doing and don't have, don't have it exactly, do you understand? Then comes about the issue of the need for university staff and personnel, or people with some notion on follow-up and assessment. I think we don't have responses now to know.

23) Political Articulation

The Grupo PELA VIDDA/SP participates in the following forums: NGOs/AIDS, MSM and on Pathologies and Deficiencies. At national level, it is affiliated to ABONG.

24) Partnerships

Major political partnerships are established with the State STD and AIDS Coordination, the Municipal STD and AIDS Coordination, Government Prosecutors Office, NGOs/AIDS and other social movements.

25) Incidence on Social Programs and Public Policies

The NGO participated in the outlining of governmental public policies concerning access to early diagnosis, medications, treatment, preventive devices, NGO capacity building, human resources/citizenship and supply of HIV tests during pre-natal care.

It is member to the National Health Council and frequently attends the ERONG and ENONG, since its foundation.

26) The Organization Sustainability, in Medium and Long Terms

According to the group, the financial sustainability takes place through governmental financing based on public bidding, the sale of products and services executed by professional NGOs, besides the support of foreign financing entities. “I advocate for sustainability with public resources, even because it is legitimate and feasible”.

The group identified difficulties related to the increased activities and political demands; lack of resources available. Furthermore, there is the issue of losing the movement leadership staff. On the other hand, in the field of strong points, it emphasizes the movement organization and the activism power:

Many activist have already passed away or are working in government, in international organizations, or left the movement in rates much lower than those for people becoming activists.

The movement is more organized and, sometimes, everybody stop their consultative or executive agendas to work on activism and claim. And ENONG and ERONG provide the space for that.

27) Interlocution with Governmental Spheres, in the Field of AIDS Epidemic

The Grupo PELA VIDDA/SP initially highlights the positive impacts of the National STD and AIDS Programme financing. In this sense, it emphasizes the issue of sustainability to NGOs involved in fighting the HIV/AIDS epidemic in technical and political terms. “The group would survive, but without the projects they would not have the quality and scope they have nowadays; sustainability depends on public money, which also belongs to society, and that is very well employed”.

In the field of negative impacts, the NGO highlights the dependence on the State financing, which interferes on the executive and consultative agenda, thus jeopardizing the actions on social control and political activism.

Within the context of the relationship between government and organized civil society, established in response to the

epidemic, the group states that works in the field of AIDS should be supported by public financing, rather than by the World Bank or private initiatives.

According to them, the Brazilian Unified Health System – SUS is the major financing agent, and sustainability undergoes a political discussion that would result in greater allocation to civil activity, since the NGOs perform social control. Therefore, it argues that AIDS model could fit into other fights for the effectiveness of the Brazilian Unified Health System. The PELA VIDDA/SP made two criticisms to the government, in terms of establishment of that relationship. One concerns the lack efficient assessments, whether on implemented actions or on the employment of committed resources. The other concerns how these relationships have happened, since the National Programme uses to hinder the dialogue among different spheres, mainly if a NGO criticizes or challenges it with more emphasis: “most of the time, the partnership is crucial to develop; nevertheless, it lacks clear assignment of roles and the understanding about the other’s right to think, to complain”.

The NGO also adds that the relationship between organized civil society and governmental instances in the fight for citizenship and human rights depends on balancing the four agendas:

1) Consultative agenda: “the relationship between the movement and official programs and Executive Power, concerning policies on AIDS”; 2) the projects executive agenda, which also implies in the relationship between the NGO and the Public Power, and “ranges from public bidding to the project elaboration, submission and execution, including rendering of accounts to assessment”; 3) the social control agenda, comprising health policies, SUS and demands, the claim for social control spaces in AIDS-oriented policies; 4) the political activism agenda, which is gradually changing from proposal-based to a consultative or executive agenda, what “could let people imagine that AIDS is under control, and make it an ordinary stuff”.

E. 5. GTPOS – Grupo de Trabalho e Pesquisa em Orientação Sexual

- 1) Organization Name: GTPOS – Grupo de Trabalho e Pesquisa em Orientação Sexual**
- 2) City/State:** City of São Paulo/SP.
- 3) Date of Foundation:** Officially in 1989, but it started its activities in 1987.
- 4) Started Working with STD/AIDS in:** 1992.
- 5) Kind of Organization:** Association.
- 6) Address/Phone:**
E-mail: gtpos@that.com.br
Phone: (11) 3842-21-74
- 7) Situation Concerning Headquarters**
Rented. They pay the rental with proceedings from financed projects.
- 8) Where it Performs the Activities**
In the NGO headquarters, besides delivering lectures at schools, communities and municipal health units.
- 9) Field of Action**
Movement of Health Professionals and Education Professionals.
- 10) Priority Field of Action**
Movement of Children and Adolescents;
Prevention against STD/HIV/AIDS in the field of sexuality.

11) Geographic Area of Work: National.

12) General Purposes

Qualify professionals of education in sexuality to work with children and adolescents.

Contribute to the construction and implementation of critical and innovative actions concerning sexuality, in the fields of education, health and community, aiming at the individuals' welfare;

Contribute towards the implementation of public policies oriented to adolescents and the youth, with emphasis on the guarantee of their sexual and reproductive rights.

13) Target-audience

Health and education professionals; children and adolescents (5-18 years old)

14) Core Activities

- Courses and capacity building to education and health professionals, in projects in the field of sexuality;
- Workshops and capacity building to educators and adolescents as multipliers to actions in prevention against STD/AIDS;
- Elaboration and publication of educational materials;
- Assistance to institutions, corporations and media professionals.

15) Ongoing Programs and Projects

GTPOS first project concerned the implementation of sexual orientation in São Paulo municipal network, financed by MacArthur Foundation, under the leadership of Paulo Freire, Education Secretary – Luiza Erundina government.

Project in cooperation with three NGOs, aimed at preparing a guide that, by that time, advocated for the rights of children and adolescents to information on sexuality. This guide became a reference on sexuality to the 15-18 age group.

It has also developed project on prevention at the Heliópolis slum, financed by Petróleo Ipiranga: *What took us there was the vulnerability of poor adolescents to AIDS.*

They are now starting a new project with São Paulo Municipal Government, addressed to qualify all teachers of municipal elementary and basic schools in sexuality.

16) Services Provided to Population

Lectures, courses, workshops, assistance and enforcement on the implementation of actions and/or projects about sexuality and prevention against STD/AIDS, through financed projects and services provision.

Free distribution and sale of educational materials produced by the institution.

17) Works only with AIDS: No.

18) Advertises the Work Developed Through:

They have developed a *book* where they disclose the *scope of their work*

Magazines; books; journals; printed material; newsletters; Conferences; meetings; seminars.

NGO Background

19) Origin of the Institution

It was established through the association of psychologists, pedagogues and psychoanalysts interested in studying the

sexuality issue. It places priority on qualifying education professionals in sexuality, to allow them to work with children and adolescents.

20) Organization's Motivation Towards Working with STD/ AIDS

From 1989 to 1992 it worked on the project oriented to implement sexual orientation in São Paulo municipal network, qualifying 1,100 educators and reaching 16,000 adolescents and many children attending pre-school.

The project also approached the issue of AIDS, but in a secondary plan. As AIDS becomes more visible, the GTPOS also decided to invest on the links with the debate on sexuality and AIDS, expanding its team aiming at capacity building in this field. Then, it started developing projects on prevention: *the relationship between AIDS and sexuality was clear, the sexual transmission and the importance of public health intervention, i. e. , whoever worked with sexuality could not avoid engaging into the fight.*

21) Resources and Financing Sources

It relies on diversified sources of financial resources, as follows: International Cooperation Agencies (MacArthur Foundation, Merc Foundation); corporate actions (Ipiranga, Levis); agreements with public entities (Municipal Local Government); and timely sponsorships. Basically, resource intake is through financing projects. It also makes efforts towards raising resources with companies interested in getting committed to the NGO field of action.

22) Human Resources

In its early stages, the team was made up of people working in the field of studies on sexuality. As the group grew, they started selecting individuals interested in working at the Institution, and the older members provided training to them. Currently, many individuals apply to work in GTPOS, but the organization lacks

favorable routine conditions that allow for expanding the team, since the interested candidates are not available to undergo, at this moment, the capacity building required to work with the NGO.

23) Work Methodology

It employs participatory technicians, based on the tripod body – gender – prevention. In the scope of activities to follow – up and assess the actions developed, GTPOS employs external consultancy services.

The entity believes that the methodological orientation employed provides opportunity to bring about topics other than the priority ones, i. e., body – gender – prevention. Usually, the topics arising from these discussions are not under the NGO competence, because they are very specific.

The methodology places priority on holding workshops and courses, and employs the experience of the community and professionals to disseminate information on the Institution. It stresses the emphasis on the role played by gender stereotypes in the construction of vulnerability. The discussion arising in the workshops and courses allow to think over the sexuality exercise.

24) Political Articulation

It is represented in the local NGOs/AIDS Forum. It is part of the Latin American Consortium on Emergency Contraception, and is member to ABONG.

25) Partnerships

The NGO says it does not have militant profile, despite its contribution to the setting of national parameters in sexual orientation.

It holds partnerships with the State STD and AIDS Coordination; Municipal Health Secretariats; Municipal Education Secretariat; Program Coordination; Ministry of Justice; NGOs/AIDS; NGOs/mixed; Private Institutions; other Programs and/or Secretariats of the Ministry of Health.

26) Incidence on Social Programs and Public Policies

It participated in the elaboration of public policies on NGO capacity building.

27) Organization Sustainability, in Mid and Long Terms

Since its foundation, it has been supported by the MacArthur Foundation. However, since the Foundation left Brazil, the entity is facing a huge challenge, considered substantial. It is also supported by private institutions, such as Ipiranga and Lewis, in addition to the agreement signed with the Municipal Government. It is very concerned about the decentralization of resources allotted to NGOs by the National STD and AIDS Programme.

As far as we are concerned, decentralization has not been installed yet. The NGOs need the partnership with the State, and the State needs the partnership with NGOs. The NGOs have agility, plasticity, flexibility, and the State somehow restrains it. I fear it will come to be diluted.

28) Interlocution with Governmental Spheres, in the Field of the AIDS Epidemic

In the field of implications of financing allotted to STD/AIDS over the institution agenda priorities, the GTPOS claims to have participated in all the National STD and AIDS Programme bidding processes. However, it highlights that “Resources are always short; there is no counterpart to the institution. Well, we work with scarce resources from agreements with the State”. On the other hand, they think it is an opportunity to develop relevant projects in this field.

As successful experiences in the Brazilian action, the NGO points out the dialogue and partnership between NGOs and the government. They also mentioned, as a factor of success to the program, the creativity, the courage and the responsibility by both participants, since they undertook the required actions, epidemiologically justified, trying to place emphasis on most vulnerable populations.

In the field of relationships between civil society and the government spheres, in the scope of responses to the epidemic, the NGO considers that they succeeded in effectively establishing a high-quality partnership with the National STD and AIDS Programme, internationally acknowledged. At state and municipal sphere, the NGO believes that this partnership was not so visible:

We seldom see governments making policies consequent and committed to the state-of-the-arts actions; I think this is a merit of the AIDS policies at the federal and state levels. At the municipal level, I wouldn't know what to say about the current leadership.

The NGO points out a challenge concerning the decentralization of resources to states and municipalities, which threatens the sustainability of any NGOs, not only NGOs/AIDS:

I think that the NGOs still need the State partnership in the issue of the proposed decentralization. I don't know what will happen to decentralization, with the reduction of resources, income, and the issue of self-sustainability to NGOs. I think that we have performed a nice work in the last few years. It seems to me that decentralization is being hard for everybody: How will they articulate municipality, government and federation? I think it is not related to the field of AIDS; it's a matter of how a new thing is done.

Concerning the relationship between civil society and governmental spheres in the advocacy for citizenship and human rights, the NGO emphasizes the curious proliferation of institutions, partnerships, projects and initiatives in this sense: "Against violence, in defense of special needs holders". However, it makes an exemption to those actions *that are just talks* in several fields, which do not necessarily convert initiatives into practical changes. According to them, government financing is not translated into limitation to the NGOs.

E. 6. GAPA/SP – Grupo de Apoio à Prevenção à AIDS

- 1) Organization Name: GAPA – Grupo de Apoio à Prevenção à AIDS de São Paulo**
- 2) City/State:** São Paulo/SP.
- 3) Date of Foundation:** 27/04/1985.
- 4) Started Working with STD/AIDS in:** 1985.
- 5) Kind of Organization:** Association.
- 6) Address/Phone:**
Phone: (11) 333-5454
gapabrsp@vento. com. br
- 7) Situation Concerning Headquarters**
The premises are assigned, in partnership with the *Ação e Cidadania*. They are located in the State Health Secretariat facilities.
- 8) Field of Action**
Prevention against STD and AIDS; assistance to HIV/AIDS carriers and Human Rights.
- 9) Priority Field of Action:** HIV/AIDS.
- 10) Geographic Area of Work:** national, state, regional and municipal.

11) General Purposes

- Education, information and prevention against STD/AIDS;
- Contribute towards establishing public health policies in HIV/AIDS;
- Social assistance and grant of human rights in HIV/AIDS; and
- Social service and legal orientation.

12) Target-audience

HIV/AIDS carriers and their family members, sex professionals, men working in civil construction work, and the population in general.

13) Core Activities

Social assistance (daily) upon booking; legal guidance; works with sex professionals (women); food assistance (monthly donations to participating families).

In the field of assistance, the Target-audience is people living with HIV/AIDS. The Social Service works providing all sorts of information, counseling and referral. The Legal Department provides services to people seeking legal counseling / assistance because of discrimination or lack of medication. Concerning prevention, we have a specific work with sex professionals, with civil construction workers and the population in general, through lectures and workshops, where we establish partnerships with schools and businesses.

14) Services Provided to Population

Social service; lectures; workshops; home visits; legal and psychological assistance; food assistance, donated to the NGO and distributed monthly to participating families, during home visits.

Department of Archives and Documentation, open daily to the public, mainly to high school students, for their works, consultations and researches.

15) Works only with AIDS: Yes.

16) Advertises the Work Developed Through:

Magazines, books, journals, videos, printed material;

Lectures, workshops;

Articulation in forums

They prepare documents, participate in seminars, congresses, conferences, meeting with GAPA Network, since it brings more visibility and political power.

NGO Background

17) Origin of the Institution

Through the action of people from civil society, health field, autonomous professionals and people who work with and for other social movements (gay movement and health unions).

18) Organization's Motivation Towards Working with STD/ AIDS

Lack of public policies in the field of AIDS, lack of information on AIDS and assistance to HIV/AIDS carriers, at the time.

19) Resources and Financing Sources

Their sources of resources are the international cooperation agencies, agreements with public entities, timely sponsorships, individual and corporate donations. The NGO stresses that their first financial supports were through agreements signed. Later, they relied on international foundations and partnerships with national

secretariats and the national, state and municipal coordination. According to them, timely partnerships basically promote the events they hold.

Over the years, the organization has tried several strategies for resource intake. Some were successful, but most of them failed. One of these strategies is the establishment of partnerships with institutions, whether private or not.

We are trying to find an efficient way, but we have not succeeded yet. We have established timely partnerships, which have presented good results. That is where we obtain the resources to maintain the institution for two or three months, and then we make another timely partnership. Since our expenses are low, because we don't pay rent, condominium fees, and have only one staff member hired, the partnerships are enough for covering our expenditures. Concerning printed material that are not paid for by projects, but mainly by governmental and financing agencies – we establish private partnerships. Since a short time ago, part of prevention and printed materials has been afforded through timely partnerships as those with SENAI, SESC and other institutions that are sensitive to the cause.

Another strategy is to hold itinerant bazaars and sewing workshops under the responsibility of the institution's volunteers, who are not members to the board of directors. Furthermore, the Institution has non-financed projects, which are self-sustainable.

20) Human Resources

It provides specific training to all volunteers. The team makes adjustments to this training every year. There is also a course on replication in prevention against STD/AIDS, required to any new volunteer to the institution. According to the entity, professional qualification is provided through participation in seminars.

21) Work Methodology

According to information provided by GAPA/SP, the Social Service has a 3-month planning, where they decide the activities (meetings, workshops) and services (home visitations). They also hold workshops for sex professionals. They hold fortnight meetings,

where they plan and guide the discussions. They are endowed with a systematic annual assessment process, during a strategic meeting where they assess the actions developed along the year.

GAPA/SP believes that many people and institutions still think that only homosexuals, drug users, and sex professionals make up the populations of high vulnerability, and don't place attention on the general population. The housewife, the adolescent, and the worker also belong to high vulnerability groups.

I think that vulnerability is anything we don't know and don't domain. To me, a worker or autonomous professional, with their heterosexual lives and who remain apart from the discussion on STD/HIV/AIDS, have not incorporated this discussion into their daily lives, know things only superficially, because they heard something in the media, TV, carnival, or see a poster during Carnival or on 1st December – to me, these guys are highly vulnerable, because they are not sensitive to this issue. We become susceptible to any external action.

In the legal field, they observed that NGO users have been discriminated in their works and have become desperate and insecure as concerns their survival.

According to the institution, the major challenge towards reducing risks among the beneficiary population is to empower them in relation to the lack of information and the need for claiming for better health services and assistance. Workshops and focal groups are the strategy adopted to have this population challenging and overcoming difficulties.

According to GAPA/SP, the innovative aspect in the actions they develop is the promotion of discussion on public policies, through partnerships with other social movements (women's movement, black population, homosexuals, state and federal health councils).

There are other players and partners. That is why we have tried to increase the visibility of all these things and the institution visibility as well. It happened with the social movement and movements working on AIDS. We have a state forum (the first forum in Brazil). We have state and national meetings. They have great impact.

I think it doesn't have the impact we expected. Now we live in a context where you have other priorities in the country, additionally to AIDS. You have the Zero Hunger Program; you have domestic and police violence. Now, it depends on the movement to insert this priority (AIDS) into the agenda with other organizations. The movement exists for this – to avoid that people forget about AIDS. You have AIDS in every segment, in public security, in prisons. I think that the organized social movement should moderate the AIDS issue, should run jointly with this segment to avoid oblivion, and that is why the partnerships with other segments are so important.

22) Partnerships

It is affiliated to the Mercosur Forum and the Laccaso, at international level. This brings international visibility not only to GAPPA, but also to the movement in general. At the national level, they are members of ABONG.

GAPPA/SP integrates São Paulo NGOs/AIDS Forum. It established partnerships with the State STD/AIDS Coordination; Municipal STD/AIDS Coordination; Health Secretariats; Education Secretariats; Human Rights Secretariat; Ministry of Justice; Government Prosecutors Office; NGOs/AIDS; NGOs/mixed; Private Institutions; and other segments of social movements.

23) Incidence on Social Policies and Public Policies

The NGO participated in the elaboration of public governmental policies concerning the free access to medication, treatment, preventive devices and human rights and citizenship.

In the field of implementation of public policies and governmental actions on the fight against HIV/AIDS, they participated in the assessment of AIDS I and II.

At the municipal level, they are inserted in the newly established Municipal AIDS Commission (established at the end of 2003) – pursuant to the decision made in the latest Municipal Health Conference. Within the Municipal Health Council, which works jointly with the municipal health program, they succeed in setting the agenda for the Municipal AIDS Commission discussion. It was a recent victory and GAPPA/SP effectively participated in it. At the state level, it has actively participated in

the building of a policy on medications, mainly state-of-the-arts medications, which are not available through the public network. They also participate in the STD/AIDS Forum and the State Pathology Forum. At the national level, GAPA/RS represents it at the National Health Council. GAPA/RS represents not only the GAPA Network, but also the whole AIDS movement and other advisory committees. GAPA/SP holds seat in the Legal Committee and Advisory Committee to Female Sex Professionals.

24) Organization Sustainability, in Mid and Long Terms

Some of GAPA/SP's departments are oriented to the institution sustainability, and the NGO participates in exhibitions and bazaars.

Daily sustainability in administration comes from events, participation in exhibitions, parties and donation campaigns. Individuals and corporations make these donations. Usually, the government itself grants them. This year, we are working with a donation made by the Federal Revenues. With these resources, not in cash but in apprehended merchandises, we could grant the institution sustainability until the end of the year. Furthermore, we participate in events and grant our daily sustainability concerning payment of telephone and electricity bills, condominium fee, office material, and all these things.

In fact, our sustainability is not as we expected it to be. There is no annual estimate on collection. We may say that we have tried to establish ways and mechanisms in an easier way, but we have not yet succeeded. Now, our sustainability is quite precarious, since we cannot grant what we'll have next month. I can't make any 6-month planning on expenditures or revenues. Everything is extremely immediate. Partnerships are established all of a sudden. All events come almost suddenly. We cannot estimate monthly sustainability.

The NGO states that, since 1995, it has effectively participated in debates, seminars and training on resources capacity building, sustainability; therefore, it says that there is no recipe or magic formula. In fact, the different realities among the NGOs are what exist.

The NGOs must follow what is happening. They can't stop or remain static, loosing the history. For us, there is something extremely perverse, but to civil society there isn't. Nowadays, there are countless organizations working with a universe of target-audiences, such as the elderly, HIV, women. These NGOs

are fighting for market in several ways. Each NGO should grant its space in this universe to attract resources. They have to establish partnerships and effectively do things, even because competitiveness in this market is gigantic!

The NGO argues that the state has been developing and promoting, over time, several actions and activities on sustainability, such as seminars and debates, among civil society, private institutions, corporations, foundations and the state itself. They understand that the state is not solely responsible for these issues. The society should also mobilize and advance this discussion, in partnership with the state, instead of letting the government play a paternalist role. The state is co-responsible: It wants the NGOs to remain active, to continue actions on prevention, because the state is not as far-reaching as the NGOs and the community.

The major strength here is the space conquered and being conquered at several social control spheres, whether in municipal, state or national councils. These spaces are effectively converted into partnerships.

Concerning threats, the major one mentioned by the NGO are the cuts in public health in general, ranging from assistance, education, prevention and health promotion – to the economic situation of the country, which may lead to cuts of budget to actions and public health.

25) Interlocution with Governmental Spheres, in the Field of the AIDS Epidemic

According to the NGO, governmental financing allowed for actions in prevention and assistance, but on the other hand increased competitiveness among different NGOs.

Concerning negative aspects – not only for GAPA, but also for other institutions in the region – some actions became extremely dependent on partnerships with the State and the Ministry of Health. Therefore, many cooperation agencies have suspended financing, mainly in South and Southeast regions – particularly in São Paulo – because these regions present a scenario of likely partnerships in the private field, that are much broader than in other Brazilian regions.

Concerning the success of the National AIDS Programme, GAPA/SP highlights the civil society articulation towards several actions, mainly in the field of assistance. In the entity view, the relationship between the civil society and government is very positive. However, when civil society is called just to validate a program constructed by the government, they should be careful.

It is extremely positive and important, since this partnership is effectively constructed and really becomes a partnership; otherwise, NGOs should be careful, because the government sometimes – and I am not saying they always do that – but sometimes the government calls on the civil society only for it to validate a program constructed by the state or government.

E. 7. GIV – Grupo de Incentivo à Vida

1) Organization Name: GIV – Grupo de Incentivo à Vida

2) City/State: São Paulo/SP.

3) Date of Foundation: 08/02/1990.

4) Started Working with STD/AIDS in

Since it started working, it has focused on patients carrying the HIV/AIDS virus.

5) Kind of Organization: Advocacy.

6) Address/Phone:

E-mail: giv@mandic.com.br / giv@giv.org.br

Phone: (11) 5084-02-55 / (11) 5084-63-97

7) Situation of Headquarters: Assigned.

8) **Field of Action:** Gay movement and women's movement.

9) **Priority Field of Action:** HIV/AIDS carriers and Human Rights.

10) **Geographic Area of Work:** National.

11) **General Purposes**

Provide better alternatives to the quality of life of people living with HIV, at family and social environments, besides physical and mental health, by promoting their integration and exchange of experiences.

- Advocacy of people living with HIV;
- Direct delivery of care;
- Works in the field of social control.

12) **Target-audience**

HIV/AIDS carriers, family members, children and adolescents, population in general.

13) **Core Activities**

- Follow-up policies under development in the field of HIV/AIDS;
- Meeting of the *Grupo de Vivência Terapêutica (GVT)* – mutual assistance
- Workshops on activism, social control and citizenship;
- Computer courses: aiming at qualifying individuals for their further introduction into the labor market, to work at home, to seek for self-management, for their survival;
- *Grupo Somos* – deals with the issue of homosexuality (identity, rights, behavior, prejudices, self-esteem);
- *Toque de mulher* – feminist topics (self-esteem, sexuality);

- *Viver Criança* – children and adolescents whose parents are HIV/AIDS carriers, and children and adolescents, whether HIV/AIDS carriers or not (discuss sociability in schools, shelters, community, family relationships, and sexuality);
- Cultural activities: bingos, barbecue parties, *feijoada* parties, aimed at integrating people and recover their self-esteem. This activity is non-profit;
- Timely activities: such as courses on handmade candles, handmade soaps, bakery, and sweets;
- During the process, they encourage the settlement of work groups to implement the cooperative association system, aiming at strengthening and seeking for partnerships with the private initiative, to provide income generation and continuity to the process.

14) Ongoing programs and projects

Sustainability actions

Aimed at the promotion of institutional development to sustain and qualify the actions developed by volunteers and professionals among people living with HIV/AIDS. The professionals of the institution and other community sectors cooperate in the execution of this project, financially supported by the National STD/AIDS Coordination of the Ministry of Health and UNESCO. The project objectives are:

- To qualify professionals and volunteers towards developing actions on technical, technical-political, political and financial sustainability;
- To foment the participation of volunteers and qualified technicians in each specific sector of the institution;
- To share, internally and externally, GIV experiences in building technical, political and financial sustainability.

It holds continuous training for the institution volunteers, comprising three modules: technical (workshops on institutional view, managerial skills, updating workshops in HIV/AIDS, classes on AIDS history and Institutional Management, workshops on group experience and projects elaboration, courses on skills in telephone services, groups leadership and administrative techniques); political (classes on social control spheres, workshops on activism and working strategies); financial (classes on financial management, workshops on resources intake and partners identification). *Construindo Caminhos* – This project intends to improve the quality of life, increase self-esteem and provide tools for the reinsertion into labor market for people living with HIV/AIDS, assisted by reference centers in the São Paulo metropolitan area. The project is financed by the National STD/AIDS Coordination and UNESCO.

Viver Criança e Adolescente Project – project developed by GIV aimed at contributing towards building sympathetic children and adolescents, who respect human diversity and life, and provide them the required conditions to fight the AIDS epidemic. It is an open room for any child and adolescent, especially those living with HIV/AIDS, children to or relative of seropositive individuals, and those who want to know more about AIDS, or how to prevent it and how to become more friendly and sympathetic to HIV/AIDS carriers in schools, clubs, and communities. Additionally to the work with children and adolescents, the project develops activities on qualification to health and education professionals, counseling for parents and chats at schools.

Toque de Mulher Project– It aims at empowering women living with HIV/AIDS in the State of São Paulo, approaching issues of the daily life of women with AIDS, such as self-esteem, autonomy, information on AIDS,

sexuality, vertical transmission, gender relationships, etc. *Geração de Renda/Captação de Recursos* Project – It is intended to implement actions oriented to institutional sustainability, simultaneously generating income to people living with HIV/AIDS, over the years. They develop works on sewing workshop, paper arts, painting, cooking, bakery, silkscreen, shoe making, and also a group of autonomous photographers.

Metodologias Participativas em Relações Externas e Sustentabilidade para ONG/AIDS Project – A technical team made up by GIV – *Grupo de Incentivo à Vida*, *Grupo Pela Vida/Niterói*, Municipal STD and AIDS Programme of Praia Grande (SP) develops this project, in cooperation with the International HIV/AIDS Alliance/England, through its technical and financial support, aiming at providing some responses to the issues of sustainability of actions against AIDS in Brazil. Therefore, they contribute to reduce the epidemic impact, through effective and sustainable responses at three levels: technical, political and financial. Up to now, the project has been supported by the Ministry of Health, National STD/AIDS Coordination, State STD and AIDS Programmes in São Paulo/Rio de Janeiro and DKT do Brasil.

Throughout the process, the participatory methodology enjoyed an outstanding place, assisting the NGO representatives in undertaking the process as part of the construction of joint alternative to respond to the issues of technical, political and financial sustainability.

Corpo e Mente Project– Developed in partnership with the NGO *Lutando Pela Vida* of Diadema, it aims at expanding the access and improving the quality of diagnosis, treatment, assistance and prevention against lipodystrophy in people living with HIV/AIDS, assisted by reference centers in the Great São Paulo.

Encontro Project – Developed by a work group made up by representatives of NGOs linked to São Paulo NGO/AIDS Forum, health professionals, experts and representatives of the Municipal Programs of São Paulo and Jundiaí, and the São Paulo State STD/AIDS Programme. The GIV participates in the project coordination, which aims at empowering and improving the quality of life of children and adolescents living and co-existing with HIV/AIDS in the State of São Paulo.

Cidadã Positiva Project – Through its actions, this project seeks improving the quality of life of female HIV/AIDS carriers in all Brazilian regions, promoting individual and collective strengthening, encouraging practices of social work and the citizenship exercise. With technical and financial support of the National STD/AIDS Coordination of the Ministry of Health, GIV in partnership with the National Network of People Living with HIV/AIDS (RNP+) Nucleus of Campinas/SP, RNP+/Porto Alegre, Grupo VHIVER/Belo Horizonte, Grupo ALIA/Londrina, Mulheres do Cabo/Recife, Grupo Arco – Íris/Brasília, develop the project in all the Brazilian regions.

CDI – Informatics Project – In partnership with the CDI (Center for the Democratization of Informatics) of São Paulo, and the Japanese NGO PASSO, the GIV launched a school of informatics in December 2000, on its premises. The proposal is to promote citizen inclusion by employing computer-based resources, developing skills to manage software, aiming at using it in work and social-political relationships. This project subsidizes other initiatives by the institution, such as for example, the Projects: “*Construindo Caminhos*”, “*Captação de Recursos e Geração de Renda*”. The course has its own room, with seven computers, each computer being used by two students.

The methodology has its own strategy and dynamics, towards changing the reality of the students and their communities, respecting their historical background.

15) Services Provided to Population

- Workshops (citizenship, gender, treatment adherence, life with the family, HIV/STD/AIDS, sexuality, pregnancy) and courses (telemarketing, informatics, photography and sales techniques);
- Individual and group psychological services;
- Massage;
- Lectures;
- Leisure activities;
- Workshops;
- Open meetings to interested participants;
- Closed meetings, only for seropositive individuals;
- Library.

They provide a cultural department, where main users are university students developing works and researches.

16) Works only with AIDS: Yes.

17) Advertises the Work Developed Through:

- Magazines, journals;
- Printed material; folders;
- Congresses, conferences, meetings, seminars.

NGO Background

18) Origin of the Institution

The organization has existed for thirteen years. It was founded in 1990, by people living with HIV/AIDS who,

at that time, had no access to medication, and not even to a space where they could deal with issues related to living with HIV/AIDS. The *Grupo de Incentivo à Vida* – GIV, emerged while seeking for alternatives for survival, treatment, better quality of life. The psychologist José Roberto Peruzzo idealized it, jointly with other persons, who started to hold meetings at his house. Over time, the meetings expanded and, through the help of a person sensitive to the cause, they obtained a space, where they still work. Over these thirteen years, the GIV grew a lot, if compared to its early stages, when it worked only as a mutual assistance group, with more direct services, psychological services. Now, it places focus on the issues of activism and social control, but keeping in mind that mutual assistance is necessary, as well as the improvement to the quality of life of HIV/AIDS carriers.

19) Organization's Motivation Towards Working with STD/AIDS

The lack of treatment to HIV/AIDS carriers led a group to seek for alternatives to live with HIV.

20) Resources and Financing Sources

The sources of financial resources to the *Grupo de Incentivo à Vida* are: Individual donations, agreements with public entities and timely sponsorships. Concerning resources intake, it relies on the monthly contribution of some partners, and technical and financial support of the Institution members. It also promotes parties, bazaars and bingos to raise funds to sustain its activities. Therefore, it relies on creative ways to afford its financial expenses in the event of difficulty to projects financing. It has its own premises.

21) Human Resources

Human resources selection is made at the GIV headquarters, since people living with AIDS continuously seek for the entity. Based on the demand, the institution holds training and workshops to deepen

its knowledge on the public served. Volunteers are continuously trained for providing greater integration to the Group and to activities implemented. Through this process, the NGO has achieved better institutional and personnel performance in face of the demands that permeate the fight against the epidemic.

We are always providing qualification courses, recovering the issue of the institutional mission, the goals we have to reach, and it is very important. We are always debating. At the end of last year, we held training to all volunteers, and there we recovered the institution's history, its mission, and its goals.

The partners undergo a process of introduction to the institution. Initially, they attend a meeting for newcomers. After the meeting, each member is interviewed and assessed, having in mind, above all, their responsiveness to the NGO profile.

When the opportunity of attending some external course or training arises, especially when the topic is sustainability and/or the third sector, the NGO tries to send a representative, with the objective of keeping the team up-to-date with important debates.

22) Work Methodology

GIV plays a decisive role concerning living with HIV/AIDS. It was one of the first non-governmental organizations developing works oriented to this specific audience, although it is no longer an NGO only for people carrying the AIDS virus.

The Institution has served as a space where HIV/AIDS carriers can express their afflictions. They still face the reality of difficulties such as isolation due to discrimination and prejudice, fear of losing their jobs, or even to withdraw from treatment.

A person who is always afraid that someone notices what he/she is doing, cannot be productive, becomes stressed, and this influences and weakens his/her immunity. At some point, the person will say: "Enough! I am tired of that!" And so, what happens? The person ceases adhering to the medication and becomes sick. It would be very nice if we could deal with this issue anywhere, and say: "Look, I have the HIV, but I am here, I am like you, I

work!” Take the medicine in front of the boss, and have no need to hide it. It would improve these people’s quality of life a lot. And have access to basic needs of any human being.

The GIV was the first organization made up by people co-existing with HIV/AIDS, because it is made up by people with or without HIV/AIDS in their blood, but they have souls. So, it is contaminated from the cause, and is as important as any person living with HIV/AIDS. Therefore, this institution is exclusively made up and headed by people who feel the problem of discrimination and embrace the cause. They are not thinking just about themselves, but thinking on the collective. The fact that these very same persons were directly affected led them to mobilize, and we recall this fact all the time. The starting of the group, the difficulties, the limitations to these hopeless people. Now we have hope, and fight for it. So, I think this is what makes people get really engaged in the institution and to this cause, which is above anything else.

23) Political Articulation

The NGO is part of São Paulo NGOs/AIDS Forum, and is member of the ABONG.

24) Partnerships

Since 1994, the GIV has promoted several activities in Japan, in partnership with the Japanese NGO CRIATIVOS. This partnership is mainly aimed at the prevention of STD/AIDS among the Brazilian population in transit in Japan, besides improving the quality of life of foreign workers (Brazilian and Latin Americans living with HIV/AIDS) in Japan. The activities are simultaneously developed, and involve health professionals, governmental and non-governmental organizations, both in Brazil and Japan. They hold training, workshops, preventive interventions, and establish network among people living with HIV/AIDS. In 2001, the partnership was expanded, involving GIV, CRIATIVOS and the Brazilian National STD and AIDS Programme.

Furthermore, the NGO has partnerships with the State STD and AIDS Coordination, the Municipal STD and AIDS Coordination, other Programs and/or Secretariats of the Ministry of Health, and ONGs/AIDS.

25) Incidence on Social Programs and Public Policies

The NGO participated in the elaboration of public governmental policies concerning the access to early diagnosis, medications, treatment, preventive devices, NGO capacity-building and human rights and citizenship.

It targets to follow-up policies on HIV/AIDS under development, such as distribution of medication and hospital beds, genotypic assay and, finally, inspect governmental organizations.

We have daily duties of sending letters to secretariats, concerning the lack of medication, lack of hospital beds. We are in a passionate discussion with the Municipal Government of São Paulo because of the lack of hospital beds for AIDS patients.

The NGO participates in several networks related to STD/AIDS: It holds seat in the National AIDS Commission; Municipal STD and AIDS Commission; State STD and AIDS Commissions; NGOs/AIDS Forum; Work Group on Governmental and Non-Governmental Organizations in the State of São Paulo; Committee on Vaccinations, CONEP. At the local level, it articulates with the Reference Center Hospital Emílio Ribas, Casa da AIDS and the CRT. It is also member to the Health Council and to the Advisory Committee to the National STD and AIDS Programme.

We participate at several levels, always trying to insert our volunteer members – regardless of their academic background – and having them prepared to participate in such discussions. We are always invited to participate in some commission or Forum. When we are not invited, we make pressure. So, in my opinion this is a major advance. To be acknowledged not only for the work performed, but also as the main player in clarifying the policies under analysis and, sometimes, to argue with the government. We just can't be confined to four walls, unaware of what is happening, especially concerning public policies, not only on AIDS, but also on health as a whole. I believe we have to fight for health since according to SUS principles it is a universal right. We don't place AIDS as an exclusive issue. Obviously, in our line of action it becomes the major focus. We are concerned about remaining in these spaces, to challenge authorities, but challenge them with competence.

26) Organization Sustainability, in Mid and Long Terms

According to the respondent, financial sustainability is a major problem, not only to GIV but also to other NGOs. Therefore, the NGO included in its statute the total independence from projects financing, since the major project is GIV itself.

Concerning technical sustainability, the NGO qualifies its volunteer members for several social control spheres, to follow-up policies on HIV/AIDS, at the municipal, state and federal levels. Financial sustainability is the last concern, being placed after technical and political sustainability: “If we miss technical and political sustainability, money becomes useless because we won’t know how and where spend it. We are concerned about this technical sustainability”.

Concerning threats, the NGO mentions the fund-to-fund transfer, since this sort of resources decentralization involves qualification of states towards receiving the resources. The Health Secretariats and STD and AIDS Programs are extremely bound to, subject to resources transferred by the World Bank. Currently, this transfer is made as incentive, through the Ministerial Administrative Rule 2. 313, i. e. , the Fund-to-Fund. This Ministerial Administrative Rule was issued last year and, up to now, some states have not yet registered to receive these resources. Therefore, the resource is returned to the Global Health Fund. The consequence of such administrative incapacity is that states do not receive the resources and, therefore, cannot transfer them to the NGOs, thus jeopardizing the development of end actions.

Out of total resources transferred to the state, only ten percent are allotted to NGOs projects. Furthermore, the NGOs face the issue of administrative bureaucracy (projects elaboration and approval; infrastructure to develop the project), thus restricting their access.

If the state itself is not prepared to receive the resources, the money is returned to the health fund, and people keep on dying from HIV/AIDS, keep on having to go to other cities. Furthermore, AIDS is viewed in health as the rich cousin. The municipalities, states as a whole, must become responsible, must be timely qualified to receive these resources.

27) Interlocution with Governmental Spheres, in the Field of the AIDS Epidemic

According to the *Grupo de Incentivo à Vida*, the Brazilian action on fight against AIDS is partially successful. Despite the status of best program worldwide, mainly due to free distribution of antiretroviral drugs, it is worth taking into consideration that social unbalances and the impoverishment of the epidemic hinders many HIV carriers to have access to other conditions of life that have directly impact on the treatment to control the virus in the body. “They are carriers who don’t have anything to eat; they have no jobs, no house and, therefore, don’t have the minimum quality of life required to manage the required care”. Under this light, the group reports that part of the Brazilian success in the access to treatment is due to civil society, which has always made pressure on the State towards converting the right to free medication into a reality.

What is the use of having medication, if a person doesn’t have anything to eat! The guy will die faster, because he will think: “why keep on living?” So, I, think that not only in relation to AIDS, but as a whole, it needs improvement to living conditions, the person needs a job, they need opportunities, and they need schools.

According to the NGO, the relationship between organized civil society and the government in fighting the epidemic has developed. Currently, the group participates in spaces created by the government, where the NGOs may discuss the paths for AIDS-oriented public policies “with the same power”.

According to the GIV the relationship with government in the State of São Paulo is excellent, because they participate in the process of constructing public policies to be implemented. However, they observe, sometimes these policies *come ready*. For eight years the group felt “total negligence and waste” by São Paulo local government. Currently, there is a commission, established at the end of last year. Furthermore, the government held the first Municipal Conference on STD/AIDS.

Nevertheless, the group believes in a favorable space for articulation between NGOs/AIDS and the Government, but emphasizes that usually they are not heard:

There is no medication, now we have the antiretroviral, but it was missing. When we argued, forwarding a memorandum to the secretariat, they answered: ‘Unfortunately, there were some problems in the bidding process; we expect to solve the problem in x days!’ But they don’t know we can hardly work the adherence of the patient to this medication. And then, to make the patient use the medication again is complicated. And not to mention the time they remain without the medication. They have the antiretroviral, but don’t have a medication to an opportunistic. But until then, someone dies! It is necessary to have quality in services, a humanitarian service. If we have what we have now, it is because the civil society made pressure, because the judicial power was a partner, because we went to streets to fight, we went to the secretariats.

On the other hand, the NGO also recognizes failures by the non-governmental organizations in relation to their capacity of articulation with government. Furthermore, they report that Judiciary Power is a great partner concerning the fight for citizenship and human rights.

E.8. SOCIEDADE AMIGOS DA VILA MARA

- 1) Organization Name: Sociedade Amigos da Vila Mara**
- 2) City/State: São Paulo/SP.**
- 3) Date of Foundation: 1969.**
- 4) Started Working with STD/AIDS in:1996**
- 5) Kind of Organization: Community-based organization.**
- 6) Phone:**
Phone: (11) 6585-18-07 / 6585-44-55
- 7) Situation Concerning Headquarters: It has its own premises**
- 8) Priority Field of Action: Prevention against STD/AIDS and Assistance.**

9) Geographic Area of Work: District-based groups: Vila Mara and Goianas/São Paulo.

10) General Purposes

Prevention against STD/AIDS and qualification of community-based multipliers for the prevention of STD/AIDS, aimed at improving people's quality of life.

11) Target-audience: General population living in the district and surrounding districts.

12) Core Activities

Development of prevention actions among men, women, children and adolescents.

- Preventive actions in STD/AIDS;
- Distribution of condoms;
- Workshops;
- Lectures at schools and corporations.

13) Works only with AIDS: No.

14) Advertises the Work Developed Through:

- Printed material;
- Meetings;
- Community-based radio

NGO Background

15) Origin of the Institution

The NGO started working in 1969 due to emergence of movements, and is focused on rendering services to the

district where it is located. Initially, it was made up by district leadership groups that wanted to follow-up on the local development: *In principle, it was concerned about improving the district, because the region was very poor and disorganized; it was not paved, had no sewage services, had poor lighting. As time went by, other needs emerged, and we started organizing ourselves and seeking for partners to solve the issues, mainly the social ones.*

16) Organization's Motivation Towards Working with STD/ AIDS

People related to the movement promoted by the districts, church, and industry, people who work in the school and participated in the women's movement, and started thinking about women's health. In 1996, a psychologist proposed the development of workshops on prevention, since the figures for contamination among women were increasing. So, they continued this work with the support of the National STD and AIDS Programme, the State STD and AIDS Coordination.

17) Resources and Financing Sources

The sources of financing for the *Sociedade Amigos da Vila Mara* are: Donations made by individuals and corporations, and sporadic sponsorships. The resource intake strategy is based on project financing. The members and businessmen provide contribution.

18) Human Resources

Concerning training to its members, it relies on the support of the *Centro de Educação Operária* (CEOP) – an old institution, renowned in the field of NGOs oriented to provide advisory services to qualify professional staff. Furthermore, the *Unicastelo* University provides support to the qualification of community-based agents.

19) Work Methodology

It tries to assess its actions, by performing regular group assessments to identify the perceptions involved in the work development, as well as the obstacles related to the compliance to institutional goals.

One of the obstacles faced is related to the lack of information, mainly among the population living in São Paulo's vicinity areas. This lack of information intensifies and worsens the vulnerability of the audience targeted by the NGO.

The institution also mentions another problem concerning evasion from it, as its audience's needs are not met. Therefore, the commitment to the entity is low.

The work is considered profitable, mainly because of its concern in elaborating projects. The projects' construction also follows-up the needs acknowledged within the community.

We can't just do it; we can't come out of the blue into a community, into an NGO. First, it is necessary to discuss the issues, and then prepare a project, because otherwise it doesn't work. We must know the community's needs. For example, when we are developing any actions, we apply questionnaires to check if that is exactly what people want. This kind of mechanism in services supply is crucial because technicians should participate in the community, enter the community to know what is happening. I think that technical work is very important, and we need it; but they must change their view on reality.

The NGO points out some positive aspects such as improved self-esteem of women, increased participation in groups and strengthened community.

20) Partnerships

The major partnerships are with the State STD and AIDS Coordination, Municipal STD and AIDS Coordination, Program Coordination Units, NGOs/AIDS and NGOs/mixed, in addition to other segments of social movements. It relies on other partners to develop the actions, such as the University of São Marcos and the Unicastelo University.

21) Incidence on Social Programs and Public Policies

It participates in the Health Councils, the State STD/AIDS Commissions and in the Inter-managers Council.

22) Organization sustainability, in Mid and Long Terms

The *Sociedade Amigos da Vila Mara* understands that the solution for challenges posed by the sustainability is the permanent pursuing for new projects and new partners, including the support of local businessmen. Now, the NGO is concluding a project financed by UNESCO.

Concerning threats to sustainability, the NGO stresses the lack of diversification of the financing sources. On the hand, it emphasizes as strengths the fact of having their own structure to work and develop their work, as well as their interlocation with other NGOs.

23) Interlocation with Governmental Spheres, in the Field of the AIDS Epidemic

According to the institution, the governmental financing focused on actions on STD/AIDS had positive impact, since the resources allowed for promoting quality in daily work. Moreover, they highlight the partnership with non-governmental organizations in the field of AIDS as the major success of the National Programme.

According to them, this interlocation did not lead to a loss of NGOs autonomy; however, they emphasize that many NGOs depend on the state to maintain their actions, especially those that failed in being inserted into a community context, since they depend exclusively on the government.

It argues that citizenship and human rights promotion should be strengthened. Nowadays, people talk about citizenship and human rights, but the agenda for these topics is very weak. The NGOs must be strengthened in order to have more incisive performance in these political fields.

Concerning the loss of autonomy by NGOs, in exchange for financing by the National Programme, the *Amigos da Vila Mara* Institution argues that it depends on the NGOs, “If the NGO political or work agenda relies on one single source of financing, it will be hard to build a favorable negotiation field for actions and resources”. Therefore, the Institution believes that if NGO has an objective, a mission, and tries to develop actions with other partners, additionally to what the government may provide, it will always ensure the maintenance of their actions.

E.9. NGOs/AIDS Forum

1) Organization Name: NGO/AIDS Forum

2) City/State: São Paulo/SP.

3) Date of Foundation

Officially founded on 2 July 1997, although it has been working since 1996.

4) Started Working with STD/AIDS on: 2 July 1997.

5) Kind of Organization

Social Movement – Non-profit civil entity, of humanitarian and representative nature, working at the state level. It articulates the aspirations of non-governmental organizations working in the field of AIDS pandemic, regardless their religion, race and creed, gender and sexual or political party orientation, for undetermined period of time.

6) Address/Phone:

E-mail: forumongsp@uol.com.br

Phone: (11) 9800-94-84 / Tel: (11) 3334-0704

7) Situation Concerning Headquarters

It does not have its own premises, and holds meetings in a space that was temporarily assigned, or in the headquarters of its affiliated NGOs.

8) Priority Field of Action

AIDS-oriented public policies;
Prevention against STD/HIV/AIDS;
Assistance to HIV carriers and/or people living with AIDS.

9) Geographic Area of Work

State of São Paulo. It works at the state level, and the highest instance of deliberation for the movement of fight against AIDS is the National Meeting (ENONG), held at every 2 years. The last meeting was in June 2003, in São Paulo.

10) General Purposes

- Closer monitoring of public policies at several spheres (participatory management), checking what was planned against what is being executed; strengthening the fight against AIDS;
- Encourage and promote campaigns on prevention, support and education;
- Provide guidance, follow-up and denounce any kind of breach of laws in force that damage the rights and obligations of the association's members and non-members to the Forum;
- Prepare joint proposals aimed at strengthening the NGO work with public, civil and religious authorities;
- Influence the pertinent legislation in the sense of conquering and granting new rights and/or change provisions contrary or harmful to prevention against AIDS, as well as legislation on assistance to HIV/AIDS carriers;

- Intervene and participate in the process of formulation of public and sanitation policies, to define policies on prevention against and control of AIDS, as well as on assistance to HIV/AIDS carriers;
- Denounce all forms of omission, transgression and violation of human, civil, political and social rights, resulting from discrimination against HIV/AIDS carriers, and seek for mechanisms to place accountability on and punish the perpetrators;
- Support and reflect the actions carried out by Entity Members, whenever such actions meet the forum collective, respecting their identities, autonomy and dynamics.

11) Target-audience: HIV carriers, governmental spheres and NGOs involved in this issue.

12) Core Activities: Follow-up and proposal / implementation of new policies.

13) Works only with AIDS

Yes, but in the field of prevention. The NGO articulates with different fields of knowledge.

14) Advertises the Work Developed Through:

Participation in networks and cross – network forums that gather different segments;

Journals, printed material;

Meetings, seminars.

Background

Origin of the Institution

São Paulo NGOs/AIDS Forum is a pioneer and successful initiative in social control of HIV and AIDS. It has been

replicated in several states. It started its activities in 1996, and was officially founded on 2 October 1997. At the state level, it now has 162 affiliated non-governmental organizations throughout the state.

The meetings are held on a monthly basis. The democratic discussion and joint submission guide the Forum deliberations, with no damage to the autonomy of each entity. It works at the state level, articulating and harmonizing the aspirations of Non-Governmental Organizations in the field of AIDS pandemic, regardless of their religion, race creed, gender and sexual or political party orientation. It is intended to encourage and promote campaigns of prevention, support and education, provide guidance, follow-up and denounce any kind of breach to laws in force that may jeopardize the rights and obligations of associations, whether they are members or not. It seeks for preparing joint proposals focused on strengthening the NGO's work among them and with public, civil and religious authorities, towards influencing the pertinent legislation, in the sense of conquering and granting new rights, and/or change provisions contrary or harmful to the prevention against AIDS and assistance to HIV/AIDS carriers.

Over the years, it strengthened the articulations of NGOs/AIDS with public organizations, by denouncing omissions, transgressions and violations to human, civil, political and social rights, resulting from discrimination against HIV/AIDS carriers. Furthermore, it pursued several mechanisms to place responsibility on and punish the perpetrators.

In order to improve its actions, it established six regional forums bound to the State Forum of NGOs/AIDS: a) *Movimento Paulistano de Articulação e Luta contra AIDS* –MAPAIDS; b) NGOs/AIDS Forum in the ABC Paulista; c) NGOs/AIDS Forum of Campinas; d) NGOs/AIDS Forum of the Baixada Santista; e) NGOs/AIDS Forum of São Paulo's northwest region; f) NGOs/AIDS Forum of West Zone of São Paulo's metropolitan area.

The work of activists in the fight against AIDS in Brazil, which started even before the epidemic was installed in Brazil, through gay groups that claimed for governmental responses to prevent the epidemic to arrive in Brazil, has significantly contributed towards reaching current victories, whether in the field of prevention or in assistance, grounding the discussions in the light of human rights.

Regardless of some individual actions, most activists in AIDS have articulated in groups to increase and enhance the possibility of reaching the expected results. The NGOs/AIDS were established in this context of collective search for more efficient responses, and aimed at the commitment of governments and society with the prevention and assistance to people living with HIV/AIDS.

F. RIO GRANDE DO SUL

F.1. GAPA/RS – Grupo de Apoio à Prevenção à AIDS no Rio Grande do Sul

- 1) Organization Name: GAPA/RS – Grupo de Apoio à Prevenção à AIDS no Rio Grande do Sul**
- 2) City/State: Porto Alegre/RS**
- 3) Date of Foundation: 3 April 1989.**
- 4) Started Working with STD/AIDS in: 1989**
- 5) Kind of Organization: Association.**

6) Address/Phone:

gapars@zaz.com.br

Tel: (51) 3221 – 63 – 63

7) Situation Concerning Headquarters

The State Health Secretariat assigns premises. The house is rented by the state, but the owner's family wants to retake the house. However, the house was remodelled through a project between the NGO and the Ministry of Health, complemented by a state project. They did not use to pay for water or electricity bills, but were informed that they will have to pay for electricity.

8) Where it Performs the Activities: ONG headquarters.

9) Field of Action

Male and female sex professionals and women's movement.

10) Priority Field of Action

Prevention against HIV/AIDS and support to HIV carriers and/or people living with AIDS.

11) Geographic Area of Work: State.

12) General Purposes

- Promote reduction of infection from HIV, through preventive actions, and advocate for the rights of people affected by the AIDS epidemic.
- Become a regional reference in programs on prevention against HIV and support to people living with AIDS.

13) Target-audience

Seropositive individuals and family members, female sex professionals and the general population.

14) Core Activities

- Works on prevention and support to people affected by STD/HIV/AIDS, through person-to-person and telephone services;
- Legal and psychotherapeutic services;
- Group of mutual assistance to people living with HIV/AIDS;
- Groups of adhesion to antiretroviral treatment;
- Training to internal and external audiences;
- Hospital visits;
- Behavioral intervention among sex professionals and women;
- Campaigns and informative materials;
- Legal researches.

15) Ongoing Programs and Projects

- Project on prevention against HIV/AIDS among women in general.
- Project on vaccination cooperation with the State Health Secretariat, to assemble a vaccination site in Porto Alegre, one of the cities that will start with vaccination testing in Brazil.
- Specific project on vaccination to follow-up and training.

16) Services Provided to Population

- Timely counseling services, information transfer and referral, personal or by phone, through the Dial Solidarity (*Disque Solidariedade*);
- Therapeutic service (individual and in group);
- Work on prevention against HIV/AIDS with men, women, and travesties that prostitute themselves;
- Visits to hospitalized people living with AIDS;
- Information and distribution of male condoms;

- Capacity building to new volunteers, and internal and external upgrading courses;
- Organization of events, informative materials and campaigns;
- Services to meet needs related to rights of people living with HIV;
- Center of Information and Documentation;
- Space for exchange and sociability to people living with HIV/AIDS and information;
- Elaboration and production of materials;
- Represent the category in several forums.

17) Works only with AIDS: No.

18) Advertises the Work Developed Through:

Campaigns and information material to the general public and specific populations; books, texts, printed material, folders, bi-monthly newsletter, congresses, conferences, meetings and seminars.

NGO Background

19) Origin of the Institution

The NGO states that, because of *the disagreement with services rendered, and their limitation*, emerges the willingness for fighting, and even of establishing an organization in the shape of some existing in Brazil.

The assembly that marks GAPA/RS foundation was held at the Lutheran Church Reconciliation room, gathering over thirty people, among which several Lutheran religious, health professionals at the central level and of the public network, male homosexuals, hemophiliacs, seropositive individuals,

AIDS diseased individuals and their partners, family members and friends. This initial composition guided the early claims and actions of the group: *a concern towards granting due and worthy assistance to people with AIDS.*

20) Resources and Financing Sources

The sources of financial support to the institutions are: Agreements with public entities, international cooperation agencies, donations made by individual and sporadic sponsorships.

Concerning the strategies adopted for resource intake, they are assembling a team to work on the issue, especially intake through events. They are trying to establish a support society, named *Sociedade de Amigos do GAPPA*, to collect donations in a more systematic way. They also develop works in the field of prevention at corporations (Pólo Petroquímico, Albares - Automobile industry - and Petrobrás), through lectures, activities, workshops, and propose follow-up for fixed terms. They charge for these services. This is how they are trying to restructure the financial aspect.

Projects are specific and for fixed – terms, and they cannot employ the resources to pay for electricity and telephone bills and staff. They can purchase equipment, under given conditions, “We can purchase a computer, but can’t pay the electricity bill to have the computer working”. They can pay staff members such as project coordinators, but not supporting staff (secretary and telephone operator).

Therefore, they must work with other sources of financing. “And also because this kind of financing is finishing; we must have other ways to raise resources, besides other World Bank-financed projects, because in AIDS III the resources are even shorter, and will end. The purpose is for it not to be endless”.

21) Human Resources

To enter GAPPA, the applicant must undergo 40-hour training, involving the history of AIDS, political history – i.e., far beyond focusing AIDS as an epidemic and it refers to social issues involving

AIDS. They talk about the legal aspects, prejudices and discrimination. In their opinion, they are somehow creating multipliers. The individuals undergo training and an assessment, to know where they fit better. People attending the training assess one another to know where each one can work.

When they send a volunteer to attend a course, they consider it as capacity building or upgrading. The capacity building of GAPA's remunerated staff and volunteers is always performed through training. However, GAPA has other capacity building ways. For example, new medications are always appearing, thus demanding for continuous capacity building.

So, we have volunteer doctors working here in GAPA with specialized services, and we call them and ask them to talk about these new medications. If it is something we deem as of general interest. The same is happening in the legal area, in the *Núcleo de Estudos da Prostituição* NAESP –, which works with groups of travesties and male sex professionals. So we call them, book the lecture and make it in the auditorium, hold a course.

22) Work Methodology

They are changing their strategy, diversifying the practice of entering into agreements with priorities established by governmental agencies and institutions. They prepare projects and submit them to an international foundation. If they are not approved, they send them to another institution.

This is not what they want to finance, so we will look for someone that wants to finance it. It isn't like that; then we don't know what to do when the money is over. Because that was not our audience, didn't look like us. We are trying to follow this line in our planning.

They hold assessment meetings to discuss what is happening. These discussions are recorded in minutes, mainly their impact. However, they assume the lack of a formal assessment process, and that they are limited to assessing the projects, the expected impact, i.e., they discuss if the objective was reached or not.

The best assessment is that related to our work, its impact, if it is producing results, what is happening. We should always be alert to do what the NGO can do. I say something to somebody, but the others also say something to me, so I think that the others' view is our best assessment, because the assessment about us is important.

23) Specific Problems with Experiences

The NGO considers that the success of the Brazilian actions on the fight against AIDS is threatened, because of the cost of antiretroviral drugs, new sub-types of the HIV virus that are increasingly more resistant, and the problem of adhesion to the treatment, with low levels of dissemination.

The other issue concerns SUS resources, since people's outlives are increasing, i.e., there are more virus carriers, increasing expenses with health, while others are entering into the health system, "So, you imagine that in the long-term, the increased the number of people, the SUS won't have money to support them".

Most beneficiaries affirm that, before knowing about GAPA, they had pre-conceived ideas on seropositive individuals, like someone who "only cries, is thin, sick, worn-out". The NGO assisted in changing their views on seropositive individuals.

They also mention the doctors working in health units, pointing out difficulties in the doctor-patient relationship, besides the lack of training of some professionals in dealing with AIDS diseased individuals.

24) Political Articulation

The Association is affiliated to ABONG, to the Mercosur Forum of NGOs/AIDS, to GAPA network, and to *Rede Mulher*.

According to them, the approximation to ABONG is troublesome, because they cannot fulfill ABONG agenda and the NGO agenda with the movement of AIDS, "Our agenda with the AIDS movement is very intensive and, in the end, we cannot comply with ABONG agenda, which discusses much broader issues, I don't mean more important ones, but those that are more comprehensive".

They keep closer relationship with the Global Social Forum, and ABONG organizes this participation. They highlight the relationship with GAPA network, which allows Brazil to develop a policy that is “quite uniform, working like a coordinated network”.

They attend the ERONG, the ENONG, ABIA seminars, as well as Health Forums and GAPA meetings. Furthermore, they participate in the National Health Conference, Human Rights Conference, Mental Health Conference, and Worker Health Conference. They attend almost all conferences that, to some extent, involve their line of action.

Concerning councils, commissions and committees, GAPA has representatives at the State Health Council, State STD/AIDS Commissions, National Health Council, Advisory Committee to the National STD/AIDS Coordination, Vaccination Committee in CEPS and in Committees on Ethic and Research.

According to GAPA leader, when the Municipal Council was established the organization was appointed to make part of it. In the State Health Council they represent the pathology carriers in the state. The NGO also holds seat in the National Health Council, representing the National AIDS Movement. It participates in the Municipal Council on Women Rights, as well as in the Human Rights Council, but they are not attending the latter because they lack personnel, but its vacancy is granted. Concerning the Vaccination Committee – a national sphere – it is one of the five participating Brazilian NGOs. They also have representatives in the Committee on Ethics and Research, besides participating in municipal and state AIDS Commissions that belong to the Health Councils. Furthermore, they participate in the Advisory Committee of Sex Professionals and in representations that deal with human rights and gender. The NGO participates in the Coordination of the Commission of the Conference on Pharmaceutical Assistance of Drugs and, therefore, they were invited to participate in the Organizing Coordination of the State Health Conference.

According to them, these representations bring other invitations and the organization lacks personnel for so many representations. Therefore, GAPA works at federal, state and local levels.

They do not participate in the state AIDS Forum, although GAPA is one of the organizations that founded it.

According to the NGO leader, emphasis is placed on social control:

The people who assembled GAPA always followed the principle of social control. GAPA is comprised by the Law of the Municipal Health Council of Porto Alegre. GAPA is an appointed institution, it is not representing. For example, in the National Council – GAPA is there, but it represents the National Pathologies Forum. In the Forum, GAPA was elected by the AIDS movement to be there. Here not, in Porto Alegre we are part of the law. The law reads: Grupo de Apoio à Prevenção da AIDS. Similarly, the State Health Council: We have always been there, since the beginning. Since the State Health Council establishment, in 1992, GAPA has participated in it. GAPA understands the participation in social control as a priority of the institution, rather than of a person.

25) Partnerships

The NGO has partnership with State and Municipal STD and AIDS Coordination, with the Health Secretariat, the Program Coordination Units, the Human Rights Secretariat, the Government Prosecutors Office, the Ministry of Justice, NGOs/AIDS, NGOs/mixed, private institutions and other social movements.

According to GAPA leader, they keep good relationship and partnership with the Judiciary Power, with other social movements, with the federal and the municipal government. However, they claim difficulties with the state government in relation to the field of public security and health.

The Judiciary Power is a strong partner to GAPA, we have good relationships with prosecutors, attorneys and judges. We have a sound partnership with the Federal Government Prosecutors General, and much lesser to the State Government Prosecutors Office. Our partnership with other social movements and the government is good – sometimes better, sometimes worse.

We are facing difficulties in our relationship with the state government, due to the repression against prostitution in Porto Alegre. The repression comes from state government, rather than from the municipal. And it brings difficulties to everything. This government is taking down things we have fought for over the last fourteen years. Problems came with this new management. It is an important partner for us, and we have difficulties in this field of public security.

In the field of health, our partnership is facing some problems, but they are important partners. We must keep this partnership; we have to try to enhance this partnership. This is something that is being left aside. But with the social movements our relationship is very good.

26) Incidence on Social Programs and Public Policies

The NGO participated in public governmental policies related to access to early diagnosis, free access to medications, treatment, preventive devices, NGO capacity building and human rights and citizenship.

According to GAPA leader, they are expanding the debate on AIDS beyond a given field, to health as a whole.

When we participate in the Council, and discuss AIDS-related policies, and extrapolate to the discussion on health as a whole, we show people that AIDS is not isolated. We show that it has much to do with the National Programme on Women's health, its strong interface with pregnant women. And we have to qualify the professionals who work on AIDS, so that they indicate a HIV test during pre-natal exams. We start the training here. The Women's Health Programme held a qualification program to work on other issues in pre-natal care, and they must go together to optimize things.

Furthermore, the NGO states that they are influencing public policy as a whole, at all levels. Not only in health, in terms of services, but they are also working on financial issues, such as the budget.

If the money for health is short, we have to fight for more money; but if you don't have much, you should at least employ it well. I think this is something we have succeeded in the councils and when we are discussing public health policies. We are doing it well. When we participate in the Women's Council, or Human Rights Council, we bring this issue and extrapolate from health to other topics. I think we do it well; we are doing it. We may have not yet made this message clear to more people.

According to them, even in the forums people think that conquers in the fight against AIDS are privileges rather than rights. And this right is the same for all, for AIDS, hepatitis, tuberculosis or cancer. They ratify the thesis that when public policy is worked in a broader way, it enters in the field of basic rights, and discusses issues of gender and worker's health. So, when the discussion is on AIDS, it also

approaches issues broader than a mere epidemic, “It does not mean that it is more important than the other epidemics, but it comprises factors that go beyond the HIV virus, such as factors of vulnerability or risk, or added risk”.

GAPA/RS affirms that it must work, at the political level, challenging the budget, pharmaceutical policy, public health policy, since GAPA represents and is supported by the national AIDS movement in the National Health Council. They are joining other social movements to grant better quality of life and health services – a principle of SUS.

We are in the National Forum on Pathologies and Persons with Special Needs, gathering to people with visual impairments, physical impairments, and with Down’s syndrome. Because it is a fight of the Brazilian society of health quality, better quality of services, we have to work under the concept set forth in the Conference of Alma Ata [International Conference on Primary Health Care, in Alma – Ata], in 1978, according to which health is not the opposite of disease. Health is quality of life, comprising food, transportation, housing and labor. So, let’s discuss health over this – a principle of SUS: Health as quality of life.

The respondent emphasizes this expanded perspective, where health is equated to quality of life and epidemics are also considered according to conditions of life, social exclusions and unbalances. This requires not only for care with a disease when it is considered an epidemic, but also when it is conditioned by situations that structure social life. Still according to the respondent, it is also the base for the NGO political sustainability that, in turn, activates its economic sustainability, “And it provides us political sustainability, and we believe that through it we will obtain the financial part when we provide visibility to our political actions. We have to work on public policies to have the financing”.

The NGO stresses that the state should play a basic role in this picture, and the national production of medications is crucial:

But the state should comply with its responsibility. There is the issue of imported medications, people are appealing to court. The Health Secretary went to the State Health Council and said that the number of suits claiming for

medications and beds will take the State of Rio Grande do Sul to bankruptcy. What is this policy on pharmaceutical assistance that we have in Brazil, where our all of our medication is imported? Why don't our laboratories produce them domestically? To produce even the most ordinary antibiotic, like Bactrim, we have to import raw material from India. If India does, why can't we do it? What will our posture be in the National Conference on Pharmaceutical Assistance in this matter? Because there is no use in saying, "The state will go bankrupt". What is the state doing to revert this situation?

27) Organization Sustainability, in Mid and Long Terms

According to the NGO, it is necessary to become more and more independent from the World Bank financing through the STD/AIDS Coordination. "Break this link of state paying to NGOs. If we could now finance us without resources, not of the World Bank, but of the Ministry of Health, that would be better for us". On the other hand, it defends the continuity of international financing, and that it should be direct, with no interference by the Ministry of Health: "So we submit the project to the MacArthur and the MacArthur finances GAPA. The Ford Foundation finances GAPA. Direct negotiation between them and us".

They state that they know how to manage this kind of direct relationship, in opposition to the institutions that feels committed to their financing agent, and do not feel easy to claim for actions, for fear of loosing the financing. Sometimes it is hard to criticize the organizations that grant financing, and the NGOs must have this freedom. At the same time, the institution reports that usually NGOs are subdued: "We, here in the GAPA, would rather to be independent from state financing, to have direct relationships".

They argue that GAPA work has more to do with political sustainability than with financial sustainability. In thesis, political sustainability would lead to financial sustainability, but they assume that this is not a linear association, easily put into practice, mainly because AIDS is not endowed with the required social legitimacy.

First, you have to become known, and then respected, then ... But we have built political sustainability and the financial, despite the society support, we still depend on the government's needs. On the relationship with the government, because AIDS is still a hard topic to the civil society. We understand that political sustainability leads to financial sustainability. We have this view, we have not yet reached it, but we believe in it.

28) Interlocution with Governmental Spheres, in the Field of the AIDS Epidemic

The NGO affirms that, when they have governmental financing and the use of this resource is not part of the organization's priorities, they just don't perform the action.

Concerning the relationship between the civil society and governmental spheres, concerning the fight against AIDS and assistance to HIV carriers, GAPA representative affirms that their initial intention was not to establish a relationship between the civil society and the governmental spheres but, somehow, "the state co-opted the AIDS movement". Therefore, they became executors of a policy on AIDS and service providers, since the government cannot be up with the demand.

For this major good, we were taken to become executors of governmental policies. So, we have to play the government role in relation to legal assistance, but the work we perform in legal assistance – which is specialized, we have lawyers specialized in AIDS – is nothing else but free justice, and the state should provide for this. We are a sort of public prosecutors office. But, since they cannot meet the demand, we have to take care of their demand – either in an absolutely volunteer way, or executing a defined and paid project.

So, we will play the role of capacity builders in this legal assistance, we will organize great seminars at low cost, but within the scope of that project financed, and so we will execute the policies that should be governmental policies.

The state was awarded with the Bill Gates prize – one million dollars. How nice would it be if we won a million dollars, let's grant fifty thousand to the Global Forum on AIDS, Tuberculosis and Malaria, and the remaining nine hundred and fifty thousand dollar we will share with NGOs developing works on supporting houses, temporary shelters! So, we are once again service providers, we are changing towards becoming service providers. We receive money to render a service that the public sector can't cope with, so they hire

the private party through agreements – the same thing that SUS does. The SUS can't cope with all public actions in public hospitals, so they hire private hospitals. Here, the state cannot cope with social issues related to AIDS patients, so, we are an executing branch to the Ministry. When we talk about prevention or support to people living with HIV/AIDS in another way, human rights, work on citizenship, self – esteem. All that we do pretty well, and the government can't do it, and we do it well. So we are playing our roles.

The institution believes that NGOs' involvement in services provision has weakened their autonomy besides the state, i.e, their perspective of pressure and criticism, while financing would have contributed towards increasing the number of NGOs/AIDS.

What happened is that many of us have extrapolated this role, and became executors of a policy with which the government couldn't cope. And then we lost the independence.

As of 1994, Brazil had about a hundred NGOs and, from then on, we grew to about five hundred. In 1994 the Ministry started financing and projects, we can't deny that many NGOs were established because of these resources, except for the homosexual movement that already existed. So, this resource was employed to increase and improve their insertion. Great, this is your role and this is the financing role! But when we start creating and can't cope with the creation of this service, we loose our point of criticism: "Will I criticize those who pay me won't criticize those who pay me".

Concerning the success of the fight against the epidemic, the NGO affirms it is strongly related to political power, the willingness to do, activism, the Brazilian way of solving problems: "because when we have a common enemy, we gather powers". According to GAPA leader, AIDS is a common enemy to many people and many institutions, as were cancer and tuberculosis when they arouse.

The statement of GAPA leader discloses the concern with the sustainability of the successes reached by the AIDS movement, their fear that the movement gradually lowers the guard, the investments, the political willingness currently place on this field. They fear that, if a different pathology appears, AIDS comes to undergo the same situation as other diseases:

We will no longer have this position, and then I don't know if what happened to our success (in AIDS) the same as what happened with cancer and tuberculosis. The services to tuberculosis patients, in some places, are totally wasted for the lack of investments. A service was being performed, the active pursue for treatment was wasted along time. The same will happen to AIDS services. Over time, this mega-construction may become totally wasted. So we should re-think this success deeply and calmly. I have a concern in relation to AIDS: people say it is working well, because in fact this is the right time to work well; but if we don't think about forthcoming moments, this 'going well' will go down the river, in my opinion.

Another GAPA coordinator raises the issue that the epidemic brings a view of personal tragedy, in the sense of disease, mortality, and dependence. Nevertheless, the coordinator also points out some positive aspects of the Brazilian actions on fight against AIDS, which influenced the way of being with AIDS, like enhanced self-esteem, self-determination, improving the individuals' quality of life.

Following the same line of stressing expanded effects of the epidemic in general, and particularly of the movement that undertook actions against it, they mention the visibility to socially marginalized and hushed groups, like the homosexual. They also believe that it enhanced "the discussion on gender and rights".

According to the respondent, this process of discussion on rights happened due to the government financing, through projects, and they claim that, more than financing services provision, the government should provide investments in cultural citizenry, for rights:

Homosexuality, lesbianism and gender issues are discussed because they rely on financing. I think this is the government role: to foment and finance discussions over these concepts; promote the discussion about these background issues, rather than financing service provision. You will discuss gender issues.

They believe that the investment on cultural socialization about AIDS allowed, for example, the expansion of gender beyond the circle of feminists, "to be horizontally discussed, instead of vertically", i.e., by several groups. In this regard, the investment that allowed enhancing the civil society action in the field of AIDS would have been positive also to promote rights, and civil society

in general should be re-educated in the field of rights, interlacing the specific and the universal, and deconstructing asymmetries and discriminations. It would also contribute towards the organization around AIDS, to challenge traditional ways of exercising knowledge, as in medicine, calling attention to the importance of a systemic perspective about the treatment:

AIDS brought about this discussion even in the field of medicine. I think that AIDS did that, and the medicine did not notice. Because when we say that we must perform the systemic approach of treatment, we are proposing the work with psychologist, social assistant, doctor, nurse; you perceive that the body is no longer one, and AIDS brought it. Let's define all together, let's review everything. And I think that AIDS caused it, to some extent. We succeeded in showing that things depend one on another.

The systemic perspective defended by the respondent also comprises the importance of relating medical investments to conditions of life: "There is no use in providing a wonderful treatment if the person doesn't have food, basic sanitation, job and housing".

Furthermore, the respondent highlights the contribution of the Brazilian National AIDS Programme to the recovery of individual and collective self-esteem, the acknowledge of rights to groups such as travesties and sex professionals:

I think that when the National AIDS Programme financed some projects, it also financed this discussion. For me, this is one of the major merits of the National AIDS Programme. To show that travesty is a human being, not only for him, but also for the society. That he has the same rights, pays the same tax. He has the same rights as a doctor.

The respondent has doubts as if the Brazilian Programme on fight against AIDS "is the best worldwide, or is the only one and, therefore, there are no parameters to compare it to other programs". The respondent also highlights that this success is partially due to the fact that it is inserted into the Brazilian Unified Health System, "which allows for these things to happen".

Another question posed is if the Programme is *optimum* because it distributes medication. According to the institution, the Programme distributes medications because there is a law in Brazil that sets forth that: “Health is a right for all, a state duty”, and provides for universal treatment. According to them, this is not a privilege of AIDS, but acquired rights, above a conquering prior to AIDS.

But it does recognize the Programme merit in affording with medications and universal access, since the World Bank resources do not finance assistance actions.

They report structural limitations to the actions developed in the Programme: “In the whole structure, you spend six hundred dollars with a drug named Fenofovir, and the person received the drug and don’t have even a hundred reais to eat. So, there is no use in spending six hundred dollars to purchase the drug”.

About its criticisms to the Programme, the respondent argues that, although having a constructive sense, the civil society is negligent in making such criticisms and, on the other hand, the government barely understands them in that sense:

We are not against it; we are arguing that, although it is a Programme on AIDS endowed with a capacity of resolution stronger than the other Brazilian health programs, it doesn’t mean that it is an excellence as a program. Because it is not closed on itself, it is related to other programs. So, it suffers interferences from the others, it must interact and it doesn’t know to interact. Then, when you criticize, they think it is a personal criticism, they get hurt. And then people are afraid of criticizing, because they will hurt [the government] and loose the financing.

F.2. MMRD – Movimento Metropolitano de Redução de Danos

- 1) Organization Name – MMRD – Movimento Metropolitano de Redução de Danos**
- 2) City/State: Porto Alegre/RS**
- 3) Date of Foundation: 9/2000**

- 4) **Started Working with STD/AIDS in:** 2000
- 5) **Kind of Organization:** Social movement.
- 6) **Address/Phone:**
tonmachado@bol.com.br
Tel: (51) 9181 – 12 – 82
- 7) **Situation Concerning Headquarters**
Currently, it has only the address but does not have headquarters.
- 8) **Field of Action:** Prevention against HIV/AIDS.
- 9) **Priority Field of Action:** Damage reduction.
- 10) **Geographic Area of Work:** Regional.
- 11) **General Purposes**
 - Develop activities on damage reduction related to two axes: Prevention against AIDS and undue use of drugs;
 - Capacity building and Training.
- 12) **Target-audience**
Drug users, HIV/AIDS virus carriers, community-based health agents, health technicians and the population in general.
- 13) **Core Activities**
 - Implementation and maintenance of projects on damage reduction;
 - Training to health experts and the population in general about prevention against AIDS and the undue use of drugs;
 - Workshops on awareness building.

14) Ongoing Programs and Projects

Two projects financed by the National STD/AIDS Programme (one PRD and one on capacity building to community-based health agents on drugs/AIDS):

We have three approved projects. One is called Treina Gente, with specific Target-audience made up by community-based health agents, aimed at damage reduction, exchange of syringes and collection of hospital waste. It reaches most populations, aiming at building sensitiveness and capacity among community-based health agents towards basic care to drug users and their network of social interaction. One is the project that aims at building sensitiveness among the municipal narcotics councils, to sensitize managers in relation to the policy on damage reduction. Another is that of Cachoeirinha, the only one aimed at a specific audience of users of injected drugs.

The NGO also has special approved projects: three projects approved by the National Programme, UNODC and UNESCO and *according to the actions developed in these projects, we establish the so-called workgroup – WG.*

15) Services Provided to Population

- Workshops on awareness building;
- Practical internships for individuals who want to know the work of damage reduction;
- Supervision of teams working in programs on damage reduction;

16) Works only with AIDS: No.

17) Works advertised through:

Books, videos, printed material, congresses, conferences meetings and seminars.

NGO Background

18) Origin of the institution

The *Movimento Metropolitano de Redução de Risco* was founded in September 2000, by people with experience in the field who were from the Rio Grande do Sul State Network on Damage Reduction Agents. It intended to expand the damage reduction actions to the cities in the metropolitan region of Porto Alegre, since this region accounts for over 70% of AIDS cases in the state. They have about twenty members.

19) Organization's Motivation Towards Working with STD/AIDS

The organization has worked with STD/AIDS since its foundation. The people who organized the institution had already worked with chemical addiction for over ten years, *since in this picture of chemical addiction there is an increased number of drug-using individuals who were virus carriers*. Those who did not work with AIDS had some family member who was virus carrier. Currently, due to financing, they work more on STD/AIDS, but have not changed their focus on the issue of chemical addiction.

20) Resources and Financing Sources

The sources of financial support to the entity are: Agreements with public entities, international cooperation agencies and sporadic sponsorships. According to the NGO representative, the direct sources of financing are the three projects approved by the Ministry of Health, and there is the perspective of holding a partnership with some municipalities in the scope of the fund-to-fund transfers. They also undertake some works from time-to-time and raise funds by teaching classes and providing consultancy services.

21) Human Resources

The MMRD employs the strategy based on the experience and daily practices. In light of this, the professional psychologists and

lawyers may learn something with the incoming user, with the ex-user who works, and vice-versa. There is not formal capacity building. Through a partnership with the Public Health School, some people attend the course they sponsor, while others participate in the elaboration of courses delivered by the school on drugs and AIDS, “So there is no moment we could call formal, but there is a broad repertoire of activities. Thus, we try to spread and exchange this knowledge by sending other people to participate in other events”.

They intend to establish capacity building activities to reduction agents, because there are too many newcomers.

22) Work Methodology

The MMRD performs its actions and projects based on workgroups that discuss projects and topics. Each workgroup and project is endowed with autonomy to develop their actions, while keeping constant communication with the respective coordinators.

To assess the actions developed, the MMRD prepares a plan at the beginning of each year. By the end of that year, they assess what was undertaken and the impacts on the target-population.

The *Movimento Metropolitano de Redução de Danos* faces difficulties in developing its activities because of delayed transfers of resources.

The fact of not having received the money greatly jeopardized some things we had to do; there were many things that we couldn't do, regardless of how hard we tried. Last year, we did it things to a minimum because through the partnerships we established with schools, with the Health Unit, we succeeded in achieving our objectives.

In the field of problems faced, they also highlight the factors of vulnerability to their target-audience, which contributed towards worsening the situation and limiting the NGO's actions and scope:

It is a vulnerability situation to our target-audience that the project sometimes must face, and it requires for deeper reflection on the action being performed. This is also a vulnerability of the NGOs. It is necessary

to understand the situation of the target-audience, and then value these persons, their daily lives, their realities, and try to develop an action. They are in a vulnerable situation, be it for the use of drugs, or for poverty. So, the situation of vulnerability may be granted with a public policy on better income distribution, improved quality of life; meanwhile, we try to do something, possible to be done. While it doesn't change, we keep on drying the floor while until we can get the rood fixed, because whenever it rains the floor gets wet. What we are doing down here is drying the floor.

The MMRD also emphasizes the difficulty in obtaining enough devices (condoms and syringes) to deal with prevention against HIV/AIDS.

Concerning the NGO technicians who work with users, the movement also highlights the visible changes in these users' lives, because they change their view on the situation, the prejudice, and the way of working:

I have already seen extremely complicated drug users changing; I am not mega-crazy enough to state that it was because of the NGO or the work it develops. Maybe at that time, the user noticed something he/she appraised, and it led him/her to leave this process. So, we have noticed some improvement, at least where a PRD is installed, and where there are people or logical actions that follow the philosophy of damage reduction. At least, this user already has something he/she missed, i.e., a place to go to complain, talk and be welcomed that didn't exist short time ago.

As the major challenge to be faced to reduce individual and collective risks concerning HIV infection among its target population, and to changing the life of beneficiaries, the NGO mentions the method they employ to develop their actions. "I could notice that the capacity building brings something of that classic training, that thing of teacher, student, everybody sitting down. It lacks that progressist thing of valuing the subjects, their story, and touch them: it lacks interlocution, a chat with the population".

23) Political Articulation

MMRD is affiliated to the Brazilian Association on Damage Reduction – ABORDA and to RELARD.

24) Partnerships

The major partnerships established to develop the MMRD actions are with the State STD and AIDS Coordination, the Municipal STD and AIDS Coordination, the Health Secretariat, the Program Coordination units, NGOs/AIDS, and other segments of social movements.

25) Incidence on Social Programs and Public Policies

The MMRD participated in the discussion and elaboration of public governmental policies concerning the access to early diagnosis, free access to medication, to treatment, to preventive devices and NGO capacity building.

It participates in the Health Council, the Municipal and State STD and AIDS Commission and the Advisory Committee to the National STD and AIDS Programme. Furthermore, it integrates the advisory group to the Health School.

The MMRD usually has representatives attending the Municipal and State AIDS Conferences.

26) Organization Sustainability, in Mid and Long Terms.

MMRD's concern on sustainability can be observed in two aspects, mainly: Actions on damage reduction, and sustainability of participants working in this area.

There are two concerns: whether we work towards having actions regardless of our existence, or we hold this way of acting, whereby damage reduction would happen only if our participants could work. So, this is an identity crisis that, in short-time, is under control. The issue of AIDS is far from being solved, and the issue of chemical addiction requires for actions. The problem is that some people have no other earnings than the NGO, so they make their lives there. So, militating without earning is very complicated. The NGO is small, resources are short. So, this is a crisis we could say has been under control up to now. We are trying to put out the fire and put things straight today. Tomorrow will be fruit of what we succeed in working and accomplishing today.

In the representative's view, a threat to the actions' sustainability is related to the professional qualification of those working with HIV/AIDS.

Another problem mentioned was the lack of continuity to actions, even when they are financed, "We are trying to provide some continuity to all actions planned".

A strong point mentioned was the approximation between different governmental spheres and the NGOs, when discussing some action to be undertaken in a given municipality:

Because of the work it performs, the movement is called to participate and is heard, also in the field of policies for some municipalities, mainly on the issue of HIV/AIDS in some Municipal Health Councils. When we go there to discuss some actions planned for the city, we discuss with the Municipal Health Council, and this brings us closer. Sometimes we talk to the Health Secretary or even to some Mayors.

27) Interlocution with Governmental Spheres, in the Field of the AIDS Epidemic

Concerning the impacts of governmental financing over NGOs priorities, the MMRD states that one of the negative aspects is the delayed transfer of resources by the Ministry of Health and local municipal government. "We are afraid of developing the actions, because the financing may fail. We waste time, and our work becomes jeopardized".

In the plan of positive aspects, they underline the victories through this same process of resources transfer. It allowed for purchasing equipment, transportation means and materials. According to the organization representative, some gaps are yet to be filled, because the NGOs have, in fact, "Became addicted to working with projects", and have no time to invest on their own projects. In their opinion, the NGOs are now dedicated to the National Programme, "Which is now decentralized, and takes all of the time". Furthermore, they add, this environment leads to non-investment in other sources of sustainability.

Another issue in the field of sustainability concerns the technical field, since people working in the organization must share their time, thus limiting the work with volunteers:

People must survive; people must have their earnings. They cannot be dedicated to the organization without receiving payment. They must have a source of income to survive. So, in my opinion, this is one of the major problems in the social movement: the lack of people's engagement with the movement, because they don't have time available for that. And then, it affects sustainability. And lacking personnel, they don't create projects, and even lack personnel to develop the institution projects.

According to the MMRD, the lack of projects does not jeopardize the NGO work, "Because we keep on working with or without projects". They state that, initially, NEP spent ten years without any projects. "So, it wouldn't be a project that would stop us as a movement. But it jeopardizes the financial aspect, even because we can't pretend, we don't have money. This is our reality".

As a positive aspect in the Brazilian experience, the NGO mentions the government donation of material, mainly condoms. However, they emphasize that financing is not enough to afford the NGO's needs, especially in relation to its development. The MMRD criticizes the non-engagement of the state with the organized civil society organizations:

What we ask the state for is what must be made available, i.e., the condoms, and we have that. But the fund-to-fund is extremely low, and cannot even afford the monitoring, because who will work, who will monitor streets, day and night, with no financial gains? It is complicated, because wages are very low. The amount to pay personnel is one hundred reais, if enough, and this also jeopardizes the intervention mainly when we are dealing with street intervention, because one or two people cannot do that and the internal work as well. We must have a team to work on the streets and another to work here because we have expanded. Now we are a reference in the work of prevention among female prostitutes.

I think that the state should be committed to the institutions. But in the sense of being with us in our difficulties, being together, follow-up. Neither does the

state transfer funds, nor do the follows-up. So, either they don't notice the difficulties, or they neglect them, and then they don't have to transfer, because they don't know about the difficulty. So, I think that the state should be with us, know the work, because our doors are always open. And if they know about our difficulties, they may help us in something, but they don't even worry about following-up.

They state that STD/AIDS financing is a priority to the maintenance of NGOs/AIDS. Therefore, they report the impossibility of planning for long-term actions:

Our state doesn't finance our projects. We don't have any project financed by the state. Only at the federal level. What the state did for us, last year, was to provide subsidies to an event we hosted. When we have these emergencies of events, where the National Coordination projects don't work, so we appeal to the state and it covers this deficiency of those projects. Because the condoms provided by the state are also provided by the National Coordination, distribution is decentralized.

As a consequence to the statement above, they find a great dependence of NGOs/AIDS on the federal government, in the field of financial support to sustain the prevention actions carried out on the streets. And this is a negative aspect, because there is no other alternative to continue these actions.

The MMRD considers people's awareness on prevention as the outstanding component of the Brazilian actions of fight against AIDS:

I used to hear a lot of people saying that AIDS was nothing but another disease; but now they know that this is not so. They know that AIDS may become nothing but another disease if properly treated, but also that it may bring about many conditions and, therefore, it is worth preventing. They are now aware that the best way is prevention, there is no use trying to remedy later; it is cheaper to prevent than to remedy. So, I think this was a gradually-built way of thinking.

Concerning the relationship between the civil society and government, the *Movimento de Redução de Danos* has indirectly influenced this construction, by raising the issue in commissions

and, therefore, the problem is contemplated in policies aimed at the HIV/AIDS in municipalities. This fact qualifies the Movement participation in the social control spheres. “Maybe we don’t have direct influence because of the resistance. But, when you say where you work, who you take care of, when you talk about those who suffer from the HIV issue, prejudice and fear, you sensitize these spheres”.

According to the representative, despite some self-criticisms and criticisms to the Ministry of Health and to the National STD and AIDS Programme, such as the lack of skilled personnel to deal with the issue and therefore expand the autonomy, the MMRD considers its relationship with the federal government as positive:

This relationship was good, but I think that – and here I make a self-criticism – if I had not become so dependent on this money, maybe I would be better now. Concerning the Ministry more specifically, they should – they could even furnish us with the required tools, provide us subsidies, train us, and allow us to walk by ourselves. Sometimes we don’t do things not because we don’t want to, but because we don’t know, we can’t, but we want to do things. So, I think that the Ministry – not only the Ministry of Health, but the National Coordination as well – should invest money in the qualification or training of people to work and thus allow them to walk by themselves.

Concerning the impacts of governmental financing over the organization’s political actions, they affirm that, to some degree, partnerships lead to the loss of autonomy. On the other hand, they believe it teaches a different policy that is based on dialogue:

The Government and the NGO must learn to sit together, disagree, make alliances, talk freely, with no threaten by the NGO to go to the press, and without the threaten by the government of cutting down on the financing. They should keep a dialogue for something consensual. If governmental institutions are really interested, and the NGO is really interested, so I think that things flow; however, sometimes the participants don’t have good intentions.

Look, our actions have not been influenced because we have strong autonomy for doing whatever we want, the way we want. Obviously, when we receive foreign financing, they influence only over the financial aspect, to know how the money is employed, the expenses must be very well documented. Our actions are totally autonomous.

F.3. NEP – Núcleo de Estudos da Prostituição

- 1) Organization Name:** NEP – Núcleo de Estudos da Prostituição
- 2) City/State:** Porto Alegre/RS
- 3) Date of Foundation:** 2 November 1989 – Registered in May 1993.
- 4) Started Working with STD/AIDS in:** 1989.
- 5) Kind of Organization:** Civil Society Organization – OSC.
- 6) Address/Phone:**
neppoa@portoweb.com.br
Tel: (51) 3221-45-08
- 7) Situation Concerning Headquarters**
Through partnership with the local government, they received the premises. The local government pays for electricity, water and condominium fees. Their telephone line belongs to the *Corregedoria dos Conselhos Tutelares* and they have an extension. The *Corregedoria* pays the telephone bill.
- 8) Where it Performs the Activities:** NGO headquarters.
- 9) Fields of Action:** HIV/AIDS and female sex professionals.
- 10) Priority Field of Action:** Female sex professionals.
- 11) Geographic Area of Work:** Regional.

12) General Purposes

- Work with female prostitutes in three areas: self-esteem; health (prevention against STD/AIDS), rights/obligations and citizenship.

13) Target-audience: Female sex professionals.

14) Core Activities

- Intervention in prostitution zones;
- Workshops on health to qualify multipliers of information on STD/AIDS;
- Referral to first consultation and preventive exams.

15) Ongoing Programs and Projects

Tenda dos Desejos Project, financed by UNODC in partnership with the Ministry of Health, aims at providing information on prevention to population in general.

Damas da Prevenção Project, holds specific workshops in the institution, dealing with: Prevention against STD/AIDS, knowing the body in general, damage reduction, and all sort of legal and illegal drugs, rights and citizenship, workshops with lawyers, adhesion to medication and better quality of life to seropositive women.

Mulher no Ponto Project, financed by UNESCO, works with workshops on rights, citizenship and health, in the institution.

Esquina da Noite Projeto – this project was carried out by the Brazilian Network of Sex Professionals coordinated by the NEP, with the partnership of the State and the Municipality. This project was aimed at bringing twelve institutions from the south region unit to deliver forty-hour workshops on capacity building. Classes on issues such as: What the social movement is, how to work on self-organization; how to work the stigma, the prejudice and discrimination against

prostitution; how to work on prevention against STD/AIDS; and the establishment of movements in all cities of the States of Rio Grande do Sul, Santa Catarina and Paraná.

16) Services Provided to Population

- Educational lectures at schools and universities;
- Timely campaigns: December 1st, Carnival and International Women's Day.

17) Works only with AIDS: No.

18) Advertises the Work Developed Through:

Pamphlets, posters, brochures, magazines, journals, printed material, participation in congresses, conferences, meetings, seminars and other means, such as TV, radio, newspapers and e-mail.

NGO Background

19) Origin of the Institution

Association of female prostitutes, aimed at working on prevention against STD/AIDS, fight against prejudice, discrimination and police violence.

After the meeting of the association of female prostitutes in Rio de Janeiro (DA VIDA), they decided to start working on prevention against STD/HIV/AIDS in Porto Alegre, with prostitute women. The first actions were performed on the streets, at the most visible prostitution zones in Porto Alegre. Initially, these actions were focused on the distribution of condoms and information on prevention against STD/AIDS. Throughout the work, the group learned about the violence against prostitutes. So, they decided to leave prevention against STD/AIDS aside, and started working in the field of advocacy and citizenship:

The prostitutes should be organized to denounce this violence. And we left aside the prevention against STD/HIV/AIDS to work on citizenship and prevention against violence. Our thought was that no one would care about health while they were being attacked; no one would care about health while they are starving and are unemployed; no one would care about health while being taken to the police station. Later on, in the late 1990's, they incorporated their initial priority: to work on prevention against sexually transmitted diseases and AIDS.

In the beginning, they were called the *Associação Gaúcha de Prostitutas*, but when they tried to register the name in 1991, the Public Notary Office refused the name because, according to them, prostitution was not recognized as a profession and, therefore, could not be registered as an association. From 1991 to 1993 they tried to change the name, and finally obtained the register as *Associação Núcleo de Estudo da Prostituição*.

20) Organization's Motivation Towards Working with STD/AIDS

After the meeting of the prostitutes association in Rio de Janeiro (DA VIDA), they decided to start working on prevention against STD/HIV/AIDS in Porto Alegre, with female prostitutes.

21) Resources and Financing Sources

The sources of financial support to NEP are: Donations made by individuals; agreements with public entities; international cooperation agencies; sporadic sponsorships; and the *Função Luteterana de Diaconia*.

In the beginning, the NGO had no projects, and was supported exclusively by the World Council of Churches. The prostitute members of NEP contributed to the organization with monthly quotas equivalent to half of the price charged for a *work*. This contribution was employed in transportation to get condoms at the Secretariat, to take someone to the hospital when necessary, or to funeral services for deceased members.

22) Human Resources

It attended the capacity building training delivered by the Brazilian Network of Sex Professionals. In 1999, after the capacity building course, they carried out the first project to the Ministry of Health. It was the *Mulher no Ponto* Project, the first one financed by UNESCO. As of that year, NEP carried out several workshops to qualify prostitute women as monitors and multipliers of the institution's projects.

The *Esquina da Noite* Project was an action by the Brazilian Network of Sex Professionals, coordinated by NEP. This project aimed at bringing twelve institutions of the south regional unit, two from each institution, to promote 40-hour capacity building workshops. These workshops were focused on the following topics: movement; how to work on self-organization; how to work the stigma, prejudice and discrimination against prostitution; how to work on the prevention against STD/AIDS; and the establishment of movements in all cities of the States of Rio Grande do Sul, Santa Catarina and Paraná.

23) Work Methodology

The NEP undergoes continuous assessment. They hold regular meetings, that usually take place once a month, to discuss the daily life of the institution: compliance with working hours, interventions, compliance with duties assigned, projects assessment and their development.

Everybody knows about what is happening, we discuss about what is to be purchased, we discuss about everything to be paid for. When the year starts, we discuss the programming for the following year. Based on strategic planning, if we cannot afford for a strategic plan, we prepare a work program.

24) Specific Problems with Experiences.

In the field of experience with Sex Professionals, the NGO points out a problem concerning the lack of media cooperation to the campaign on the use of condoms. They also believe that the federal government investment concerning hepatitis is not enough:

(The media) does not provide enough information to educate people. They show the condom very quickly. They don't say where and how people can purchase them. I think it should be more focused on information, because people lack information. STD-related issues are yet to be worked on. Like this hepatitis epidemics; the National Coordination has not yet invested enough. People do not even know what hepatitis is.

25) Political Articulation

NEP is affiliated to the NGOs/AIDS Forum in Rio Grande do Sul and to the Brazilian Network of Sex Professionals.

26) Partnerships

The major partnerships established by NEP to carry out its actions are with the State STD and AIDS Coordination, the Municipal STD and AIDS Coordination, the Health Secretariat, the Program Coordination Units, the Human Rights Secretariat, Government Prosecutors Office and other Programs and/or Secretariats of the Ministry of Health, the NGOs/AIDS, the NGOs/mixed, the private institutions and other segments of social movements.

27) Incidence on Social Programs and Public Policies

It participated in the discussion and elaboration of public governmental policies concerning access to early diagnosis, free access to medication, to treatment, to preventive devices and NGO capacity building.

It holds seat in the Health Council, the State STD and AIDS Commissions, the Advisory Committee to the National STD and AIDS Programme, Forums and Secretariats.

At the municipal level, we participate in the human rights entities, Municipal Health Council, State NGOs/AIDS Forum, COMDIM, and Municipal Women Rights Council and in the City Council. We participate in the municipal and state councils on human rights, health, women and NGOs/AIDS Forums.

The organization usually sends representatives to ERONG, ENONG and Global Social Forum. Furthermore, the institution held the 1st National NEP Seminar, entitled '*Prostituição não dá para discutir em qualquer esquina*'. The event was financed through the partnership with

the state and local governments. The seminar was attended by people from Montevideo, Rio de Janeiro, Belém, Fortaleza, and Recife, i.e., several places that rely on Prostitutes Associations. The Seminar – a sporadic project – was oriented to advertise the work, provide visibility to the issue, foster exchange of experience with other prostitutes, bring foreign institutions, and strengthen the institution's internal movement.

28) Organization Sustainability, in Mid and Long Terms.

The organization sustainability is based on proceedings from financed projects, which are mainly employed in action, and not necessarily to maintain the institution's human resources.

We work rather with project resources that are not for us. I keep instructors, monitors and project coordinators. Here everybody works as volunteers, because if we don't have projects, we won't stop the work, it will continue. But it is very hard for us.

But that is how projects are: When we sum up everything and divide for all, each person earns something, at least to cover transportation costs. Because if the institution pays for project coordination, project coordination assistant and monitoring, I think that sometimes it is unfair, taking into consideration that the others also have needs. This is an especially hard year for us; we have two small projects, with terrific cuts because of this readjustment, because these changes are in the Ministry. But we are seeking for external resources.

The NGO believes that financial difficulties are to increase in mid and long terms, because of the budgetary cuts, decreased financing and increased number of new organizations.

They argue that the projects signed with the National STD and AIDS Programme, in partnership with UNESCO and UNODC, are very important. In this regard, they highlight the work developed by the NGOs and social movements that are worthy of state acknowledgement:

It is very important and must be sustained at any price. Because I usually tell the girls in the National Coordination, both in state and municipalities, that they are not doing any favors when contributing to the institutions, they are doing a work. Because I doubt that with such short resources allotted to the institutions, they succeed in reaching their target audience.

So, if there is anybody doing a favor in organizing, besides working, these are the movements of Civil Society Organizations – OSC and serious NGOs that develop work. If anybody is doing a favor, that is us, because they are doing their obligation when they transfer this minimum amount they are transferring, which is really short.

29) Interlocution with Governmental Spheres, in the Field of the AIDS Epidemic

The NGO identifies as strong points to the sustainability in HIV actions, performed by the civil society, those actions developed jointly with the National STD and AIDS Programme, as well as the resources transferred to this purpose:

I think that our strengths are the works performed in partnership with the National Coordination, in the scope of national prevention projects. I think that the OSCs should take advantage of this strength. Take advantage of resources, because we practice the actions. In fact, they only do their duty of sending us the resources, and we are the ones to work.

Among threats, the entity points out those related to changes brought about by shifts in government. “The government changes, all the work that had been started stops, and it brings uncertainties, we don’t know when it will assist or jeopardize our work. In my opinion, these changes occur and jeopardize our work”.

F.4. NUANCES – Grupo pela Livre Orientação Sexual

- 1) Organization Name: NUANCES – Grupo pela Livre Orientação Sexual**
- 2) City/State: Porto Alegre/RS.**
- 3) Date of Foundation: 11/1991.**
- 4) Started Working with STD/AIDS in: 1995.**

- 5) **Kind of Organization:** Advocacy for the homosexuals' human rights.
- 6) **Address/Phone:**
nuances@nuances.com.br
Tel: (51) 286 – 33 – 25
- 7) **Situation Concerning Headquarters**
They pay rent, condominium, telephone, and electricity fees to the *Fundação Solidariedade* – a foundation bound to the *progressist Catholic religion*. They agreed on lower prices, because *they are political and sympathetic partners*.
- 8) **Where it Performs the Activities:** NGO headquarters.
- 9) **Field of Action**
Prevention against HIV/AIDS, male and female sex professionals.
- 10) **Priority Field of Action**
Gay movement, lesbian movement, bisexuals and the population in general.
- 11) **Geographic Area of Work:** state.
- 12) **General Purposes**
- Advocacy for civil, political and social rights of gays, lesbians, travesties, bisexuals and those who suffer from any kind of discrimination or violence because of their sexual orientation.
- 13) **Target-audience**
Lesbians, men who have sex with men and travesties.

14) Core Activities: Advocacy.

According to the NGO leader, the main focus is on human rights. Since the organization does not rely on specialized professionals, such as psychologists and lawyers, they work as middlemen, forwarding the denouncements on discrimination. Depending on the situation, they go farther, making protests. In the field of AIDS, they work on preventing, improving self-esteem and carrying out interventions in the distribution of condoms.

15) Ongoing Programs and Projects

The *Boa Noite Homens* Project, develops interventions in pubs, nightclubs and dancing clubs to provide condoms and information on STD/AIDS.

16) Services Provided to Population

- Counseling and follow-up on situations of discrimination;
- Lectures and conferences to educate and inform other social movements, state sectors, among others;
- Prevention against HIV/AIDS oriented to MSM, youth and adults; distribution of condoms.

17) Works only with AIDS: No.

18) Advertises the Work Developed Through:

Post cards, newspapers, books, journals, printed material, congresses, conferences, meetings, seminars and other events.

NGO Background

19) Origin of the institution

It results from the social organization and mobilization in face of challenges posed to improve the quality of life in general and, particularly, to the homosexual population.

They report that, in the end of the 1980's, a movement emerged in Brazil that was more focused on the issue of gays, lesbians, concerning the issue of AIDS epidemic. Several NGO/AIDS were created. Concerning NUANCES, it was initially composed of people from GAPA who were concerned about discussing issues that were more oriented to sexuality, homosexuality, prejudice, in addition to AIDS: *We wanted a NGO participating in political discussion, to intervene in the state and elsewhere to develop work with homosexuals, and to work on the issue of self-esteem and so on.* They registered the NGO in 1993.

20) Resources and Financing Sources

NUANCES' sources of resources: Agreements with public entities and sporadic sponsorships. The result from projects financing, partnerships, or even from sales.

These partnerships are projects, sales. The Ministry of Health gave us permission to sell space in a page of the newspaper's advertisement section. So, in addition to this sale, there are the partnerships with pubs and dance clubs, parties, and things like that. There are few contributions. And we sometimes sell things.

21) Human Resources

The NGO does not work under the usual format of other NGOs. There is no annual planning because they do not think it is relevant. Furthermore, they fear bureaucratizing the actions developed by the group, "It depends on how the entity works in political terms. We have never had an annual planning on how the NGO is to work; some day we may come to need it, we may become a bureaucracy".

They consider information on ongoing policies crucial to the NGO. Therefore, the NGO invests in the participation in courses, in maintaining open channels of communication with strategic people and other NGOs, with universities and, internally, with the institution.

We are participating in everything, discussing both institutional and political issues, courses. We are in contact with people who are skilled in this field, with other NGOs, other spaces, and universities. When things get complicated, we discuss among us a mini-planning, how things must go on, the best way, the role of each player in the entity, the do's and the don'ts.

22) Work Methodology

The group employs continuous assessment through meetings, “We assess what should be surmounted, the major problems. So, we undertake, let's say, a continuous assessment: we go on working, assessing and adjusting”.

At the time of the survey, NUANCES was organizing a publication on the *Boa Noite* Project, which had already terminated. The publication was intended to report an analysis on the project impact on the population, the campaigns developed by the group and potential unfolding, considering the implemented actions. The respondent highlights that the working principle of the NGO is the transparency of information. “Any decision by the Board is informed to everybody. All decisions, actions, follow-ups and project assessments are discussed during the meetings, are recorded in minutes”.

The NGO reported difficulties in the early stages of the project, due to the refusal of its target-audience in using condoms. This refusal was, for a while, a dilemma in implementing the work, since the NGO believes that, in the field of decisions on the the individual exercise of sexuality, they should interfere to the minimum extent. The use or no use of condoms is a personal choice and decision. Another difficulty pointed out, still in this field, concerns the unmet demand for condoms. They also state that, in some facilities, they trade the freely distributed condoms.

Despite the problems faced, the NGO considers its experience with the population served by its actions and activities as positive. This assessment is grounded on the receptivity of its audience to the NGO material. Among the homosexual populations, the NGO observed satisfaction and gratitude for there being an institution that advocates for their rights.

23) Partnerships

To carry out its actions, the NUANCES relies on the partnership of the State STD and AIDS Coordination, the Municipal STD and AIDS Coordination, the Government Prosecutors Office, the Ministry of Justice, NGOs/AIDS, NGOs/mixed, private institutions, the Culture Secretariat, Commission on Citizenship and Human Rights of the Legislative Assembly, the Security Secretariat, of other social movements and, in sporadic events, some sauna and nightclub owners.

Concerning the Brazilian Social Security System – INSS, we established a partnership with the Government Prosecutors Office, through a public action, to implement the INSS law. We also have partnership with the Human Rights Commission of the Legislative Assembly.

With the NGO *Igualdade*, we have a partnership concerning the denouncements of discrimination forwarded to us, because they have a project financed by the Ministries of Health and Justice on free public advisory services. So, since we don't have a lawyer on duty, we forward the denouncement to them, and they take the required legal steps. These people work on this cause, they are used to it, and the NGO relies on several lawyers.

24) Incidence on Social Programs and Public Policies

It participated in the discussion and elaboration of governmental public policies concerning NGO capacity building.

It integrates the Health Council, the State STD and AIDS Commissions, the Advisory Committee to the National STD and AIDS Programme and the MSM Committee.

The NGO representatives attend the ERONG forums and conferences on STD/AIDS. The Institution is frequently invited to participate in congresses, mainly at the state level, so as to disseminate its work. The group participates and cooperates, jointly with other institutions, in the organization of the Free Parade, “Every year, during the free parade, we promote an academic debate on homosexuality”.

25) Organization Sustainability, in Mid and Long Terms

The NGO considers its future unknown. It has some projects for one year, if they are renewed with the National Programme, “I could say, until January. But, for the other years, it depends on our energy, our willingness”.

According to them, several entities have become dependent on the National Programme of the Ministry of Health, because of the AIDS projects that it finances. To the institution, few NGOs, “mainly those belonging to the gay movement”, are capable of properly employing the resources and developing projects; most of the organizations, due to the lack of political debate, would have poor performance, being limited to developing assistance projects as the distribution of condoms. On the other hand, they emphasize that, probably because of the existing financing to the field of AIDS, homosexual groups are now linked to the epidemic issue, with political problems to such approach, like the fight against homophobia and against the situations of discrimination and violence that affect the homosexuals:

They organize an entity, for example, a gay group that is apparently advocating for rights, but they direct it towards total dependence on AIDS, on the epidemic. And, for us, it is a major tragedy, politically thinking as a militant to the gay movement. An issue that has more impact than AIDS is the issue of discrimination and violence. I am absolutely sure that, if financing is suspended, ninety per cent of these groups will close their doors.

Another limitation stressed concerns the control exercised by the state over the organized civil society, since it attenuates criticisms and as a counterpart says that civil society organizations should hold a social movement statute, caring for their autonomy and for the right to criticize.

They establish a relationship where that civil society sector will never have a critical sense on the state, i.e., criticize, say what they think. Because it doesn't mind, since they are fighting for hegemony. We fight all the time. Because we place our social movement as independent ones. Therefore, we believe that we may criticize any other group, any other

NGOs, any state, and any secretariat just as they can criticize us. We must keep this independence. That thing about respect, about finding out what can be done. And the state doesn't want to discuss it.

A threat to the organizations aimed at advocating for homosexuals' rights would be the discovery of a cure for AIDS, since several NGOs are specifically financed to face the epidemic.

26) Interlocution with Governmental Spheres, in the Field of the AIDS Epidemic

The group also mentions the positive impacts concerning the financing to STD/AIDS actions by the government, because these resources grant the political space they now enjoy in Porto Alegre. Without these resources, they would not reach the NGO beneficiaries, "Developing a work that the Ministry would not be capable of doing". They are aware that this happens because of the financing received.

Concerning negative impacts, they claim to be challenged by the National Programme to establish greater involvement of the Institution in more direct actions on the fight against AIDS:

We always combat asking for financing for activities related to AIDS. For example, we have never asked Ministry of Health for money for the Free Parade because we believe it is an event of the movement, and so we have to solve it by ourselves rather than asking for money, but this was not a consensus within the entity. This year, we developed a project financed by the Ministry of Health for the first time: The parade in Porto Alegre, state of Rio Grande do Sul. We know we have a price to pay for that, because we have always criticized it, as you probably understand. So, the poster will bring the name of UNESCO and the Ministry of Health. We had never had this happen, because we thought it would not be interesting in political terms. For example, we believe that seminars and meetings of the gay movement should not be financed by the National Coordination.

Concerning the execution of policies, they consider the criticism to the state bureaucracy and political interests as crucial.

I think that our performance in terms of carrying out projects is fine. It has many deficiencies as for example the transfers that suffers from delays of four or five months, and sometimes misses the rendering of accounts, sometimes for the lack of planning. I think that, sometimes, greater financing is assigned to projects that will provide more visibility, more political return, and thus this has less to do with the issue of being involved. But, at the same time, I notice a concern in reaching all vulnerable populations; there are partnerships.

The *Nuances* argues that, concerning the relationship between government and the organized civil society, it is necessary to take into consideration: The parameters linked to interests and representation, by both parties.

When the state seeks the civil society for partnership, what does it have in mind? Is it because the state cannot cope with the work? Does it intend to use the civil society because it has more legitimacy? Or is it because the civil society is inserted into this population? I mean, which is the notion, what does the state intend by doing it? And then, to whom will the state associate? Do the entities to which the state is associating and transferring resources have this work, this legitimacy?

They also argue about the role played the state in face of the difficulties existing in several levels of NGOs sustainability. Therefore, the group is contrary to governmental investments in NGOs staff qualification.

Should the state prepare the NGOs for the work? Wouldn't it be the opposite? Will it be effective? How are these NGOs trained? Based on the financing, solely and exclusively linked to financing and condoms. We don't agree with it. We believe that this is a mistaken strategy of the government. We think that it is totally wrong and that it won't be effective in practice.

According to the NGO, one factor that has contributed to the success of Brazilian actions is the interlocution established between the governmental institutions and the civil society. Furthermore, it mentions the demystification, the break of the persistence in talking about AIDS as a terrible disease, that only affects the gay population. "We notice that, in the beginning it was pretty hard

to talk about AIDS. AIDS was a gay thing, so nobody wanted to talk about it. If they heard that a person was seropositive it was terrible, people were afraid. And that is no longer so”.

Concerning policies and the programs and measures adopted by the Brazilian Programme, the break of patents is outstanding. It was an example to other countries, and allowed “Access of individuals to medication, when they found out they had AIDS”.

According to the group, the relationship between organized civil society and the government is *complicated and complex*. It involves dependence, accommodation, political interests of people and groups, mainly concerning financing. They suggest that the government should be better organized, to have legitimacy in their partnerships with NGOs:

Usually, with few exceptions, these are relationships of dependence and a relationship that is the pact. This is not a positive pact; it is a pact for accommodation, for interests. Such interests are on behalf of people in the coordination; they are political interests of maintaining the political relationship because it involves political interest of groups or peoples within these spaces established and the NGOs. They establish games of interest: for financing, for the possibility of financing, and for the possibility of holding offices.

Concerning the fight for citizenship and human rights, the NGO mentions that, “Many interesting things have happened and happen”. However, they stress that it highly depends on both participants involved, i.e., the state and the social movement, “Because the state, in principle, tries to co-opt in a natural way, I’d say. The state, regardless of the political party – some that have more power, more dedication, and others in a more paternal way”.

Concerning the impacts of governmental financing on the organization’s political actions, the Nuances did not lose its autonomy due to governmental financing, because of the legitimacy of its work.

Our duty is clear to us despite being financed by the Ministry of Health or by any governmental entity. For us, it is also clear that the state has transferred these demands to an organization, empowered a given NGO, because these are demands they are not coping with and there is nobody better to suggest the required demands to a given population or minority than those who are inserted in the universe.

In fact, governmental financing is nothing more than the facilitation of demands that would be necessary, and that they don't know this in depth. This relationship between the government and us, regarding the stance towards our work is pretty clear, and we communicate it through our newsletter and our position when we participate in conferences and seminars.

F.5. THEMIS – Assessoria Jurídica e Estudos de Gênero

1) Organization Name: THEMIS – Assessoria Jurídica e Estudos de Gênero

2) City/State: Porto Alegre/RS.

3) Date of Foundation: 8 March 1993

4) Started Working with STD/AIDS in: 1998.

5) Address/Phone:

themis@themis.org.br

Tel: (51) 3212 – 01 – 01 / 3212 – 59 – 70

6) Situation Concerning Headquarters

They have had their own headquarters since 2002, when they registered the ownership document with resources granted by the Ford Foundation. The equipment, painting, carpet and air – conditioning were purchased with resources granted by the Federal Government, through a parliamentary amendment made by Congresswoman Ester Grossi.

7) Where it Performs the Activities: NGO headquarters.

8) Field of Action: Women's movement.

9) Priority Field of Action

Human rights; capacity building in gender and rights; legal advisory services; feminist advocacy; qualification of community-based leaderships; researches and publication.

As line of action: qualification of popular female promoters and advocacy, introducing the perspective on gender and women's rights into the judiciary power.

10) Geographic Area of Work

National, state, regional, municipal, district or group of districts.

11) General Purposes

Expand the conditions of women's access to justice, health, human rights, sexual and reproductive rights.

12) Target-audience: Women, right operators, health and security providers.

13) Core Activities

Prevention is a specific focus:

We develop a specific work in the field of sexual violence. However, jointly with this service, we provide information on means of contamination and how it may take place. We have already developed a work on female condoms, with the Popular Legal Promoters and with women in general. Concerning the ways to prevent STD/AIDS, we focus on the relationships with sexual violence. We obviously explain that this is not the only situation where contamination happens; there is also the non-use of condoms.

14) Ongoing Programs and Projects

The *Formação de Promotoras Legais Populares* Project. The first project dates back to 1999. There were three projects: 1999 – 2000, 2000 – 2001 and 2001 – 2002. The latter was extended and is now coming to an end; it is aimed at the legal qualification of women with low levels of formal education, towards multiplying information and awareness about rights among and within their communities.

15) Services Provided to Population

Workshops, lectures, capacity building, campaigns, duties and a hotline to report cases of sexual violence.

16) Works only with AIDS: No.

17) Advertises the Work Developed Through:

Magazines, books, journals, videos, printed material, congresses, conferences, meetings and seminars.

NGO Background

18) Origin of the Institution

THEMIS was founded in 1993 by three women who idealized this project. These women belonged to legal carriers and were activist of the women's movement, and who decided to share their professional knowledge and articulate their militancy by working under a perspective of equality and gender construction. As a problem requiring for intervention, they focused on the difficulty of women in accessing justice, based on two assumptions: *1) The fact that most women, especially the poor and those with low levels of formal education, don't know their rights, and;*

2) *the right to equality as part of the qualification of rights operators. And this universality of the right subject, which is the abstract of somebody with no differences, no gender, no color, no social class. Based on this positivist and liberal view on legal qualification of the organization members, and on the acknowledgment of both obstacles to women's access to justice, they thought about starting an NGO aimed at expanding access conditions. And for this purpose they set two intervention areas, as follows: Qualification to Popular Legal Promoters, which gave birth to the project on Promotoras Legais Populares, the backbone to Themis' work. However, they have always kept in mind that they could not be limited to women's capacity building, but they would have to change the culture of legal thought, facing it as one of the social institutions in charge of replicating the mechanisms of discrimination and reproducing the difference. Of the lowest value that women enjoy in the society. Focusing as right reproduces it, through institutes and practices. Start making this denouncements and bringing up this discussion.*

The qualification of popular promoters and advocacy would be a way to bring to judiciary the debate on women's rights. THEMIS considers that the recognition of human rights as a paradigm to the intervention played a special role in its configuration. They state that up to then the women's movement used to work under the perspective of equality, and was not very familiar to the understanding on the category of gender:

The paradigm of human rights brought about a crucial differential to feminism, i.e., the acknowledgement on the difference. And the importance of including women into the fight against exclusion. And it happened in a crucial moment, when we had the first International UN Conference, held in 1993, in Vienna, which recognized the women's fight, the idea that women's rights are human rights. THEMIS was founded on that same year. It was a moment when

the women's movement was no longer isolated. It did not even recognize the importance of the State in relation to violence and violation of rights. And this idea was then broken, when it started considering violation to women's rights as a violation of human rights. It is a public, social problem, whose solution demands for state intervention, and the state is neglecting its duties. So, the violations of human rights become recognized as violations of the state. And 1993 is the milestone for the international movement of acknowledgement on state responsibility, and to change the view on who the violator is. And THEMIS came about within this context; a rupture within the women's movement. Because the women's movement did not accept women within human rights, as this would take them over. The feminist movement still did not have this view, which is now pretty incorporated and recognized. And it was very strong to the founders. And, so, Themis arose with these purposes.

19) Organization's Motivation Towards Working with STD/AIDS

In 1999, they decided to expand their scope of intervention and their main work, i.e., violence against women, because they realized that they were very isolated by thinking of violence only under the light of the perpetrator's legal responsibility, impunity or the defense of such woman, forgetting about the health field. They had no dimension on the other problems that violence could bring about, such as AIDS. Therefore, they stress that the link between violence against women's human rights and AIDS has contributed to lead an institution like THEMIS to actions related to the epidemic and women.

Since THEMIS had always worked under the view of human rights, and AIDS has always been a topic

comprised by the human rights movement, the NGO focused its work on AIDS. On the other hand, it was deepened by the practice with poor women:

We have an audience to the Promotoras Legais Populares made up by extremely poor women, we were working with the community, observing things happening, and it was quite clear that THEMIS should play an important role in this issue. And that was when we discovered how to make a link, since our work scope is not health. It would be through the way of sexual violence and the Promotoras Legais Populares.

To the qualification curriculum, for capacity building courses delivered to Promotoras Legais Populares, the NGO included the topic of STD/AIDS, and thus expanded the notion of rights, in addition to the legal focus and violence, also taking into consideration the right to health, expanding the horizons to the NGO intervention. According to the respondent:

This expansion of horizons was very important to THEMIS, so that the slogan for the first campaign, the first project with the Ministry of Health, was: "Sexual violence: don't become a victim twice". This search for references external to law, and this view on repression were very important. Furthermore, when thinking THEMIS and its work in the field of the human rights paradigm, we are thinking in this justice not only by the judiciary power, but as effective rights. And the right to health is a basic right.

20) Resources and Financing Sources

The sources of resources to THEMIS actions and activities are: Agreements with public entities; international cooperation agencies; multi-lateral financial institutions; multi-lateral institutions; and sporadic sponsorships. In this aspect, the Ministry of Justice, Ministry of Health, the Ford Foundation, IADB, UNESCO and

UNIFEM are worthy of special mention. Additionally to these sources, the institution was awarded with some prizes, “We were awarded with a McKinsey Foundation prize. Sometimes we are awarded with a prize here, another there, and money comes”.

THEMIS financial sustainability is granted by projects financed by international cooperation agencies and agreements with public entities, basically to grant qualification in the intervention and remunerated actions.

Sometimes we have agreements with local governments; small projects, but with remunerated actions. So, that is how it is: The NGO has remunerated action, whichever action it is, and regardless of the amount, but always aiming at providing professionalism to the intervention.

We think that social responsibility is a field that deserves high investments, and the idea of development requires the participation of all sectors. Because this idea of just taking from the state doesn't work. I think we don't have this idea of knocking on the business' doors. And we don't know the way. We are holding capacity courses on resources intake, but this way must be expanded in Brazil, the culture must change. This topic is now a hit, the issue of social responsibility and the third sector. The local development cannot go on without the businessmen.

21) Human Resources

THEMIS has seven lawyers, three professionals in the field of social sciences, one anthropologist, a sociologist, a historian and another professional with graduation in administration. Ninety per cent of THEMIS team holds master's degrees. Professional and volunteers' capacity building is performed through studies on specific topics. When a given topic is under the spot, or is emerging, they bring experts to discuss with the team. The incentive, as autonomous professionals, is to be remunerated for the projects, and the NGO encourages the continuity of the study. Every year, a member is selected to run for a scholarship in the GRAL Program by Fundação Carlos Chagas and, usually, has a project selected. It also encourages the application for a scholarship granted by the Human Rights Consortium.

According to them, their experience in working with volunteers was not good, because they have not yet built a volunteer policy. First of all, because they did not reach volunteer personnel who had a view and care in the sense of receiving and supervising the work. Another issue is the lack of space, “Such volunteers could be administrative personnel, work in the library to organize the archives, could be public relations, or work in the field of law. But it requires an organization of space, not only physical space, but institution space for them to develop the works”.

22) Work Methodology

They assess their actions and, since early stages, the NGO sought for partnership with the field of anthropology of the Federal University of Rio Grande do Sul – UFRGS, to implement project assessment. In two given moments, they hired external consultancy services to develop this duty.

More and more, the project implementation leads THEMIS to consensually build the assessment and monitoring on each project segment. According to them, a NGO that has already been working for ten years could have a sounder basis to assess the social impact of their interventions, through structured research. In the NGO’s opinion, if they had any work of support, in the sense of having an assessment methodology to set indicators, they could improve the social intervention in the county.

The projects are usually evaluated at the end of their activities, in meetings. The respondent mentioned the lack of a specific assessment tool, “Even because there are too many different actions, and the systematization of works performed is yet to be done”.

The NGO emphasizes that one of the major issues of the AIDS-related experience, is the awareness and value given to women. The available information, especiall on neonatal transmission, is not enough.

It lacks awareness, prevention. There is a long way to go before women appraise themselves. To understand themselves as women and value themselves. To understand that women have their value, because in fact they are battered and

suffer several types of violence and usually don't notice it. They lack awareness about their individual value. Regardless of being a woman, a dignity.

THEMIS develops specific work concerning awareness building, information dissemination on what citizenship means to women and to the *Promotoras Legais Populares*, aiming at qualifying multipliers. The work is aimed at enhancing their positive aspects and seeking for dignity, equality, condition of access, both in health and justice. The NGO also works in the field of sexual rights and reproductive rights.

Concerning the work developed with the population services, there are several difficulties, such as making them understand the work. However, communication flows more easily because the *Promotoras* have built strong links with the community.

THEMIS emerged with the intent of providing professionalism to the intervention. According to the organization leader, this perspective is very innovative in the NGO's field of action and grants sustainability to the project: These are actions on quality, seeking for professional qualification and specialization.

The women's movement is consolidated in the field of health. There was a fight in the field of public policies, but not on rights, not as a claim for economic and social rights. It was a different language, it was a search for professionals in other areas, few linked to the field of rights. There was no legal language nor legal grounds. We opened another space of interventions, including at the national level. When dealing with access to justice and rights, the first name in our minds is THEMIS.

The repercussions and impacts caused by the actions on THEMIS target-population, concerning STD/AIDS, are assessed as positive. These actions have transmitted to most women *accurate information* on the means of transmission, the possibilities of contamination in a violent relationship, their right to receive medication for STD/AIDS and the emergency pill in the event of sexual violence or sexual intercourse without protection, "Thus reducing the beneficiaries' vulnerability".

23) Political Articulation

THEMIS is part of the Latin American Committee to Women's Defense – Cladem; the National Network on Health, Sexual Rights and Reproductive Rights, and the Articulation of Brazilian Women – AMB. At local level, they coordinate the State Network on Justice and Gender. They have partnership with the Family Court and Criminal Court because of their work with violence against woman.

24) Partnerships

The NGO emphasizes the partnerships with the State STD and AIDS Coordination, the Municipal STD and AIDS Coordination, and the Health Secretariat, Human Rights Secretariat, Government Promoters' Office, the Ministry of Justice, with other Programs and/or Secretariats of the Ministry of Health, NGOs/AIDS, NGOs/mixed, and other social movements. It also participations in the discussions promoted by ABIA. They hold partnership with renowned individuals in law. Furthermore, there are partnerships for debates and courses with the Human Rights Commission.

Concerning the partnership with the Ministry of Health, they state that, "It was very positive, and we hope to maintain this condition in the partnership with the municipality and the state, since it is something to be built".

25) Incidence on Social Programs and Public Policies

The NGO participated in the discussion and elaboration of public governmental policies concerning free access to medication, to preventive devices and NGO capacity building.

To them, the role played in the discussion and implementation of public policies and governmental programs to fight AIDS is not very expressive since THEMIS' agenda is not focused on AIDS. It is not a NGOs/AIDS, although it has as reference to its intervention the policy and strategy used by NGOs/AIDS.

It is part of the Council on Women's Rights, participates in the Advisory Council of IADB Civil Society, and is part of a consortium of entities invited to prepare the first Brazilian report to the International Commission for the Elimination of All Forms of Discrimination against Women – CEDAW.

It usually sends representatives to the meetings held by the women's and human rights movement. It participates in national, state, and municipal conferences. At the international level, it participated in the conferences in Beijing, Durban and Mar Del Plata.

26) Organization Sustainability, in Mid and Long Terms

The NGO stated that it is continuously trying to increase its visibility because it is already acknowledged by the public; its name is internationally known in the women's movement, and it can compete for resources, which are becoming more and more scarce. At the same time, it claims that because of this structure and acknowledgement, a share of the financing does not reach the NGO, as the financing agencies also place priority on other regions of the country that they consider needier.

On one hand, our consolidation facilitates, but because of this structure and our renowned name, part of financing is prohibited for us. When choosing who they are to finance, currently the North and Northeast regions are privileged. We work with excluded segments, poor women in the South, but to financing agencies, this is not a sector in need.

They argue that THEMIS' strategy to sustainability would be to try to articulate new sources of resources, such as the private sector and generation of its own income. At present, the NGO has no problems in raising resources, but it should expand the financing sources and this is a major challenge to the NGO, 'We are just fine now, undergoing an intake stage. We have booked a hearing with the Ford Foundation. July 30th is the deadline for several institutions to submit projects'.

Concerning the organized civil society sustainability, as regards AIDS, the NGO claims to be suffering from the consequences of new policies, since the National Programme resources will be decentralized by the Ministry of Health. Thereon, the actions will be developed through the municipality.

Concerning sustainability, we will engage in a partnership with the Municipal STD and AIDS Programme. The major source of resources to

THEMIS does not come from them. Our projects in the Ministry of Health usually amount to something around thirty thousand reais – programs very small to our budget. So, they are not essential, but in terms of program maintenance, they are important, and now this new project that we are about to submit is in the field of sexual violence, and will keep our line of work with the programs that we develop. We are negotiating with the Municipal Coordination. But I can clearly state that this project won't make major financial differences to the institution's sustainability. It is very small, has always contributed, but I think we also do much for the cause and provided return to these thirty thousand reais, because we provided materials, qualified people.

27) Interlocution with Governmental Spheres, in the Field of the AIDS Epidemic

According to THEMIS, the state plays a core role in building the Brazilian response. When we compare Brazil to other countries, concerning the AIDS policy, “We reached this visibility and leadership at an international level”. They mention that Brazil held a vanguard position in the Conference of Durban in South Africa, but underlines that the State is stepping back in its position of intervention, and even of partnership:

We think we are going to lose this reason for pride: the Brazilian intervention in AIDS, compared to other countries in the world. And I think it was crucial, I don't know the figures very well, but I know it had an impact on holding back the virus spread, on social education and on reduced mortality. I don't think it would be profitable changing it.

According to them, other successes in the Brazilian actions on the fight against AIDS are: free distribution of medication, the good work developed in conjunction with the NGOs, and also in the field of information provided on the disease.

According to them, the relationship between civil society and governmental spheres in the fight against AIDS and assistance to HIV carriers is good:

The NGO used to work on the topic when the government seized upon this knowledge, and even brought some civil society workers to make up their staff. But, they think it provided sustainability. So, the NGOs were

registered or became members of a network, improving their conditions and, therefore, it was positive to carriers. The issue of medication is a nice example: at that time I worked in GAPA, we filed over a hundred suits against the state and municipal governments, claiming for medication. We succeeded, we won all suits, and it led them to make arrangements to provide medication to the carriers, with no need for suits.

According to THEMIS, the NGOs played an important and influent work in advocating for AIDS carriers' rights, in prevention and combat against discrimination. Nevertheless, they stress that the organized civil society should work jointly with the state. However, "They should not support everything that government does", i.e., "they should provide support in given moments, criticize in others, but always pursuing solutions".

According to them, the NGOs/AIDS successfully managed several issues other than AIDS, including citizenship and human rights. "The work against discrimination, for the right to health, access to justice and citizenship have been discussed and accomplished within the scope of the NGOs/AIDS". As a positive aspect in the work developed by the NGOs/AIDS, they mentioned the fact that they are not restricted to a single audience.

THEMIS believes that a partnership between NGOs and government is profitable, provided that it does not jeopardize the NGO mission and action, due to financing received. They say that autonomy depends on the level of consolidation and independence of the organization and the people who are part of it.

Depending on the posture held by the NGO, some may even be bought, but most don't do this kind of work. Sometimes they accept things because they need it to develop their works, their projects: We had experiences, the Comunidade Solidária invited us to develop a project, at the national level, which would bring huge resources to the organization. The proposal was not part of our institutional mission, and would make us deviate from it. If our problem were just earning governmental money and keeping relationships with the government, we would have accepted to develop the project of the same government that financed us in other projects. To be co-opted by the government is a weakness. THEMIS has always defined that if our projects are financed by this or that government, we are the authors, we are in control. I think this relationship is pretty clear to us.

5.5 GENERAL TRENDS IN THE INTERVIEWS WITH NGO LEADERS

Following, a list organized by state and, then, at the general level, some topics and feelings that have marked the dialogue with the NGO leaders. These references do not imply that the topic or posture pointed out as recurrent to cases in a state have not appeared in the field concerning another state, but that in the state under focus they were underlined by several NGOs in the sampling.

5.5.1 REGIONAL TRENDS

NGO in Pará

Among the several issues surveyed, the most complex to the NGOs in Pará concern sustainability, vulnerability to HIV/AIDS and political representation. This is probably so as they imply experience with political debates that are not part of the more immediate reasons and practices engaged by the leaders. But there are exceptions, such as GAPA, GEMPAC and PARAVIDDA. In these NGOs, the leaders would be more involved in militancy and political articulations.

NGO in Bahia

The NGO respondents in Bahia stressed the importance of different partnerships, be them with financing institutions, or with institutional partners for the smooth development of the activities performed.

Still in Bahia, several NGOs had difficulties in answering the questions related to notions such as vulnerability, sustainability and social control – common to the vocabulary of activism in AIDS.

Some NGOs already rely on a consolidated organizational and administrative structure, with diversified sources of financing and participation in different spheres of social control, in the field of education and human rights.

Concerning specific issues on the fight against AIDS, they appraise the state/civil society partnership, although they understand the complexity involved in such relationship, stressing the need for differentiating it from a mere outsourcing of services. They emphasize the differentiated roles for both, and criticize the bureaucracy of managerial institutions at the federal and mainly state levels. Sometimes, this bureaucracy leads to discontinuity in works. They underline the increased articulation of the NGOs with such governmental spheres, aiming mainly at improving the interlocution and the communication channels, besides making the administrative processes of end activities more agile. They stress the need for greater incentives to actions on prevention, rather than on remedial actions, and the insertion of the issue of STD/AIDS into the field of human rights.

NGO in the Federal District

A relevant issue noticed in the responses provided concerns the need for providing the AIDS movement with political actions that are more independent from the National STD and AIDS Programme.

If on one hand the partnership between organized civil society and the National STD and AIDS Programme is considered profitable, on the other hand the NGOs are concerned about the urgent need for a political agenda to the AIDS movement.

These concerns have also permeated the XII National Meeting of NGOs/AIDS, where the Plenary approved proposals towards re-thinking the political structure of the AIDS movement and streamlining the partnership with the National STD and AIDS Programme.

Nevertheless, in the scope of local interviews, there are contradictions between the fear that the NGOs and AIDS movement comes to loose autonomy, concerning the National STD and AIDS Programme. Sometimes, the desire for renewing political actions and recovering an activism unbound to the demands by the National STD and AIDS Programme faces the difficulties of no longer having

the resources that have effectively been important to structure some of the institutions surveyed. These contradictions are evident in the NGOs that are basically focused on working with AIDS. They have difficulties in expanding financing possibilities, and the initiatives that may promote self-sustainability are very incipient.

There are also NGOs that work on topics where AIDS epidemic and the need for interventions on education to prevent HIV are inserted into a broader universe in the field of health. In this sense, there is some lack of knowledge on public policies concerning AIDS. The issues posed by the epidemic appear only in the field of the need for meeting the prevention measures.

Some NGOs deal with the issue in a transversal way, and understand that AIDS is a problem to be thought in several fields of political action, such as CFEMEA that states that the challenges of living in society with the epidemic have impacts on the field of sexual rights and, above all, reproductive rights.

NGO in Rio de Janeiro

They disclosed consensual views on the concern about the new challenges brought about by the changes in the perspectives of social projects financing, impacting on the sustainability of several organizations.

The leaders' report suggests some variations concerning the NGOs' experiences in social movement. There are professionals with huge knowledge on the topics approached in the survey, with expressive participation in the discussions about public policies and more intensive work in terms of social control actions. However, sometimes the activities are less political and more assistential. It is worth mentioning that some stories about the origin and work of the organizations are mistaken with the story of the NGOs leader itself, pointing out the great personal involvement with the causes defended.

They expect increased action by the NGOs, mainly among poor populations, because they are one of the most vulnerable groups to AIDS nowadays.

Another major concern is the fact that governmental institutions are now mainly oriented to the so-called international impact of the actions by the National STD and AIDS Programme, because there is still a lot to be done in the sense of providing social assistance and access to health to the Brazilian population. It is worth highlighting that, despite the international success of the policy of fight against AIDS epidemic in Brazil, the works in the field of prevention shall remain to guarantee the success of those policies implemented by governments.

The NGOs working with damage reduction underline the resistance of governmental organizations that, sometimes, fear that the NGOs defend the use of drugs, rather than work on preventing their use. They point out the difficulty in sustaining the projects and activities promoted in this field, exactly because of this governmental difficulty in understanding the proposals aimed at drug users.

NGO in São Paulo

They acknowledge that the NGOs that have more resources are those that, since their early stages, have been sponsored by international organizations and, therefore, have more projects financed by the government as they made more investments, became professional and are better prepared.

The interviews with NGOs leaders in São Paulo pointed out a trend towards considering that AIDS happens nowadays, but no longer holds a privileged place in the field of debates on health. The leaders also tend to interconnect the debate with references to the social situation of the target-audience to the NGOs programs, such as unemployment, survival, drugs, pregnancy, housing and levels of quality of life.

There are plenty of discussions on damage reduction, and even considering that this field became stronger with AIDS epidemic, the dialogue and interaction between these two social movements is still hard, because of the difference between the problems faced and the strategies defined.

NGO in Rio Grande do Sul

There is a noticeable difference between NGOs/AIDS and the remaining NGOs, concerning the epidemic. The epidemic is the backbone of all NGOs surveyed, even for those with different missions. However, even when AIDS is prioritized, there are other demands such as, for example, violence, the issue of identity/racial and ethnical discrimination, income generation, advocacy for human rights and promotion of citizenship.

Concerning the relationship with the State, the NGOs in general seemed to be engaged and active. They perceive the State as a potential partner, although some entities have criticized it. They understand that partnerships should not imply the loss of autonomy or lack of social control.

5.6 FINAL REMARKS

Finally, the NGOs leaders were transparent and self-critical. They are aware of the problems they face and, in general, have no problems discussing them.

In the universe surveyed, there are different degrees of institutional development. Some NGOs have their own premises, Councils of Trustees, personnel hired to develop specific actions, while others have difficulties in organizing their headquarters, establishing staff and defining the board of director's role.

In general, the survey pointed out the need for more effective presence of financing agents and the National STD and AIDS Programme in field, to monitor and discuss issues concerning the works developed by the non-governmental organizations and by the governmental organizations as well.

The NGOs work is strongly based on the profile of their leaders. These NGOs are characterized by works in different fronts, according to the field of action of their leaders or members.

The NGOs face very similar problems, regardless of whether the entity focus is placed on gender, race, human rights or AIDS.

It is worth mentioning that, at financial and sustainability level, there is a considerable lack of balance among the NGOs. The NGOs' financial sustainability seems to be one of the most serious problems they are facing now.

The discussions develop towards understanding that there is no sustainable development without education and health, as its major components.

Some issues were recurring, like violence and the stigma concerning seropositive individuals. In this regard, they have all stressed the relevance of the work developed by the NGOs towards allowing users to recover their self-esteem.

They discuss their victories and the new challenges posed to the relationship between the governmental spheres and the organized civil society. Nevertheless, there is some consensus concerning the importance of the organized civil society's participation as protagonists, in the major actions that have set the Brazilian Program acknowledgement worldwide.

In brief, this chapter depicts the profile of some NGOs, describing their characterization and background. It also discloses their experiences and perspectives in the field of response to the AIDS epidemic, concerning the major sources of resources and strategies adopted for intake; capacity building of professionals and volunteers and their work methodology; political articulations; partnerships; incidence on social programs and public policies; the organizations sustainability, in mid and long terms, and their interlocution with governmental spheres, in the field of the AIDS pandemic.

6. THE POLICY AGAINST AIDS ACCORDING TO LOCAL MANAGERS

6.1 GENERAL CHARACTERIZATION OF THE MANAGEMENT OF THE AIDS PROGRAMME AT THE MUNICIPAL AND STATE LEVELS

With the aim of illustrating the dynamic of the municipal and state machinery on the management of the AIDS Programme in Brazil, managers from those levels of government have been interviewed in order to recover the experience of what has been considered a new fashion of managing health programs or actions, in the scope of the Brazilian Unified Health System (SUS). From the material collected during the interviews, whose content was preserved upon the process of editing the texts, the fashion in which the process on the field of AIDS is conducted at the municipal and state levels is observed, in what could be considered its organizational culture. Later, indications of the repertoire of evaluations given by those managers in relation to the scope of the Program, the relations with civil society and, finally, some critics and suggestions for the improvement of its management capability are presented.

6.2 SOME PROFILES

BAHIA

Municipal Coordination of STD and AIDS of Salvador

Background

The Municipal Coordination of STD and AIDS of Salvador was founded in 1994, with six following coordinators since then. But

since 1994 a work of coordination has already been formed. It centralizes the actions from inside the Municipal Secretary of Health, whose primary financial resources come from the Ministry of Health. Originally, the actions against STD and AIDS prevention were taken at the basic unit level. The Municipal Coordination of Salvador do not treat patients with HIV, since its mission is to fully manage only basic care, and the treatment of HIV patients is of high or medium complexity. However, since 2003, some basic units have been set up for such treatments. Therefore, from 1994 on, the actions towards AIDS have specifically entailed prevention, from the treatment of STD to other educational actions.

Current Activities

Since 1994, the Municipal Coordination of STD/AIDS has been undertaking actions related to the National Policy against AIDS. Initially, the network was structured, since there were only 17 basic units of health, and from then on, equipment for treatment of STD and AIDS have been purchased. Furthermore, the Coordination has invested on the training of specialized human resources.

Relations with Civil Society

The Municipal Secretary of Health has early articulated to work with Non-Governmental Organizations (NGOs). Since 1995, partnerships have been established with the Regional Integrated Center for Adolescents and Children – CRIA, with the Associations of Sex Professionals – APROSBA, with the Bahia Lesbians Group – GLB, with Bahia Gays Group – GGB, and with the Bahia Association of Afro Cults. Despite the continuous actions, these partnerships are floating ones, since it is not always possible to work with all of them at the same time and with the same intensity. There are joint programs to work with the sex professionals in their work environment and others aimed at other social groups such as adolescents. As for the development of actions related to the fight against HIV/AIDS on the citizenship and human rights field, a project called Education and Health on the Exercise of Citizenship

has been developed. This project has conducted activities for the incorporation of prevention actions and the strengthening of the capacity of empowerment of sex professionals.

In relation to the development of actions related to providing access to prevention devices, condoms are distributed and damage reduction actions are taken. A strong partnership was built with the Center for the Study of Alcohol and Drugs – CETAD in order to arrange the distributions of syringes. This action involves specific populations such as homosexuals, sex professionals and also women in general.

In relation to the actions of access to diagnosis, in 1997 the Center of Attention and Serologic Support – COAS, today known as Center for Testing and Counseling – CTA was structured. Since 1997, it has had a unit for HIV testing. But until 2002, it performed only collection of material that was sent to the Central Laboratory – LACEN, but from that year on Salvador set up a laboratory to perform HIV tests. The Municipal Coordination of STD/AIDS intends to increase the testing through eleven laboratories. It has also conducted activities on the units that develop tuberculosis programs, since the disease is sometimes associated to AIDS. Therefore, there are professionals that normally demand HIV tests for people who have tuberculosis.

The free access to tests is still small, and is restricted to two municipal facilities that count on the support of the state COAS, of Lacen and of Hospital das Clínicas. There is, therefore, an unmet demand for HIV tests. At present, Hospital Roberto Santos performs only the treatment, but it has already bought the kits and has already started training human resources in a partnership with Pathfinder of Brazil. This will allow for increased access, and the installed capacity will count on eleven additional units.

What is agreed in Bahia as regards access to medication is that the Federal Government has always provided the retroviral medicines, which are the most expensive, and the municipalities has provided medication that are specific to STDs. As for the medication used to treat opportunistic infections, the state must provide and the

municipality will provide only what it has got in its basic pharmacy, which are the medicines of lowest cost that are also sent to CREAIDS, a state level structure that has partnerships with the State Secretary of Health.

Strategies for Distribution of Male and Female Condoms, and Syringes

The first strategy conceived was the distribution over the health units. People make their enrollment and then receive information and condoms. Another strategy used is the partnership with the Family Planning Program. In this one, the tactic used was protection with information on contraception methods, followed by the distribution of male condoms. In cooperation with the Health for Adolescents Program, sexuality, pregnancy and the prevention of sexually transmitted diseases were discussed. The coverage has also been extended through the use of resources like TV and video, during popular celebrations and special holidays such as Valentine's Day, World Day of Fight against AIDS, Gay Parades, religious festivals (like Saint Anthony's) and in places like shopping malls' restaurant areas in order for information to be provided, condoms to be distributed, and an educational intervention to be made.

In relation to female condoms, still considerably expensive in Brazil, a different strategy from the one used for male condoms has been created, since the latter is done through mass distribution. The action is performed in two Units of Reference, which work with two different target populations: sex professionals, homosexuals, travesties and injected drug users. "For you to have an idea of the price difference, this year the National Coordination is buying three hundred million male condoms and only four million female condoms". In the Units of Reference, groups of adherence are formed, and only then do they get into the system. Therefore, initially twenty women form the groups, since the intention is the approval of the female condom, which has a different technology from the male one. The distribution is done in a coupled fashion, which means they are distributed jointly with the male condom. At the moment access is being extended from two to six units.

The strategy used towards injected drug users is the reduction of damage through the distribution of syringes and educational action, conducted at health units that belong to the local government of Salvador. Besides that, there is a partnership with CETAD, which works with communitarian agents. And there is another strategy that is to set up a Health Unit with this profile, working with community agents, going to the communities. CETAD has local volunteer damage reduction agents for each community. The community agents are trained to make their point through the approach technique, trying to convince the user to look to the program for help. In this particular initiative, the agents have already doubled the number of permanent posts for syringe change, not only at the health units but also in other places such as their homes, drugstores and gyms.

Evaluation on Possibilities and Limits

The first limit in relation to the activities in course is related to human resources, since they are not enough to perform all activities: “Our coordination is really under stress. We are three here, the only technicians of the State Secretary of Health to take care of this whole universe of people”. Therefore, partnerships are needed.

When they develop a project in one area, they have to share professionals with other programs, since there are few nurses, social assistants and doctors in the public health system.

Many times when we propose integration strategies people get scared: When we talk about Human Resources in general, I don't think we are alone in that, because we know that out there, on the frontline, they suffer the same problem. In Salvador, a social assistant works for the STD/AIDS program, for the Adolescent program, the hypertension program, tuberculosis, and Hansen's disease. The professional for all of these programs is only one. Then things get really tough.

Another limit to the development of activities is the inadequate physical structure for the number of actions to be carried out: “We are in a really small room, three technicians dividing a table, a computer. Therefore, the physical structure is totally inadequate for the large amount of actions we have to undertake”.

There is also a difficulty in purchasing materials and equipment, since the procedures are slow and the structure of the State Health Secretary is very centralized. “It is different from being a management unit, for example. If our unit were able to perform its own purchases, if we could decentralize the resources, everything would be much easier. Everything is centralized on the Secretary”.

It is figured that the limits that exist at the Municipal Coordination are also felt at the Units. Some of them do not suffer from the physical space issue, but have to deal with the lack of equipment.

The management model of the Secretary is also a limiting factor. “We can’t carry it all, we can’t take a patient and follow him, we don’t have hospitals, and it is not under our responsibility. Due to that, we end up losing a lot”.

Another problem spotted is the communication between the Municipal Coordination and the Units.

We set up a meeting with all coordinators of the district with a week’s notice, and the attendance is only of 50% because they don’t receive the notice. Communication would be much easier if we had a digital link with the Units, but we don’t. We have to send it through paper, with a protocol, to get it to its final destination.

In relation to the possibilities, the fact of being qualified to extend the program in three units, which shall make it possible to treat HIV positive patients in partnership with the state should be mentioned. It is the Habilitation for Basic Extended Management – GEPAB.

The new Units are not going to be built. We will profit from the existing ones and create a service for the flow-up of stable HIV positive patients. People that are fine, that need only medication and follow-up of the viral charge, without intercurrence, that can be done in the basic system. Until now we haven’t been treating patients with AIDS, and this is the beginning of the task. This is a characteristic of the public health system of Salvador. The Secretary of Health hasn’t got a Health Unit for hospital internment; all Units in town are prepared only for basic care. The hospital units belong to the State. Therefore, this new service makes us glad to be finally able to provide treatment to patients who don’t require internment, but who need regular follow-up and that are currently pressing the federal and state systems. These people can be taken care of close

to their homes, without the need of displacement, and we know that the target-audience of the program is constituted of people who cannot afford paying constant bus fares. So it is a possibility that really cheer us up, because we have Counseling professionals on our CTA that can be used, since they are trained to perform this kind of service. Our dentists will be trained so that they will be able to treat HIV positive patients.

Links with Civil Society

The partnership between the municipality of Salvador and NGOs started due to the impossibility of working with all communities. Therefore, the NGOs from Salvador and the state of Bahia are fundamental partners in the maintenance and continuity of the task: “The institution of the Coordination came attached to these institutions”. As an example the GAPA/Bahia, the Gay Group of Bahia are mentioned, both of which have a program that is recognized all over Brazil. The CRIA has a brilliant work on the issue of citizenship and education with teenagers: “GAPA, GGB and CRIA have all given important support to us; there has been a great and very important exchange”.

Levels of Partnership with Civil Society

The Municipal Coordination of STD/AIDS acts in several levels, donating educational material, condoms, and pocket money for the damage reduction agents and providing resources for trainings. CETAD performs trainings with the professionals of the Municipal Coordination. They have provided the financial support for the Northeastern/Southeastern Meeting of Sex Professionals, the Bahia Damage Reduction Association – ABAREDA. They participate in launching campaigns, and have financed, for example, the art of the T-shirts of the AIDS Family Institute – INFA, which is a NGO of assistance, but that works with the Municipal Coordination. “We try to grasp what the need of the NGO is and see how we can contribute, and if it is something that really has to do with our work, we support it financially”.

Neighborhood associations are also partners, working together with the units of health, providing condoms and educational material.

Background

The State Coordination of STD/AIDS of Bahia has existed since 1994, but before its activities started, the COAS developed activities in sanitary dermatology, as occurred initially in the city of São Paulo and other municipalities as well, under the structure of epidemiological vigilance. At the time, the coordinator was the person responsible for addressing these actions and programs. The actions were growing and had to be dismembered, so people started to form groups around the program. In the beginning there were no resources directly designated to this issue: “Everything was lose”. The resources only started to come through the AIDS I program. The health team had only three or four people: a sanitary dermatologist, two nurses, and a social assistant. With the liberation of retroviral medicines and the distribution of condoms, it became necessary to add more people. Nowadays, the State Coordination counts on seven people. This team is made up by: a dentist (with graduate experience in public health) who is responsible for all contacts with NGOs, distribution of condoms and elaboration of the educational material; a nurse who is responsible for the whole area of vertical (mother to child) transmission, and another one who is responsible for the STD Area and the Anonymous Testing Center; another employee is responsible for the epidemiological part; and another one holds the prevention area and has also embraced the violence issue; finally, a pharmacist works with the distribution of medication.

With the creation of the State’s AIDS Reference Center – CREAIDS, in March 2001, it was understood that the program should be placed inside the Reference Center. Therefore, it had to be adjusted to a physical structure that initially had not been designed with this objective in mind. Since then, the State Coordination has grown in terms of physical space and currently counts on a Training Center that makes the expansion of the capacitating areas possible. This is considered as positive, in the sense that they are closer to the population. “The user is nearby, if he/she needs anything, he/she will just take a few minutes to come”.

On the other hand, it presents a negative side, since it is far from the Secretary of Health. “We also lose a little because all our interfaces are at the secretary”.

Current activities

The development of activities aimed at the combat of AIDS started with the advent of the Loan Agreement of the World Bank with the AIDS Control Program in Brazil, known as AIDS I. In reality, the work started in 1994, when the cooperation agreement was signed and the Commission on AIDS was created.

According to the technician of the Secretary interviewed, who was appointed by the manager of the STD/AIDS State Coordination, the actions of prevention and assistance were already conducted before and have been concretized during the AIDS II program, but they have existed since the AIDS I program. However, he considers that the issue of citizenship needs to be more developed. The actions started to be improved faster when the government started to work with NGOs.

Relations with Civil Society

Historically, the issue of citizenship and human right was introduced by NGOs, and the State Coordination would simply support the projects. The Ministry of Health, through the STD/AIDS Program, for a long time collaborated with NGOs in this area, which held a vertical relation with civil society, without any previous discussion with the states and municipalities. “What was proposed by the NGOs not always was what we would like the NGO to work with, but since the resource was at the federal level, we didn’t have much to do”. After some time, we were able to build a relation with civil society organizations, sending people and producing materials together with the NGOs. But they have never had the conditions to pay for the toll-free AIDS hotline or the legal Counseling program. As for the issues of medication, genotyping, CD4 and viral charge, there was a huge amount of

legal suits against the state and the municipality, until regularization was provided. Nowadays, the doubts are mostly related to benefits and social welfare.

Actions Regarding Access to Prevention Devices

As for the access to prevention materials, the distribution of condoms has been conducted since 1994, through the Annual Operative Plans – POAS. Beside the acquisition by the Coordination itself, condoms were also received from the Ministry of Health, until the moment when the Ministry oriented the Coordination bureaus not to purchase them separately anymore, since the prices offered to the federal government were extremely lower than those offered to states and municipalities. Therefore, the Ministry started to make a centralized purchase, through international procurement. With that, the states started to depend on the federal government. As a consequence, there were delays in the distribution and lack of the product, due to the complicated procurement procedures. “Once a procurement process took nine months to be completed, because one bidder, unsatisfied with the result, used legal actions to get the result changed, it took nine months for us to get the product”.

Despite the fact that they distribute a lot of condoms every month, they consider it as insufficient,

... because the more the program grows, the more actions you conduct, the more the demands increase. The quota for the city of Salvador is 100 thousand condoms, so it is not enough to fulfill the demand. But our understanding is that, since condoms are an expensive product for the purchasing power of our populations, it should be included in the “basic basket” (which normally includes only essential food items). We have been doing a campaign, with the help of DKT social marketing so as to make condoms more accessible to the general public; in gas stations for example...we want to provide access to buyers as well. We also want companies to distribute condoms to their employees, but this cannot be totally paid for by the municipality or the state government.

Actions Regarding Access to Diagnosis

The access to diagnosis is still insufficient, since it is not decentralized. Therefore the Health Posts and Basic Units of Health

cannot provide the service. “Collection, together with condoms and tests, which are all forms of prevention, is still something we cannot decentralize”. Since the procedure is not paid for by the Brazilian Unified Health System (SUS) as a basic material, the municipalities themselves have difficulties, since they are already in a precarious budgetary situation, so it is one more exam to provide that they know they are not going to be reimbursed for.

If the test is considered as an activity and a material of prevention, it should be more broadly available, especially for pregnant women. “The lack of access to diagnosis is what makes it so hard to decrease the amount of vertical transmission of HIV”. Therefore, they started the use of the express test. “As for this test, there is an irregularity of provision by the Ministry; it is not like the medications, which are sent in sufficient number every month. Some medications are on a quota, but anyway there is a guarantee of provision, which doesn’t happen in the case of tests”.

The Ministry understood that it was an obligation of states and municipalities to pay for the tests, since they would, theoretically, pay for the CD4 and the viral charge. Around 2001 and 2002, the State Coordination started to offer the genotype assay, which is performed at the *Hospital das Clínicas* on a free basis.

Actions Regarding Access to Free Exams

From 1997 on, the State Coordination has entered the CD4 National Network for viral charge, performing exams at LACEN and the Retrovirus Hospital.

Actions Regarding the Access to Medication

In 1996, only AZT was provided by the State Coordination of STD/AIDS, but new drugs started to appear: DDI, Double Therapy, protease inhibitors, constituting the so-called cocktail. In the beginning, there were some irregularities with the distribution of medication – a fact that was considered normal due to stock problems of the Ministry, but whose regularity has been attained.

In the opinion of the technician of the Coordination interviewed, the actions have been developed since the Brazilian government decided to provide medication for all AIDS patients.

Strategies for the Distribution of Male and Female Condoms, and Syringes.

The State Coordination, according to orientation received from the Ministry of Health, provides male condoms through the Basic Health Network, hospitals where HIV patients and seropositive individuals are, and through NGOs, so that users have access to them on a continuous basis, and not only on special occasions, such as Carnival and other popular parties, even though distribution through the basic network is intensified on these occasions. “We saw people using condoms as balloons; it is a disaster to see that! We spent so much to see them on the floor, after a distribution, during Carnival”. The strategy is to work on a daily basis and try to make women aware about the negotiation involving the use of condoms. “The main user of the service is essentially the woman, that’s the basis of your strategy”.

The strategy of distribution through sectors is also employed:

We would distribute a quota to the units of Salvador. In the remaining state, the strategy of distribution (to 417 cities) is through the Regional Directories of Health – DIRES, which are the representatives of the State Secretary of Health throughout the state. We have thirty DIRES on a municipal basis. Beside the State Coordination, there are seven municipal coordination units of STD/AIDS. And now with a policy of incentive, four municipalities have entered the program, so therefore we have 11 units, so that with the resources of the state we have to take care of them and another 406 cities.

According to a technician from the State Coordination, the distribution of male condoms is concentrated where the population is more vulnerable, which means, in groups like injected drug users, sex professionals, and homosexuals. And also to teenagers in a condition of social risk, and to imprisoned populations:

We would distribute condoms for all the State of Bahia, ranging the quantity, since some sectors receive more. Last year we worked on a state level framework of distribution of male condoms. We registered the institutions, essentially everybody that works with AIDS in Bahia, and we've discussed the subject of acquisition and distribution of male condoms. We have reached the conclusions that, only for the state of Bahia, we need 12 million condoms a year. But the demand is constant, and everyday we receive new requests. The idea is to distribute it to the general populations, but also to stimulate those who can buy condoms to do so, because we know that the best way of preventing the epidemic of AIDS is the male condom.

The female condom is designated to specific populations; such as injected drug users, partners of HIV positive men or HIV positive patients. The strategy to disseminate the female condom is the distribution during Carnival, and when women go to health units to get male condoms. But we notice that the acceptability of the female condoms is more difficult than the male one. As it is more expensive, the population in general is hardly going to buy it or use it unless they get it from a public service. Another strategy to this particular distribution is to take the responsibility away from men as to the use of condom, giving more autonomy for women to protect themselves. Distribution is performed by CETAD and by APROSBA. "Depending on the population that we want to access, we look for the ideal partner". The STD/COAS program works with STD patients, the Reference Centers, Ambulatorial Units and the HIV positive.

The technician from the State Coordination comments that in the case of the female condoms, priority is given to women victims of violence, injected drug users or those who eventually use it. The specific population that has most accepted the use of female condoms is the sex professionals, since it is not always easy to negotiate the use of male condoms with their partners. But before delivering there is a work of information provided to those who are to receive it, since there is a very high cost involved.

So, we have an orientation before distribution, and yet there is a lot of resistance. The amount distributed is below our intention. They have bought a large amount of female condoms, 100 thousand units for the state of Bahia, and the Ministry of Health sends us a monthly amount based on our demand. There is not a lack of female condoms as for now.

The distribution of syringes is done by CETAD: “We don’t have services, it is something the Ministry of Health even advocates that we should include the change of syringes, but we know that it is difficult”. This population is already being accessed by CETAD, in a joint action with the State Secretary of Health, and the Previdrogas Program. In a partnership with Previdrogas, CETAD has, developed some innovative strategies, such as to work with the agents of health so that they change syringes in the communities visited, with the help of the municipal government. “We understand that this is a basic action and that it has to be decentralized. They have conducted a great participation inside the state, and have also developed the Psychosocial Assistance Cores – CAPS, and NAPS. It is not that the drug issue is going to be treated like a mental condition, but it is related to the aims of the mental health program”.

The technician from the State Coordination States that the entity responsible for the distribution of syringes is CETAD and the Coordination provides technical advisory.

The work is all performed by CETAD. We buy and provide the material, we follow-up the actions, but we don’t go to the field with them. The supply is according to CETAD demand. Last time we purchased 21 thousand syringes. Every time CETAD needs more syringes, we provide it. Not only the syringes, but also the whole material that accompanies it in a kit.

Evaluation of Possibilities and Limits

The interviewees noticed that the challenges and the limits are several, as can be observed by the themes below. In order to overcome the challenges, they look for partnerships with NGOs, governmental organizations like the State Secretary of Social Assistance and the State Secretary of Education.

They consider the decentralization of actions as their major challenge, on a path towards municipalization, from the capital city to the country. Essentially, the actions are concentrated on the centers where the risk of HIV is higher,

But if we can reach to the non-infected, we are going to work with primary prevention, since people do interact in their daily lives, they have sexual intercourses, they use drugs. So, better than having the user coming sick to the hospital, it would be better if we could go to him. This is the great challenge, to take the actions further into the country.

There is a difficulty in approaching teenagers, bearing in mind the present mentality inside school boards that with this practice we would be favoring early sexual activity. “But this is already a reality, people are initiating their sexual lives earlier and it is better if they do it correctly”. Therefore, to teenagers, condoms are distributed only in Adolescent Reference Centers.

Another challenge is the teenager outside the school, the underage convicts and general convicts. As for this last group, it is hard to develop a program inside the Penitentiary system, even though the Secretary of Justice is a partner.

We intend to distribute condoms, but we don't know to whom, we don't know who is to be held responsible for those condoms, so that sometimes you go to a penitentiary and the condoms are given to the employees, not to the convicts. The same happens in relation to retroviral medication. Nowadays, we distribute medicines through the Medical Center, so that the convict does not have to be moved, avoiding demanding personnel for escorting them. But generally speaking we have difficulty in working with the Justice.

Among the limits presented, there are those related to human resources (team), low wages and short financial resources for the Coordination:

We would all like to spend the whole day working with that, but we can't, since we've got to pay our bills, so we have to keep another job. I cannot compare with the situation in Salvador that has got two people. We have a team that has been working together for a certain time, that is already organized, and is multi-professional, but it is not really the ideal.

Besides low wages and few human resources, another limit is related to financial resources, since they work with a fixed budget.

For many years this budget has come from the Ministry, with the State providing financial counterparts. The state government, several times, has put more than the necessary. The Creation of the Reference Center itself was conducted with our own resources, but it is always insufficient for all we have to do. But we understand that the State Secretary has other diseases to take care of.

The research area needs to be deepened, generating more alternatives of financing that allow us to advance in the production of knowledge.

Another difficulty is that most of state and municipal coordination units are not institutionalized inside the State Secretary of Health:

The coordination does not exist inside the flowchart of the State Secretary of Health. As the manager of the program, and sometimes we are not the official manager of the program, the Ministry of Health understands that it should not interfere with local issues, they just want the reference to exist. If there is a reference, that's OK for them.

In what diagnosis is related, they conduct the trainings and prepare the professionals of health. In relation to vertical transmission, they make the medicine available, they council the mother if she is HIV positive, they give her injectable AZT to be used during the travails, as well as the syrup to be taken by the baby, but several times they lack the basics, which would be the test kits. This issue has to be worked by the municipal managers, because there is a social responsibility to these women. Despite the fact that each citizen of a certain city that is born HIV positive will be, in terms of financial resources, much more expensive than providing the test kit.

A state Bill that obliges the availability of tests and medication to pregnant HIV positive women was passed. In theory we can sue the director of the maternity hospital that doesn't provide the quick test. We can buy the quick test, but it becomes much easier if you follow-up the acceptance of this woman during the whole pregnancy. By the same token, it is easier to recommend her not to conduct breast-feeding in case she is HIV positive, rather than offer her the test before the travails. It is a positive thing, even when you do it all in 15 minutes. But it is a desperate strategy.

Despite all difficulties and limits presented, they mention that, due to all this, it ends up generating possibilities in the sense of deepening, dissemination and decentralization of activities, which may eventually work as a strategy.

The State Coordination of STD/AIDS is currently elaborating two projects. One is to set up the Bahia Council of Companies. “The Ministry of Health initially pointed to that, but the idea of a National Council of Companies has not taken off”. The concept is that a social-driven company should perform STD/AIDS prevention programs. The actions would be carried out inside the company, targeting the healthy population, specifically the employee who rarely goes to the health unit. Another project is “Taking care of the Healer”, which is aimed at the professionals that work in contact with HIV positive patients, improving their qualification and motivation.

We didn't work much with the issue of the health professional in a context of low wages and conditions of work not always satisfactory. They lack one thing one day, another thing the next; therefore, people don't feel much motivated to work. Actually, when it was set up the emergency room 2 A at the Roberto Santos Hospital, where HIV positive patients were attended, it was considered a punishment to work there. Therefore, a professional who was not performing well in a given area was assigned to work in there. Today we are able to choose a little bit more, we've got professionals with a better qualification and more motivation than before.

Another proposal is to work the adherence to medication in two specific moments:

One moment is the work with the “virgins of treatment”, the recently diagnosed ones, so that they start to use the medication in a correct and motivated fashion, working all matters related, and not only the medical prescription, the indication of CD4 and the viral charge, but also his lifestyle, if he can use a certain scheme or not, negotiating several issues with the patient. And we have the “failed” ones, which correspond to the patients that have gone through several retroviral changes, so it is possible to see that the problem is lack of adherence. So the idea is not to fill the Center of Reference with patients, but rather to have here a selected population, so that after the patient has been working with us for six months and is already using the medication in a correct fashion, we can send him to the public network, so that we can receive more patients from the public

network. Since we haven't got enough infectologists, we have worked increasingly with general physicians. In the interior zone we work with gynecologists, pneumologists, psychiatrists, anesthetists, whoever has the availability at the time will be used, since the importance here is to deliver the medication and information to the country, so that the patient doesn't have to come to the capital city in order to get medicines, decentralizing the system. We often don't have anyone to prescribe medicines, obliging patients to travel to Salvador to get it, to undergo exams. Then, he/she even return, but becomes obliged to return.

According to a technician of the State Coordination interviewed, the limits are on the area of human resources, bearing in mind that the team is much reduced in relation to the number of tasks it performs. As for the possibilities, he believes that the new policy of incentives, with decentralization, will allow for concrete advances. The new policy will also bring an innovation in evaluation of the financial resources, answering questions as to where and how those resources should be used and trying to grasp what results are being achieved. "On the matter of results, the AIDS patients will be inserted back into society, since they are human beings that work, so they will have broader space in this new policy. In my state's program, the population is much closer".

Prevention actions have always been conducted by NGOs and supported directly by the National Coordination, so the work of STD/AIDS has led several state governments to get accommodated. The challenge is now to get closer to NGOs, making partnerships and providing a larger public support, contributing even on the matter of financial, technical and political sustainability of several social organizations. "I think we have a lot to do".

Links with Civil Society

In relation to the partnership between the State Coordination and NGOs, initially there was strong opposition from civil society towards government. With time this situation was fixed through dialogue and support provided by the State Secretary to the work conducted by NGOs.

The first time we worked with them, we had to present our plan, the second time was a joint construction and from then on it started to get going. The

strategic plan was a very gratifying experience. We've learned a lot from them. For example, on the preparation of material for the sex professionals, teenagers, homosexuals, we have learned the specific languages that should be used to reach the target groups. Today we are partners.

In Bahia, according to the interviewed technician, the partnership between the State Secretary and NGOs started through the search for participation – the need that the Coordination itself felt to make prevention and strengthen the support, initiating an exchange. As an example the homosexual movement is mentioned, as it has looked for the Coordination to obtain support for its actions, but they already knew how to develop actions within their community. Before that, there had been technical attempts of the State Coordination to develop an action towards homosexuals and sex professionals that did not reach the desired results, since it was conducted without partners.

Levels of Partnership with Civil Society

The State Coordination does not provide financial resources to NGOs, but supplies them with material such as: Condoms, computers, printers, production of information and training materials. It also provided support for air tickets and daily allowances aimed at participation in events. Likewise, when NGOs have an interesting idea, they present projects and are financed. But the Coordination does not have other means of providing financial resources, and NGOs understand the difficulties of the Coordination. “How is it possible to pay an NGO employee that is going to teach, to perform fieldwork? It is complicated. He is not a public server, we cannot insert him in the payroll, and therefore since this prevention activity cannot be inserted in the National Public System (SUS), it cannot be paid for”.

Currently, the resources that used to be sent by the Ministry of Health to the organization of civil society are being sent by the states, and those will have the responsibility of defining what they will send to strategic projects. “We understand that a certain NGO

is doing a good job in a certain community based an association, but if it does not have the strength to be competitive, we may directly finance the action in question”.

Another partnership was the SOMOS project of prevention against AIDS among homosexuals, supported directly by the Coordination:

NGOs understand that it worked well because there has been this support, since in other places where this support has not come, the actions really didn't succeed. The SOMOS project was a partnership between the National Coordination and suggestion of support of state Coordination units, on a non-mandatory basis. But we understood the importance and worked with them, they had all our support and the action went well.

In the state of Bahia there are some NGOs like FOBONG, which is the Bahia State NGO Forums/AIDS, the inter-institutional Commission of STD/AIDS, made up by representatives of the government, civil society and universities. There is a National Network of People Living with HIV/AIDS, but these representations are considered small in number, on a local basis, which does not provide them significant representation levels. “It does not matter how much we provide, the initiatives have to come from them, because we cannot tell them what is best for them, how to build their network. But sometimes they face internal organization problems of how to set up an NGO, for example”.

According to the interview done with the technician from the State Coordination, over the last three years, the state and NGOs have worked together. Not only through the support with materials, condoms, but above all supporting them with seminars. “We have not only supported them with logistic, but we have also worked together, supporting them practically. Last year we supported the Gay Parade and we will support all the popular actions related to combating AIDS”.

FEDERAL DISTRICT

Management of STD/AIDS of the Federal District

Background

The Program was created in 1980 through a specific bill. Therefore, when the Management was created, the Program already existed. The Management was created in the context of a reform that took place over the Hospital Foundation and the State Secretary of Health. With the reformulation of the flowchart, a Management with three axes was created: AIDS, STD and Vertical Transmission.

Current Activities

When asked since when and how its actions related to the policy against AIDS are being developed, the answer is that currently the Management tries to follow the guidelines of the National Coordination, not working in the fashion in which it is structured “because it gets complicated to work on the STD and NGOs/AIDS axis, we cannot work like that. We have to take care of prevention, logistic of medicines and materials”.

Actions Regarding Access to Prevention Devices

With the extinction of the Hospital Foundation, the actions were passed to the State Secretary of Health and the situation got really complicated. The interviewees comment that, at the time of the Foundation, everything was easier since it was a more autonomous institution, with its own resources, and the Secretary, on the contrary, has a slower structure, without qualified human resources, obliged to follow all the items of bill 86.666 (public procurement and acquisitions, for all state levels). “Things used to flow more easily before, so we had more material, never facing the lack of reagents and kits for exams”. Later, the Hemocentro Foundation took all the power and did not let anything lack for us. The former Institute of Health was transformed into the Directory of Central Laboratory, losing power. From 2001/2002 on, we started to have problems:

“At one time, we lacked kits, at another time, reagents; sometimes, we lacked pretty much everything”. In 2003, we had little to offer, few tests were performed. As a makeshift, we used the cooperation agreement (AIDS II) to buy some materials. At present, they feel harmed because they are not allowed to use the resources from this agreement anymore. All the processes are now centralized at the Center of Purchases of the Federal District.

At the center of purchases there are not qualified personnel to evaluate and perform the acquisition of medication and health equipment. When they get the reagents, it lacks the tubes. And without the proper equipment, we cannot work. They need qualified personnel in order to do the correct orders. At present, we have the reagents, but we lack the tubes, then we buy the tubes, but if we don't hurry to do our part, the LACEN does not do its part (which actually it doesn't have to do anyway...). The LACEN had to worry about all the material it is going to use. The CD4 issue is a serious problem, since a price for a total amount was registered, and as the purchase itself took a long time to be fulfilled, the other states got all the material available, and we had to wait for the company to send a representative for us to evaluate the matter and look for a solution, since the portion bought for US\$13 was over. Therefore, either we change our equipment, or we buy a more expensive material. But the Secretary does not understand that we are not allowed to buy it for a higher price, since the minutes state that the price is US\$13. Since the rest of Brazil was able to purchase, it had to be sold – they cannot keep the reagents. If a State Secretary made the request and paid for it, the purchase is accomplished and delivery immediately follows.

Actions Regarding Diagnosis

We have developed an action called “Porão do Rock”, directed to youngsters interested in taking the HIV test, and it was considered a success according to the Management. “If we had offered more, we would have performed more tests. Every time a band stopped playing, people would come to take the test”. With this action, it was noticed that there are people with unsafe sexual practices, and, therefore, with several immunological windows, both men and women. In these cases, they were counseled to come back for a second test, after a certain period of time. During this activity, the issue of where to take the test and the difference between the role of testing in a hemocenter (for blood collection) and the public health network were informed:

It is a matter of stating, both on the counseling as during the Porão do Rock event, the difference between the hemocenter and the need of having access to good quality blood and the issue of where to take the tests. There is a tendency for people to be afraid of exposing themselves; therefore, they go to hemocenters, whose main mission is not to provide free tests, but to collect blood for transfusions. But if the public health network does not offer the test, people will obviously look for the hemocenters.

Actions Regarding Access to Free Testing

They consider that when testing is stimulated, the demand for exams increases, and several times they lack the materials to perform it, like reagents.

Actions Related to Access to Medication

“It is a duty of the Secretary of Health to buy all medication for the treatment of STDs and opportunistic infections”.

Strategies for Distribution of Male and Female Condoms, and Syringes

As for male condoms, there has not been a lack of them yet, since a purchase through the agreement was made. But the National Coordination was asked not to perform the purchase, because purchases of small amounts end up by costing more.

Besides purchasing the materials, they also receive donations of condoms from the Fiscal Authority, but since they are imported to be sold in sex shops (colored, flavored), they are not approved by the Standardization Authority (INMETRO), so they are not distributed, but instead used in safe sex workshops.

The strategies used for distribution depend on the existence of demand on the network as a whole: local and institutions. Therefore, there are demands from PSE, from the populations of the Federal District and from the cities of the state of Goiás that are on the outskirts of the Federal District that use its services. There are also demands for condoms to be distributed in events, campaigns, Carnival, safe sex workshops. With the distribution of condoms, information is also disseminated.

In the public health network, there is regularity on the distribution since the access has become easier. In order to reach that, a card was adopted, so that a person can go to the health unit and receive his/her monthly quota. Normally, the person needs to be part of one of the programs, offered but not necessarily. Some years ago, the person had to ask for a condom at the health unit, by means of a doctor's prescription. Currently, there are two proposals. One is to unify the condom distribution scheme of the AIDS Programme of the women's program. The other is to introduce the availability of condoms in schools. Another strategy already being used is the condom-stamp, which can be exchanged for three condoms at a Health Unit. These stamps are distributed in school events. "The condoms are going to be taken by those who are really interested, for those who will really use them. It is also a way of having access to the service and also of getting some information at the same time. We think it is a good strategy".

In relation to the distribution of female condoms, some difficulties are being faced. To work the issue with professionals is complicated, because if they don't develop a good job, they cannot get to the final user, considering that the professional itself has difficulties with that. Difficulties vary from the understanding of the concept of the product to acceptance. "Some people think it is complicated, some think it is ugly, some give it nicknames and call them coffee filters". Therefore, "If the professional is not convinced, she probably won't be able to convince anyone". The female condoms are received from the Ministry of Health and also from the Fiscal Authority, which obtains them through confiscation.

Evaluation on Possibilities and Limits

Analyzing the limits, it is commented that the Program Would reach a larger audience if more autonomy were given. "The program is too restricted!". Another limiting factor is the fact that the team is small, besides the initial difficulty that people have in

understanding the dynamic of the work, and the difficulty caused by the turn over of human resources. “People won’t stand three months here due to the impact of the work. We have this difficulty in bringing people to the team. When high level people come, they end up by leaving for some reason”.

It is considered that those working in the scope of the National Coordination become more apart of the daily reality. This doesn’t happen to people linked to the Management of STD/AIDS in the Federal District, since they work directly with issues that deal with their own difficulties, such as values, beliefs and behavior, as well as those of the population to be addressed.

At a certain time I had five people, one in each region. Some were good professionals, but they didn’t accept talking about homosexuality and believed that talking about drugs would only stimulate its use. It was a totally distorted vision, because they brought their values to their professional issues.

It is also mentioned the physical conditions of the Management Unit and the problems of social relation among the employees as a limit.

The general public and even some NGOs sense certain confusion between the National Coordination and the Federal District Management Unit, since several demands that are to be dealt with by the Federal District Management Unit go straight to the National Coordination. The bureaucracy is cited as another obstacle for the good development of activities, “I believe that everything that is AIDS related must have an immediate answer, you cannot wait until tomorrow”.

The need for internal interaction of the AIDS Programme with other areas, in addition to the attempt for diversification of external partners is pointed out.

Despite the fact that for each forward step taken two back steps follow, it can be observed that actions are being developed and advances have been made, “We are on a one step ahead two steps behind sort of path, but we have reached some advances”.

Links with Civil Society

The management unit of STD/AIDS of the Federal District, when first asked about the relation with NGOs, mentioned that despite the divergences resulting from the many demands made by NGOs, a partnership was tried, so as to stimulate the marketing tools for an active program. It is believed that the Inter-Institutional Commission may show the path to be followed among the National Coordination, the Management Unit and civil society. “In order to do that, a new working structure would be needed, since members of both the Management and NGOs are not used to working in partnerships”.

Levels of Partnership with Civil Society

The level of partnership of the Management Unit of the STD/AIDS Programme in the Federal District with NGOs takes place through the contribution of materials such as condoms and educational material.

PARÁ

Municipal Coordination of STD/AIDS of Belém

Background

The Coordination is named “Reference for STD/AIDS,” both by the State Secretary as for the general directory and departments. The Municipal Coordination is attached to the Department of Health Actions, which at the state level corresponds to basic prevention. Inside the Municipal Coordination there are two units: The Unit of Promotion and Prevention, which is the Center of Testing and Counseling – CTA, and the Unit of Assistance. CTA is better known in Belém as COAD, which corresponds to Center for Orientation and Support to Serologic Diagnosis.

Current Activities

The interviewee does not know since when the Municipal Coordination is developing actions to combat AIDS. He believes that it was possibly created in 1997. CTA started to tend to women's needs in 1999, and to the needs of the general population in 2000, by providing counseling and testing. The main goal of CTA is to meet the needs of spontaneous demand, but it has also started meeting on-demand needs. This referenced population ended up by keeping the spontaneous one apart, a situation that CTA is now trying to change. Among the population of pregnant women assisted, there are large percentages of STD and AIDS carriers.

Actions in Relation to Access to Devices of Prevention, Diagnosis, Free Testing and Medication

The acquisition of equipment, HIV kits and testing material is part of the Plan of Actions and Targets – PAM. There is also a counterpart from the municipality:

And the counterpart is significant. As an example, now that PAM is taking a long time to be released, we are running out of resources and we are also facing difficulties in performing the testing. We demanded resources to the municipal government in order to buy testing material, negotiating resources from two different sources: the Municipal Secretary of Finance and the Ministry of Health, through the National Coordination.

In 2002, among the population attended, 7,483 tests were performed, from which 61% were for pregnant women. Among this population, 0.41% was HIV positive.

They often lack the prevention kits and testing materials. In such cases, the material is collected, stocked, waiting for the arrival of the kits. When all the kits arrive, all the testing is done. This situation generates a problem, which is the overloading to the employees, to which is added the stress of quality control of the exams, besides all delay in the performing of exams.

The delay in releasing resources generates problems such as the lack of medication, even though such is not characterized as a

difficulty of the Pará State as a whole. The tripartite coordination of the municipal, state, and federal levels is mentioned as a problem.

If the tripartite has already cleared the National Coordination to approve the Plan of Actions and Targets – PAM, how come have they restricted the demands to two points? 1. Approbation of PAM in the Municipal Health Council, and; 2. The definition of medication and condoms at the SIBI level.

We should only provide services to the municipality of Belém, but in practice we render services to the entire metropolitan area of Belém, because the only CTA that really works is the Belém one. “I’m negotiating to define the residence, the origin of patients, since there is an obvious overflow; we have one thousand registered patients”.

One of the targets of the Municipal Coordination is to make the CTA a regional reference center in medical terms, as well as to decentralize the Center of Belém, with the objective of reducing the level of HIV infection, vertical transmission and to improve access:

We want to decentralize the Center of Belém, since our CTA ends up rendering services to the whole metropolitan area of Belém. The first thing we have to improve is access, since we only have the CTA of Belém. Access is overcharged, since there is no decentralization, so I believe the first step is to make access easier, it is necessary to change.

The *Nascer Maternidade* Project is also being negotiated with the State Government. This project makes HIV and syphilis kits available. As for the issue of the materials, HIV positive pregnant women are treated with AZT. On the travails, the women are referred to *Maternity Santa Clara* – a maternity hospital that is registered in our system, where she and the newborn child will receive injectable AZT, in addition to counseling on interrupting breast feeding and a six-month supply of the formula. The *Hospital das Clínicas* is also registered, but it is not sufficiently equipped, and lacks an estimated date on which the necessary materials and equipment will arrive.

Today have an average of 70 cases of syphilis in Belém. The CTA performs the promotion and prevention of STD/AIDS, but our proposal is to amplify the testing on HIV and syphilis. Besides that, we want to be able to start performing testing for hepatitis B, if we are given enough resources. If we had a system for hepatitis B testing, it would probably create its own demand.

In 2001, at the Commission on Hepatitis, we agreed even on liver transplants. The laboratory is set to perform all biochemical, pathology, markers and images diagnosis.

Strategies for the Distribution of Male and Female Condoms, and Syringes

According to our plan, we intend to provide male condoms to all citizens we can register. We have a proposal of ensuring the availability of condoms for all sexual intercourses of all people listed in our registries. Another strategy is the distribution of condoms to all CTA patients. Firstly, some orientation and collective counseling related to STD/AIDS prevention is given in our meeting room, to 25 people in the morning session and 25 in the afternoon session. After that we have individual counseling. Then, the user decides if he/she wants to take the test or not. Following the procedures on STD/AIDS, there is the delivery of the result, the assistance to those that arrive here after our working hours, the workshops, the talks, when more condoms are distributed. Furthermore, we participate in campaigns during special times of the year, such as Carnival, Valentine's Day, the summer, the International Day Against AIDS (December 1st), when we distribute condoms. Distribution is also done to the participants and users of *Casa Dia* Program, and another quota is sent to the *Saúde Família* Program.

We also work on another basis, which is the collective work. In addition, we deliver lectures on prevention in schools, companies and NGOs.

Condoms are distributed during all of these activities.

The Municipal Coordination is responsible for the control and distribution of condoms for city of Belém.

The State Coordination sends us the list of NGOs, and we negotiate at the NGOs Forums the amount of condoms to be given to them. We are going to have a control of this distribution, since they are kept at the warehouse of the Municipal Secretary of Health and are only released upon our authorization.

As regards the distribution of female condoms, our performance has been low, “We can’t supply all of demand”.

As for the damage reduction policy, we have a project called *Velha Vida*, which aims at the reduction of HIV incidence among injected drug users of Belém. Mobilization has not been done yet, in the sense of having society participate in such a program.

We are working on the legal aspects. Talks with the Federal Police, the Public Ministry (investigative arm of the courts), and the National Committee on Drugs and the Lawyers Bar are also necessary so that we can put people on the streets to perform the exchange of syringes. Therefore, we first need to convince society and public bodies to participate in the project. We are already discussing the training program. We are planning to organize a seminar in partnership with Gesta, an NGO. We will invite a judge from the state of Rio de Janeiro, who is favorable to the project. We still haven’t tried to get closer to parents to ask for authorization, because if we do, we can’t even think about going through a straight execution of the project.

Links with Civil Society

Partnerships are taking place through dialogue with the State government, independently from political actions, from the lack of definitions, since it is a new administration.

As there have always been difficulties with the dialogue and relations, the Municipal Coordination is working on other projects, gathering a lot of ideas and setting monthly meetings. “This represents a change in relation to what we had before”.

Levels of Partnership with Civil Society

Partnerships exist only when there is agreement. In relation to workshops and trainings, NGOs received help from PAM, to which the resources have already been made available. “We are agreeing on the preparation of workshops and trainings and distribution of medication and condoms. I consider it a good relationship; one that brings benefits to the program”.

Background

The State Coordination has taken part in the prevention of STD/AIDS since 1987, when a unit of reference was set up.

Current Activities

The Coordination started developing actions related to the Brazilian policy on fighting AIDS in 1992, with the introduction of AZT. Initially, they offered only single therapy, but from 1996 on, with the arrival of the protease inhibitors, they started double and triple therapies.

Relation with Civil Society

They have been developing actions related to citizenship and human right since they started to work with NGOs, especially in educational projects.

Actions in Relation to Access to Prevention Device

The actions related to prevention materials take place through the access to educational material such as pamphlets. The State Coordination mainly targets the more remote areas of the country, since the interiorization of the disease in such areas is being observed.

They distribute male and female condoms, but the policy of distribution has largely changed from an indiscriminate to a selected one. “We distribute (condoms), but provide education on the issue at the same time. The female condoms have a higher cost than the male ones”.

Actions in Relation to Diagnosis

The access to diagnosis is made possible through the Centers of Testing and Counseling – CTA. In the CTAs pre-tests are conducted as well, which means that the population receives counseling prior to the exams. Some of these units are associated to SESP, others are not.

Before the existence of the CTA, there were the URIDIPs, which were units of reference in treatment, but that also worked as CTAs, since people would come for testing as well. As there has been an accumulation of demands, they requested the State Secretary of Health to decentralize the Health Units. From the five Health Units in Belém, the state coordination started to set up the CTAs. Currently there are 23 CTAs, even though not all of them are working properly. In the 123 municipalities of the State of Pará, we have health centers and units basic care, “In order to set up a CTA, we have to analyze the number of HIV/AIDS cases that have been diagnosed in a given population. In the city of Abaetetuba, the CTA is not located in the basic care unit, but in a school instead.

Actions in Relation to Access to Free Testing

The exams performed at the CTAs are free to all citizens. In these center, HIV serology is the main activity.

Actions in Relation to Access to Medication

At the CTA level, only serology is detected, and in case it is HIV positive, the patient is referred to the Unit, where he/she will receive medication. This Unit, which works with the State Coordination, is referred to as a Specialized Attending Service. But there are places in the interior, where patients are directed to Belém as a result of discrimination. “We face a serious problem of discrimination in small cities. The personnel in these units have to be convinced of the confidentiality of their service. The population has to be able to trust this kind of service”.

The technician interviewed observes that there is not a problem of access to the specific medication for HIV/AIDS, since it is ensured on a national basis. But in relation to basic medication, there may be some problems of non-availability:

Every time that we start a new treatment, we send a notification file (called SINCEL or SINCRON) to Brasília so as to ensure this treatment. When the patient takes the specific exams for CD4, viral charge, Brasília already plans for the correct number of patients for the whole state of Pará.

Strategies for Distribution of Male and Female Condoms, and Syringes

Initially, a reduction of the number of male condoms distributed had to be made, “People were making balloons with condoms, they didn’t even knew how to use them, so we had to start an educational process to show how they were to be used, and then ask them for the correct use, showing its importance”. Nowadays, the policy has changed, since we are giving priority to specific target populations, as the sex professionals (prostitutes, who are given 30 condoms a month), homosexuals (12 condoms a month), the STD populations (8 condoms a month), as well as HIV positives, convicts, under-age convicts and the indigenous populations. Besides specific populations, the State Coordination also controls the distribution according to age, “Aiming at information and education”.

The strategies used for the distribution of male condoms take the target population into consideration:

We have the regional units and they have a certain number of units, so we distribute while taking into consideration the target populations. When I send a certain number of condoms to a CTA that does not work properly, next time I’ll send this amount to a CTA that does. This also works as an alarm sign to the CTAs that are not working properly.

It is considered that the needs cannot be met in the way they were before. Therefore, a scheme for distribution has been set. A pattern was built and understood by all so that condoms are given in exchange of information, “We need data, so we are going to work with data, and as we receive more data, we release more condoms”.

The NGOs then provide monthly information regarding the population assisted, according to age, through the delivery of the distribution scheme. In the past, not all partners provided feedback, since they had no control:

I did some calculations and then provided a number of condoms to be distributed to certain NGOs that did not fulfill our criteria. Then, after the NGO provided statistic data and if I realized there was a repressed demand, I’d provide more condoms the next month. Today we have the feedback and I am adapting the scheme according to their proved needs. It is a tough process, it is an educational process, but we have to show NGOs what we are doing.

As regards the distribution of female condoms, our service includes the formation of groups of women that attend monthly meetings, during which a certain number of condoms is provided to each one. They prepare reports, and describe the difficulties that women have as a result of taboos regarding the use of female condoms, “There are many problems that we need so solve through education, so that they the benefits of the female condom are acknowledged. It is a follow-up, an educational process that takes a little while”.

The strategy is the formation of these groups. Depending on the feedback they send to the State Coordination, it increases or decreases the amount distributed. In this way they provide the regional units, the CTAs and 28 NGOs. They also distribute condoms in seminars held in companies, “As a matter of fact, the State Coordination is advising us not to organize seminars since that is not our job; therefore, we are reducing the number of seminars and talks”.

As regards the distribution of syringes, there are no projects in the State Coordination in the area of damage reduction; therefore the Coordination *does not distribute syringes*. There are projects of NGOs directly with the National Coordination on this issue:

We have a monitoring and evaluation project related to distribution of syringes, which is foreseen for two cities – Belém and Redenção. We are still carrying out the research regarding the impact of these projects related to the user, but we still don’t have the results. But the Coordination itself has no project in this area.

Evaluation of Possibilities and Limits

They work with actions that have been formerly foreseen, as the support to CTAs, implementation of information systems. They are developed according to the incentives received from the Ministry of Health.

The limit in relation to the activities is set by the resources available, “The hardest limit is when the financial resource is over, because when it is over and we still have things to do, we cannot make them viable, we have inputs, we need a lot of things”.

Links with Civil Society

The NGO Forum coordinates the partnership. For example, in carrying out an event, it is disseminated by the Forum. This particular partnership is new, but the work with NGOs dates back to 1993.

Levels of Partnership with Civil Society

The State Coordination supplies NGOs with educational material, training and several meetings, providing conditions for NGOs to organize their own events. As an example there is the sex professionals meeting.

They jointly program the activities, detailing the needs for traveling, development of courses, trainings and meetings. After the formation of the Forum, the discussion is carried out through it. There is also a partnership with the Municipal Coordination of Belém, which holds monthly meetings to organize joint actions, since in the past the two coordination units ended up by performing similar tasks, in the same regions, which resulted in a fight for power:

We had a fight for power and that is not the way we want to work. So we offered the Municipal Coordination the material, we give them the condoms and they work in the city of Belém by themselves. We also provide support to other cities, since they need the support of the State Coordination.

RIO GRANDE DO SUL

Municipal Coordination of STD/AIDS of Porto Alegre

Background

The Municipal Coordination was established in 1987 and was part of the planning advisory unit, instead of a separate coordination. It was only in 1992 that it was officially converted into coordination, separate from the planning advisory and the remaining public policies. It has autonomy although its manager, up to now, is the coordinator to the planning advisory unit. There are several policies in the planning advisory unit, which also comprise STD/AIDS, but is

does not work like the remaining public health policies such as, for instance, women health, children health, mouth health, nutrition health, the issue of medications distributions – which is also a municipal policy.

An administrative reform in the Health Secretariat is under way. Through it, the Municipal STD and AIDS policy will formally become the Municipal STD and AIDS Programme, separate from the planning advisory unit. This policy is different from the other policies because, besides defining the political issues for STD/AIDS, it also coordinates the services. The coordination has specific duties and prevention programs: “We have the coordination of policy at the city level, we have the coordination of specialized services, such as the COA, ambulatory, etc., and we have projects on prevention”.

Ongoing Activities

Since 1992, it develops actions concerning the Brazilian Policy on Fight against AIDS, developing joint works with the National STD and AIDS Coordination.

Relationships with the Civil Society

The actions concerning citizenship and human rights are more related to the Human Rights Secretariat, which is part of the organizational structure of the local government. However, all NGOs working with the Municipal Coordination develop the issue of human rights. The Municipal Coordination deals with the topic of citizenship, because they have projects on prevention, such as the ARPÃO – citizenship and human rights for prisoners; the Project on Damage Reduction – citizenship and human rights to drug users; the Multiplicadores Comunitários, which is a program on prevention, among about 4,500 community leaders in the city of Porto Alegre, duly qualified to work in several communities, providing information on STD/AIDS and citizenship.

In Porto Alegre, there are NGOs working on the topic oriented to more specific populations, such as travesties and sex professionals. They also hold partnership with the NEP, providing financial

support to the development of actions in this field. Another partnership in citizenship and human rights is that with GAPA, mainly oriented to MSM or gays.

Actions Concerning Access to Prevention Devices

The local government purchases the prevention devices. Despite the National Coordination orientation for them to seek, for example, for preservatives in the State Coordination, they have never done it, because the local government allots resources to purchase prevention devices. Since 1992, the Municipal Coordination usually purchases and transfers the devices to the local government, and this last distribute them to NGOs and to the Health Basic Units.

The local government transfers to them, we purchase and transfer [to the local governments]. We also distribute, but we know it is easier for them to distribute this sort of prevention device. We make them available at the basic health units, but sometimes people have difficulties in approaching the health professional to ask for the device. So, since 1992 we have transferred some preventive inputs. We transfer preservatives, lubricating gel, syringes, needles, etc., whatever is requested.

Actions Concerning Access to Diagnosis

According to the municipal manager, the supply of works concerning access to diagnosis is facilitated, because there are no waiting lines. In the city of Porto Alegre, four services provide this sort of service, and only one of them is municipal. According to medical prescription, the patients are required to repeat the diagnosis at every three months. They recognize as major difficulty the adherence to treatment and the non-access to diagnosis.

Actions in Relation to Access to Free Exams

The access to free exams is a municipal service and, therefore, the municipality affords the expenses with every patient. The ambulatory in Porto Alegre cannot refuse to render services and, therefore, receives several patients from the metropolitan region. "The Sanitary Dermatology and the Partenon Sanatorium have the greater number of patients coming from other parts of the State and the metropolitan region but, in anyway, we have a huge number".

Actions Concerning Access to Medication

It is part of the National System of Medication Control – SICLOM, where all patients are granted universal and free access to medication. Some specific medications, such as the antiretroviral drugs, are granted by the State: “in fact, the State through the National Coordination. The National Coordination transfers to the State, the State transfers to us”. The purchase of medications for opportunistic diseases is under the responsibility of the municipality, but they are also trying to purchase some kinds of antiretroviral medications. Currently, the local government faces some financial problems and, therefore, cannot incur in expenses beyond the stipulated level.

Strategies Towards the Distribution of Male and Female Condoms, and Syringes

The strategy employed appeals to the facility or lack of facility of negotiation between the couple. If the man accepts using the male preservative, they encourage this method, even because it is more accessible: “We always say that, if the woman feels easier to negotiate the use of male preservative, so the male preservative should be used, mainly because we have no difficulties in providing and distributing male preservatives”.

They distribute thousands of preservatives in the city, although they know that some people trade the condom they receive for free. However, their basic assumption is that someone is preventing.

And then comes the Ministry of Health statistics: we distribute X preservatives. However, I don't know to which extent the condoms are used or if the person trades it. Someone in the National Coordination told me: But, by the end, someone will use it to prevention. Yes, but maybe this person is not the most in need, because he/she can afford purchasing, while the other can't.

The State grants female preservative and is now undergoing difficulties concerning the distribution flow. The Ministry of

Health sets a quota for female preservative transfer. Since this quota was very low, the health units did not distribute it, because that would raise the population expectations, and the Municipal Coordination could not afford. They have repeatedly talked to the National Coordination, and it said they should negotiate with the State Coordination, because the quota is not so rigid. The local government cannot afford purchasing female preservatives. They are now facing obstacles in holding the sensitiveness-building workshop, because they would need significant amounts of female preservatives to support the clients' demand.

A survey carried out by the Municipal Coordination disclosed the acceptability of female preservative, and assisted in obtaining a considerable amount of preservatives, granted by the National Coordination. It facilitated the preservative dissemination, although many surveys point out that women consider the female condom very anti-aesthetical.

Concerning damage reduction actions, they compare the situation of syringe distribution in Brazil and in developed countries. They say that here, the drug user must sell the syringe to get the drug. "Then, what happens is that you give them syringes, and they sell 99 and keep one. And they remain using that same syringe everyday, keeping it there, but nobody knows who else use it".

Assessment on Possibilities and Limits

Concerning possibilities and limits in relation to ongoing activities, the most concerning limitation for a governmental organization is related to hiring human resources, in terms of quantity and quality, mainly concerning quality. The situation jeopardizes the services expansion. "We have a law that sets a limit of X contracts, and we cannot set new offices at local government, and then we cannot expand services".

Within this context, there is a major concern about the prevention programs.

We cannot continue them, because we can't hire personnel. The local government hires only through contest, and the establishment of offices by the City Council, the Municipal Executive. If they don't approve – and they don't approve, because it goes beyond the threshold set forth in Law Kandir and the law on Public Bidding – we have problems. For example, concerning damage reductions, we cannot expand for this reason. I was telling you about the ambulatory that will be assembled in the North Region. Everything is ready since two years ago, but we don't have human resources. The area was totally reformed, arranged, equipped, but we cannot open because we don't have personnel to work there. The local government payroll doesn't allow for hiring new personnel or establishing new offices.

The responded appoints as possibility for developing actions in Porto Alegre, to have the NGOs hiring the human resources with resources granted by external partnerships – because the NGOs may receive foreign resources, for example, the Ford Foundation may transfer resources to the NGOs and the NGOs hire human resources – and the municipal coordination would provide technical assistance.

We need NGOs that develop projects, we assist in the project preparation, there is no problem, but they should develop projects oriented to impoverished populations. And we could submit, supported by the local government – an important point – proposals to foundations, international institutions, etc., to assist us in expanding the programs. If we succeeded in these partners with the NGOs, they would receive the resources, hire people, and we would provide technical assistance, as we now do with all NGOs, we provide technical assistance.

Links with the Civil Society

In 1986, when the Municipal Coordination had not yet been formalized, people from GAPA started a dialogue with the Coordination. There was a secretary extremely sensitive to this issue, and it resulted in the gradual preparation to establish, in 1992, the Municipal Coordination: “The relationship among the GO, us and the Non-Governmental Organizations has always been very close. Very close in the sense that the NGOs almost showed us the way to do things”. But, at that time, the municipality experienced major advances, and even the government coordination, the vice-mayor

and the local mayor were sensitive to any AIDS-related issue. In 1996, the Program on Damage Reduction was implemented. This work had been developed for almost six years, and succeeded in sensitizing also the government coordination, the police and the public teaching system. This panorama of developments, according to the Municipal Coordination, was due to the pressure by the Non-Governmental Organizations. “But surely because of the Non-Governmental Organizations. They assisted us and made pressure, in many instances, over the municipal government to adopt some policies that, by ourselves, we would have never done”.

Therefore, all advances are due to the partnership and mutual assistance between the Municipal Coordination and the NGOs. In 1998, this partnership led to the establishment of the Municipal STD and AIDS Commission of the Municipal Health Council. Still in 1998, the state of Rio Grande do Sul housed the first Global Conference.

Since then, they started elaborating the process of strategic planning in the Municipal STD and AIDS Commission, aiming at defining the plan to the city concerning STD and AIDS. The Commission relies on representatives of the NGOs, health workers and public health institutions (like, for example, the Hospital das Clínicas) that work on AIDS.

Levels of Partnership with the Civil Society

Jointly with the NGOs, the Municipal Coordination develops courses, training, meetings, programs and activities. Furthermore, the Coordination grants inputs to the NGOs.

The Municipal STD and AIDS Commissions became the place where people go just for denouncing. According to them, the NGOs did not safeguard their capacity of thinking policies to the city. Furthermore, they do not enforce the policies established.

For us, who work in AIDS, we want the civil society to observe, to monitor, because sometimes we – the staff – cannot shift the situations, not even by talking to the Mayor. But if civil society makes pressure, we are sure that things would change. So, what we have asked to the Commission is for them to monitor the issues in general, in all senses, on the AIDS-related municipal policy.

Background

The State Coordination manager does not know exactly when they started developing actions on STD and AIDS, but she believes it was about the second half of the 1980's. Since the first case in 1983, Rio Grande do Sul – not as a Programme, not as coordination – created a STD and AIDS sector that, along years, have been developed. It was a sector, than became a Programme and, also, a STD and AIDS section. Currently, there is a STD and AIDS Coordination that works and is sustained through the social support, additionally to federal and municipal support, and the State Secretariat support, as well.

The State STD and AIDS Coordination reports to the Department of Actions in Health – DAS, which used to be called Coordination of Integral Health Care – CAIS.

Ongoing Activities

Relationships with the Civil Society

The motto to the State STD and AIDS Coordination, since its early stages, is citizenship and human rights, even because of social pressures. They have developed and became Coordination because of the pressure and spread of the epidemic.

So, it was not a spontaneous action by the Secretariat. It was a social and epidemiological pressure that led it to be organized, and technicians to become sensitive to the issue. But it arose because of the sensitiveness of one or another person, a staff member, a technician – and I really mean one technician – motivated, sensitive to the emerging epidemic and social pressure. Here, in Rio Grand do Sul, GAPA was outstanding – by that time was the GAPA. So, this concern about the rights of citizens, human rights, has always been present.

Actions Concerning Access to Prevention Devices

Since its early stages, the Coordination has always developed actions related to access to prevention devices. At the end of 1980's, they had already prepared and distributed informative material and condoms.

In the beginning of the epidemics, there was no treatment, we didn't know what to do with the patient, so all we did, in the beginning, was to talk about sexual life, talk about prejudice and discrimination, but it was too much about talking, talking, talking one to another. Our basic duty was to distribute condoms and information material.

Actions Concerning Access to Diagnosis

Rio Grande do Sul has followed a parallel track, since things started at the global level, and it was the first state to include the purchase of a flow cytometer within its needed equipment.

I remember one thing that was reason of pride for us, satisfaction, not tranquility, but we had the first or second flow cytometer in Brazil – when no one talked about CD 4, counting of CD 4 cells and CD 8. At that time, the coordinator included a flow cytometer in the list of required equipment. So, we have always been ahead or in side-by-side with the technology available.

Actions Concerning Access to Free Exams

Since the AIDS epidemic started, the state has developed actions concerning access to free exams.

Actions Concerning Access to Medication

Rio Grande do Sul provides access to medications, as they become available worldwide. It has even provided medications that are not included in the consensus (rules set forth for the use of antiretroviral medication, issued at the federal level):

Sometimes, even before the consensus, we had already purchased the medication, provided it was through administrative processes. We have a sector basically for that. When the epidemic started, we had legal suits for medications; they are no longer legal, now they are administrative ones. We have medication; it is made available as soon as possible and for free to the patient and his/her family. The expenses to the state were reduced.

Under the view of public health, the state is divided into nineteen Regional Health Coordination units, with at least one distributor in each municipality that houses a Coordination unit. Even with distributors all over the state, they claim to be below the expected performance.

Strategies to Distribute Male and Female Condoms, and Syringes

The distribution of male condoms started in the 1990's. In the beginning, there was massive distribution; the limit depended on the quantity available. Over time, they changed the strategy because quantity was no longer a limit, for they had too many condoms stored, which were provided by the Ministry of Health and through local purchases, both by the State and some municipalities. However, the distribution policy changed a little, since they noticed that distribution itself did not change behaviors in a stable way.

People could use condoms, but only those they had received. If a person received three and used them all, they had no more condoms for the fourth sexual intercourse, "If I get infected, the blame is on the state, which didn't give me the condom, the NGO that didn't have them". Therefore, the current policy for the distribution of condoms is associated to an educational process, "This is pretentious, sometimes it is just an informative process, but at least it is no longer the distribution by itself. It also happens to the female condoms, not only to the male one".

Concerning the female condoms, the Ministry of Health set some criteria for distribution, because it is expensive and not very popular. The criteria for distribution to seropositive women, or women living with seropositive or AIDS-infected partners; users of injected drugs or women living with partners who use injected drugs. Since it is a clearly defined criterion, they have decided to also distribute female condoms to women who feel vulnerable, regardless of their serological status or sexual intercourses.

If, for any reason, the woman feels in risk, she receives the female condoms and is inserted into a group that may assess this feeling: is it real, concrete, and justifiable? The perception of risk may be mistaken, but until then, and for as long as she wants, she will receive the female condoms.

The distribution of syringes is restricted to the projects on damage reduction. They have projects in damage reduction in Porto Alegre and 37 other municipalities. In addition to the projects on damage

reduction, the Coordination intends to encourage a daily practice, “So it doesn’t mean that such municipalities or such programs, or such health units that develop a project on damage reduction now have a syringe available, if there is a demand”. They also use the strategy of building awareness and providing tools to health professionals at all levels, besides providing education to professionals and those in the field of justice, to make them aware of the need, because sometimes the person comes to the health unit and doesn’t ask for the syringe. “Try to understand the need in the in-between-the-lines and say it, make it clear that if they need a syringe, they can go to this place, at this time”.

Assessments on Possibilities and Limits

Concerning possibilities, there are several, and they see that the community is getting organized; the civil society is getting organized, and they are seeking for and demanding responses from the public services. They point out the population who is eager to acquire and use knowledge as a possibility, whether in universities or community-based movements: “if we stop and listen to the several groups, people are saying it, people want and are saying it. They are available for learning, to qualify their right to access to information and devices”.

As a difficulty, they point out the issue of monitoring and assessing the activities performed, the ones they cannot develop or those they did not know how or did not want to develop. For example, they mention the male condoms issue:

We have several quantitative assessments, how much we distribute to the prison system, in health units, in STD services, in regional health coordination units, several places. But if you ask me who got these condoms, who is using them and who bought condoms, who sought for them, I don’t know. How old is this person? Men or women? Are they girls, adolescents? Married or single persons? This person is a homo, hetero or bi – sexual? Level of formal education? I don’t know the person’s profile. Liked it, didn’t like it? What did the partner say when he/she saw the person using a condom? Why did they or didn’t they like it? Still uses? Where do they get these condoms? Where would they like to get these condoms? If it is not granted by the state, does the person buy it? Can they buy it? How about the price? Do they trust the brands available? Does it smell fine? Is the taste good?

They believe that this lack of information on all such issues may jeopardize the guidelines for future actions. Furthermore, they claim that this situation happens with the projects developed by governmental and non-governmental organizations. “If you don’t assess what you did, how will you assess what should be done next?”

Links with Civil Society

In the beginning, the partnership between the State Coordination and the NGOs was conflicting, and counted on some disagreements. Over time, both sides became more mature, “When I say one side and another, I think I am contradictory, because we realized – through this maturity process – that there is no such a thing as one side and another side; we were both on the same side, but with different views”. The only side mentioned in the report below, means prevention, control, health promotion, access to devices for prevention and worthy assistance to population as a whole.

We grew in one single direction, we are complementary one to another, and we don’t fight for space. We clearly understand the NGO’s role. If the NGO denounces, shouts, makes a movement here, in front of this building, and when I, as public civil servant, as Governmental Organization, I understand it and try to contemplate it in an ethical and honest way, trying to allot all resources available to things that really deserve such resources, I think it was how this partnership, this relationship was established. We fought a lot, but always having in mind that it was a good fight, a fight knowing that the enemy was not one or another. We have a common enemy. We fight with different weapons, we have different strategies, sometimes our positions are partially opposite, but not in its final purpose.

Levels of Partnership with the Civil Society

The manager says he does not like to see the Health Secretariat or the State Coordination as mere suppliers of materials, condoms, pamphlets, courses and lectures. He understands that the Secretariat and the Coordination should not be faced as *the great mother, the supporter*, but instead as an institution that has and

holds the resources, and may allot and provide them, whenever possible and in the best way, to the NGOs. “Opening ways, facilitating ways. So, we don’t believe we are just suppliers of inputs, but the Secretariat must be together, the Secretariat must hear, discuss, talk, and look for ways”.

In practice, they want to know who the persons are, who the NGOs and all the institutions are. What are they doing, what do they want to do, what is the proposal, which is their understanding on STD and AIDS, sexual and reproductive health, drug use, life quality? What do they see, how do they see themselves in the reality; in the understanding they have about how it should be.

So a new NGO, or an old NGO, calls, we go there, visit them, we like to go and see what they are doing, how they are doing, who they are? What do they think? Which is the proposal? And, usually, we grow a lot. There is a club of mothers that come here to ask for condoms. They don’t leave here with condoms; they leave with someone, with videotapes, with female and male condoms, with the offer of discussing sexuality and the use of drugs by their children, their partner, themselves. So, she is now with us... comes here and we won’t give them peace, our policy is this. We surely cannot maintain all these approximations, but in principle this is the partnership.

They highlight that they try to encourage people to get organized. If it is a request for partnership or individual assistance, they forward it to the existing NGO that is already working. If it is a commercial, community-based, teaching institution, an NGO – working on AIDS or not – they provide, jointly with the input – condoms, folder, poster, lectures – workshops where they try to use a problem solving methodology, getting people to adhere to one or another service, in a permanent way.

We participate, we sit together, like with the Federal University, the Medical School, they asked us for a lecture and condoms, and we are now developing a joint program on the quality of life in the university. We provide assistance to prepare projects, to execute projects, to assess these projects. We participate in courses, events, granting subsidies whenever possible, or intermediating subsidies through other institutions, as the National Coordination.

RIO DE JANEIRO

Municipal STD and AIDS Coordination in Rio de Janeiro

Background

As of 1992, the STD and AIDS Programme was officially instituted in the structure of the State Coordination. Since then, they have developed activities related to this field.

Ongoing Activities

Since 1992 they have develop actions related to the Brazilian policy of fight against AIDS, in scales. Therefore, the access to preventive devices, access to diagnosis, access to free exams and to medication is not simultaneous. In the first stage, the actions were mainly oriented to issues more related to assistance. The first Center of Anonymous Testing – CTA, was established in Rio de Janeiro in 1992. Then, they developed the actions aimed at prevention. From the start, the condoms were included, especially because Rio de Janeiro has a tradition of a structured contraception program. Later, they also developed in the issue related to human rights promotion, and other actions that were gradually incorporated.

Strategies to Distribute Male and Female Condoms and Syringes

The major strategies employed in the distribution of male condoms are through the contraception program, at the units of assistance to HIV/AIDS carriers, in the CTA, in non-governmental organizations and organizations that are not characterized as NGOs (civil society organizations, community-based organizations), besides sporadic events, such as campaigns, Carnival, events oriented to prevention, Valentine's day, gay parades and lectures.

Concerning the female condoms, Rio de Janeiro was the pilot municipality in the distribution of this device, with the objective of testing its acceptability. Since female condoms are not available

in the same numbers as the male condoms, in addition to being expensive, they are provided to some specific populations, like the sex professionals and women that make regular contraception. It was also introduced to some contraception groups, because they have the opportunity to hold several meetings and work on the issue of the adequate use of this method. Currently, there are thirty units working with female condoms and the distribution of female condoms is routine in several Health Units.

Mainly oriented to sex professionals, in face of the short autonomy in the use of barrier methods, it was also introduced to some contraception groups. As an alternative to those women who make regular contraception and some other features of women who fit well and must have the contraceptive method or, here, a barrier method under her administration.

The distribution of syringes is focused on partnerships. In Rio de Janeiro, this experience is mainly related to the NEPAIDS – a nucleus of the University of Rio de Janeiro – because it has not yet been established at the Municipal Health Secretariat as something that can be distributed in the Health Units. It is developed in the scope of NGOs projects.

Assessments on Possibilities and Limits

The Municipal Coordination manager mentions that there are countless possibilities concerning ongoing activities, and that they have already tried and put many of them into practice. One issue is the possibility of spreading, provided by the partnership, reaching populations of increased risk (travesties, drug users, sex professionals, populations that have difficulties in being served by the health service), and places where public power faces difficulty, and/or does not have structure or profile.

So, this is a possibility of expanding our capacity of reaching people that need assistance. The social control by NGOs is crucial; this return, this challenging over us, are part of AIDS policy. The innovation is another possibility, since the civil society organized in all of its forms, through its demands, may foresee things that could have another pace of representation, not only in the issue of prevention, but of assistance and other areas as well. There is the

possibility of having other programs following the same path. I think we are sort of producing ways, I think we here in the Municipal Secretariat work in an integrated way, since in Coordination we also work on tuberculosis, Hansen's disease, in partnership with the program on women, program on children, program on family health, and I think that all such proposals on prevention and promotion use this way opened by the AIDS programme and its partners.

Concerning limits, they point out the issue of decentralization, the need for dealing in closer relationship with NGOs, as well as with civil organization in general. Other limits pointed out are the institutional ways to transfer resources, monitor and assess and, eventually, guide them. Now the municipality has a clearer view on the initiative gaps, not only in light of public services, but also the gaps where the NGOs do not work, "Be able of fomenting a little; provide some direction to proposals and projects". They have several limiting issues, like legal, administrative and institutional ones.

Besides the aforementioned limitations, they also consider as an obstacle a sort of parallelism existing concerning AIDS activism and the way followed in relation to SUS.

Links with Civil Society

The partnership between the Municipal Coordination and the NGOs has always existed, but it became more mature and consolidated over time. Initially, it used to be timely, through support and projects assigned by the National Coordination. They received several invitations to attend events, co-finance events, print material, and provide condoms. Over the years, the need for a model partnership proposal became clear. Currently, they have a bank of partnerships, bank of prevention, and map the ongoing projects in the city, whether financed by the Ministry of Health or not, including projects on prevention in the scope of the Health Units. These units are a privileged space, because people spend long hours there. Currently, the partnership is structured with criteria and mechanisms that allow for documenting this integration with the NGOs.

Levels of partnership with the Civil Society

Partnership is varied, comprising from the contribution to pay the rent of a bus to take people to an event, air ticket, to the participation in more structural discussion about some projects.

State STD and AIDS Coordination in Rio de Janeiro

Background

The State Coordination, as a specific program, was established at the end of the 1980's. As a technical group specifically working with the epidemic, it started its activities in 1985, when the number of AIDS cases started increasing. This technical group was part of the Secretariat chart.

Ongoing Activities

Along the history of the State Coordination's establishment, there was no major investment in the field of assistance, because in the health system this is a municipal duty: "Where the citizen lives and where he/she receives assistance. In fact, the state doesn't manage the service. The Coordination was not very dedicated to this issue". As of 2000, the State Coordination started playing a more active and visible role in relation to assistance. It gathered professionals for training, and undertook the issue of supplying medications for opportunistic infections. This activity used to be little developed.

Assistance is a field that was recently enhanced. The fields of prevention and human rights have been part of the actions since the technical group was established.

Concerning the actions on access to free exams, the laboratories in Rio de Janeiro cannot produce the number of exams (viral load and CD 4) required to serve the population:

We have virtually involved all the laboratories, all university services and services of research instruction such as FIOCRUZ; even the health units are attending. This is a feature of Rio de Janeiro, a very centralized assistance, but it can't cope. We need more services and more professionals to provide services to all patients.

Strategies to Distribute Male and Female Condoms and Syringes

The State Coordination has a group to work in the field of prevention among municipalities, providing training in this field, and one of the issues approached in training is the issue of condoms. Working the aspects of control, logistics, distribution, rendering of accounts, additionally to the educational aspect that should follow-up the distribution of such inputs. The strategy is to qualify and train more and more people to make interventions on prevention, including the distribution of condoms, always trying to insert distribution into a context of a health action, an educational action.

They also face difficulties in dealing with the distribution of condoms, due to the existing culture that it may be provided anywhere, as if there were no costs, “We receive a lot of requests. ‘There will be a Mothers’ Day party, could you provide condoms to be distributed to the mothers?’ Surely, this is not about limiting the access of people, but it should be done within a given context”.

In fact, the State does not distribute to services. The State Coordination works with the Municipal Secretariats. Thus, the Coordination distributes to municipalities, and the municipalities distribute to services; furthermore, they provide training to municipal teams to distribute condoms properly, “Surely we receive and, eventually, distribute condoms, but not for services. For an event: Gay Parade, Carnival, so we have a number of condoms that we work with in these situations”.

The strategy employed for the distribution of female condoms is more complex, because it involves several issues, such as the fact that it is not a broadly known device, it is much more expensive than the male condoms, and the acceptance and adhesion are lower. For these reasons, the distribution of female condoms should be associated to an educational work. Therefore, they register only one municipality or NGO or service to receive female condoms, and then train the person responsible, the municipality and the technicians. Training is provided on a regular basis.

Concerning the strategy on kit distributions (syringes, needles, alcohol, garrote), some CTAs and NGOs working on damage reductions are in charge of it.

Assessments on Possibilities and Limits

Assessing the limits, the major one would be the system of health services. We should not just accept it, but we must understand which issues are involved. As example, they mention the poor emergency services, because of reduced number of beds for hospitalization, the insufficient number of health professionals working in the public sector, some under skilled professionals, low salaries, the mandatory requirement for hospitals to have structured and operational commissions on hospital infection, the low number of infectologists in face of the demand, “These infectologists are priceless in the market, and we don’t get them. We have many municipalities doing whatever necessary to have an infectologist, but they just can’t hire them”. For the lack of professionals expert in infectology, the hospitals work with general practitioners who are not prepared to deal with the problem and, therefore, must be trained. Furthermore, there are some municipalities without one single general practitioner, so they provide training to gynecologists to assist not only the pregnant women, but also HIV positive women and patients from other municipalities, “We can’t find enough professionals to meet the population of patients we have”.

The state manager observes that these issues impose limitations to works, in providing high-quality services to carriers. According to him, this is not only about specific resources for AIDS, but a limitation by the system. “Surely the specific money helps, but it had more significance in the past, when we had a field to develop and partners to involve”.

Another limitation is the impossibility of performing some actions, because they belong to a different governmental sphere.

Here, the possibility would be to overcome the barriers existing in the system, improving services management, i.e., to make heavy investments in management, at all levels:

But this is not a field where we can interfere directly. It seems obvious that a poorly managed service is much less profitable than it could be. So, a way to overcome these difficulties is to make investments, heavy investments, in management improvement. We have done it in the state, investing in our technicians to better qualify them for management, to undertake more duties at the state level, and we have also invested in the qualification of programs teams.

Links with Civil Society

Initially, the State Coordination had an informal partnership with the NGOs. In 1992 a State AIDS Commission was established, and the NGOs have representation there.

Levels of Partnership with the Civil Society

Additionally to providing inputs, the State STD and AIDS Coordination also offer capacity building courses on projects elaboration. Therefore, they consider it a broad partnership.

SÃO PAULO

Municipal STD and AIDS Coordination in São Paulo

Background

The Municipal AIDS Programme is, in fact, called Theme Area, but plays the same role and follows the same logic of the Programme.

When the Municipal Coordination took office in 2001, they started outlining a work proposal because they found a situation established as early as in 1988 in the field of health. There were twenty AIDS-oriented units and three laboratories assembled by AIDS and, therefore, considered of AIDS, but which did everything, but little in. They were practically the laboratories of the forty units that remained to the Health Secretariat, and one public hospital and a maternity.

The current state government proposes to change the path taken by health in the city and, in fact, insert the city of São Paulo into the Brazilian Unified Health System – one of last cities to be inserted. For that, the new management needs to reorganize the AIDS service

existing in the city is public health service, since the history of the fight against AIDS in Brazil is very dissociated from the Unified Health System – SUS, for several reasons. One reason is because the program construction had a verticalized proposal – which, to some extent, granted success to several actions. Regardless of the specific situation of São Paulo, they point out that the AIDS Programme should seek for better integration with SUS, since the positive experiences could strengthen the SUS, and because the SUS could contribute towards expanding STD and AIDS actions.

We came to reorganize the existing AIDS system, which worked as an island in that initial period. In fact, we came to reassemble the AIDS service, but reassemble it within the public health service in the city. So we had some luck in taking the reconstruction of AIDS policy in the city within SUS, the reinsertion of the city into SUS. As some measures theoretically discussed in Brazil, we have greater ease in implementing, because the city didn't use to have SUS and had AIDS.

To develop this proposal, the Municipal Coordination would have to face three major political challenges.

The first one would be granting a coordination nucleus compliant to SUS principles, i.e., decentralization and unified command of actions at the municipal level. The municipal public power was negligent, and there was a strong presence of the executive power and NGOs that, in the end, replaced the public power. The insertion of this new player – with a decisive role – initially brought about several conflicts even pertaining to location, conflicts with NGOs, conflicts with state government, in the sense of arguing, “Which is the role of the municipal coordination? Where will it be placed and how will it, through the construction of this proposal, achieve the discussion on total exclusive command in the city of São Paulo?”

The second major challenge was in the scope of the Health Secretariat, concerning the idea of decentralization; the new management wanted to establish, since the beginning, thirty-nine health districts, “How could you, at the same time, develop the decentralization movement and a movement of policy for AIDS or for any other issue under the Secretariat. Everybody faced this contradiction between decentralization and maintaining an unified policy”.

The third challenge would be to undertake a structure with working habit, intending to provide it with political unit, without losing the specificity of its regional insertion.

And political unity was not easy, because it was one of the most visible systems of survival in the previous period. There was no public policy, the Secretariat didn't provide support, and everything depended on the good will of the staff, their local guidelines, and their local negotiations.

In the view of the municipal manager, the development of these three aspects was extremely important, besides representing the major challenge faced. The public health system should be remade, to say:

Now we have a health policy, now we have SUS, now we have a hospital network, a basic network; now we are part of it: how these units work. Obviously, they had independence, their own leadership, staff, but articulated in a unified policy on AIDS to the city. And how do we build it? I think these were the initial challenges posed to us, how could we cope with it, under the light of reconstructing AIDS policy within the framework of SUS reconstruction in the city of São Paulo.

Ongoing Activities

The Municipal Coordination guided its policy following the SUS principles, because it considers them as the broader principles that grant the integrality of actions, rather than exclusively assistance-oriented actions. These actions also comprise concerns with access to preventive devices, access to diagnosis, to free exams and medication. "For example, they grant access to the citizen; actions with several characteristics; actions pursuing equity and social participation, the grant of tools in the system scope, ranging from local managerial councils to regional managerial councils".

They were more comprehensive, when they inserted in the municipal policy guidelines not only AIDS-related policies, but also the principles of the Brazilian Unified Health System policy.

They placed three priorities on the management. The first priority was to place emphasis on the issue, because they could observe that AIDS policy background in São Paulo was basically aimed at

assistance. So, to maintain the equilibrium between assistance and any other action within this principle, they had to work more on assistance. The second point: The Brazilian Unified Health System was integrated to SUS, and granted to SUS the merits of the AIDS programme, strengthening public policies and the SUS.

For example, how can we grant control over vertical transmission exclusively in AIDS-oriented units? It is totally impossible, if there is no articulation with prenatal care or child delivery; or how could STD actions decentralization be granted without articulation with the basic network.

The third priority was granting humanization of services, qualifying health professionals to deal with reality, by expanding training, granting institutional supervision to professionals in duty, granting the articulation between services and civil society, establishing the managerial council and, thus, granting service quality control.

With priority placed on these three issues, and maintaining SUS principles, we have developed the concretization of these issues, considered crucial issues in AIDS Programme – according to UNESCO – only by providing broader views than those historically conquered by the AIDS program.

The actions on prevention were expanded, with projects all over the city; however, coverage is lower among sex professionals, men who have sex with men and among drug users. Observing and comparing it to other actions on prevention, which are under the competence of Public Power – expansion of testing supply, expansion of diagnosis treatment of the STD syndrome, expansion of vertical transmission control –, they consider it has improved in vertical transmission control along the last two years, and worsened in STD issues.

In fact, we are expanding; we are assembling at least one CTA unity in each sub-local government. We have done our part, which is more governmental, but probably the greater lack of coverage still remains in the integration of basic units, the STD disintegration and in prevention for specific populations. If we compare the situation in 2000 to the situation now, things have really improved, but there is a lot to do.

Strategies to Distribute Male and Female Condoms, and Syringes

When this management took office in the Municipal STD and AIDS Coordination, there were 15 assistance-oriented units, and only five of them developed studies on female condoms, with limited quantitative data, because the criteria for inserting were completely restrictive. So, they had no action to grant female condoms as an important input. Therefore, they started considering the female condoms – like the syringes and the damage reduction kit, the male condoms – as any other input that should be available in the units, especially in STD/AIDS units and CTAs. They have also changed the access criterion, including men. They converted the female condoms into a customary input in the AIDS network. They have not yet had the required conditions, whether financial, political or of technical organization, to expand the female condoms beyond the AIDS network.

After expanding the access to female condoms in the AIDS network, they started discussing the expansion of male condoms to the entire SUS network. Now, they serve about 1/3 of the SUS network with male condoms. Previously, they had expanded the access to male condoms to the non-AIDS network.

The same situation described for female condoms happens to syringe distribution, because they have not yet expanded the damage reduction kit beyond the AIDS network.

Assessments on Possibilities and Limits

The municipal manager believes there are several limitations to expanding the activities, but underlines that STD and AIDS actions in the city of São Paulo, like in many other cities in Brazil, remain privileged in the system. They do not think that everything is solved; instead, there is a lot to be done. Nevertheless, they had differentiated actions, because they relied on the social movement, with health professionals, and governments who are committed to the issue. These differentiated actions had impacts even on the costs of medications, “Until recently, only the medications belonging to HAART used to consume

almost 3% of the federal budget to health. This is a high amount, if we consider that it is a single disease in a country with so many diseases, so many concerns on health, so many problems of this nature". Even in the municipal scope, they have invested almost 3% of the municipal budget to health, in AIDS. Furthermore, they point out that they have 1,400 staff members to work exclusively on STD and AIDS in a Health Secretariat with 35,000 staff members. "This is significant within the structure itself; additionally to the secretariat costs, not to mention the transfers, agreements, conventions". In terms of costs, they estimate that for every two reais transferred from the Federal Government, they provide one real as counterpart. This is an expressive contribution, mainly taking into consideration a sort of "folklore", according to which AIDS is sustained exclusive with foreign resources. They comment that none of the myths is real, first because AIDS, historically and until recently, was supported with 92% of SUS resources, and only 8% of proceedings for external loans.

As of 2003, almost 100% of the resources allotted to AIDS are provided by the SUS. Currently, transfers are through the Fund-to-Fund, i.e., from the National Health Fund to the Municipal Health Fund; therefore, these are the SUS resources to actions on prevention, training, etc. So, the SUS has an important participation, where 2/3 of the resources are granted by the Federal Government, and 1/3 by the Municipal Government. This means an expressive political commitment.

We got committed when we injected 3% of the Municipal Secretariat resources, if we keep in mind that the Secretariat's total budget was around 1 billion and three hundred million reais, for 2003. So, we consider we have signed an important local commitment towards the issue of AIDS.

The major limit mentioned is to integrate STD and AIDS actions into a more horizontal way within the system. The second obstacle is to expand prevention actions with impact on the epidemic, covering the populations' needs in a city with the size of São Paulo. To advance in prevention actions, they held a seminar on the means

of integration, jointly with the NGOs, trying to understand what each participant was doing in the field of prevention, what could be done to avoid overlapping actions and to expand actions to uncovered fields.

Links with Civil Society

Initially, the relationship between the Municipal Manager and the NGOs leaderships was disturbed, because they publicly expressed that they would like to have been consulted when he was appointed. The manager was surprised with this manifestation, since he holds a position of trust, in the public service, where the Government is the responsible for deciding who coordinates.

In its early stages, the relationship was highly affected, because I am completely aware about my governmental role and the role played by the government in these issues, I am not the kind of person who advocates for the minimum state, the idea that civil society should take care of everything and our role is just to provide money and forum to organize the civil society.

During the management process, the relationship with the AIDS movement leaderships was improving, and is now considered as excellent, despite some NGO/AIDS leaderships that do not like the style, the format and the relationship, but who, however, do not represent the movement as a whole.

Levels of Partnership with the Civil Society

The Municipal Coordination provided training about the SUS for the NGOs, through seminars, because of the process of integration to SUS. The Municipal Coordination notices that most NGOs/AIDS were not prepared and skilled in relation to the institution. They also held another seminar on Civil Society Organizations of Public Interest – OSCIP, because they consider it as a way of institutional characterization. This last seminar resulted in legal assistance to any organization that wanted to be converted into an OSCIP, “What we provided to the NGOs was more in the fields of institutional development, or its institutional relationship with the system. It was never oriented to more

technical issues, because we never had such demand and, in fact, never thought about providing this kind of service”.

For events – national or international – the Municipal Coordination affords the trip-related expenses, rents a hotel, and pays for the coffee breaks. For national events, such as those for travesties, sex professionals, drug users, the Municipal Coordination provides direct assistance. It does not transfer resources, but supports by purchasing inputs, printing materials, etc.

They usually work with training as well.

State STD and AIDS Coordination in São Paulo

Background

The AIDS Programme has existed in São Paulo since 1983, but it was formalized in 1998. It was the first in Brazil and the Latin America. It emerged as a response by the Health Secretariat to a demand of the organized gays groups in the State of São Paulo, who monitored what was happening in the United States in relation to a new disease. Initially, in 1983, it was assigned to the sector of sanitary dermatology, cancerology. Paulo Teixeira coordinated the Hansen’s Disease Programme, and incorporated the AIDS Programme into the Health Institute, where the sanitary dermatology was, and the *Hospital Emílio Ribas* that, since the beginning, was a reference to hospitalization, additionally to Adolfo Lutz, as laboratorial reference. From 1983 to 1986, that was the structure of the AIDS Programme. When the Health Secretary changed, the Programme Coordinator also left, and the coordination, the ambulatory and the patients were transferred to *Hospital Emílio Ribas*. The Lutz remains a laboratory of reference. Between 1986 to 1987, the outbreak of AIDS cases started – the virus reached São Paulo in the early 1980’s, and for a long time people were getting infected, but were not presenting AIDS – and increased the search for services in a health network with no preparation. At that time, despite the epidemic spread, the Program decentralization did not follow its pace. It was a time marked by several crises and deaths.

The Secretariat had rented a small building to establish the *Emílio Ribas II*, facing major difficulties, exactly in the field of AIDS, including issues on staffing. In 1998, because of the difficulties faced, Paulo Teixeira was invited once again to work in the Programme, not as the coordinator, but to head the epidemiological surveillance, bringing the proposal on assembling the training reference center. This center was intended to be the basis to support the decentralization of the actions developed by the State AIDS Programme, in the fields of prevention, surveillance and assistance.

Since the epidemic was decentralizing, and the network capacity of responding wasn't, so it was endowed with a feature that remains to our days: It emerged with the mission of providing support to qualify the SUS network in the state of São Paulo, towards dealing with AIDS in the dimension of prevention, surveillance and assistance.

As the building rented to house the *Emílio Ribas II* did not work, remaining closed while the society complained, because it was a rented building and was empty, the people who had formulated the project of the Training Reference Center – CRT, decided to assemble it in that building. The CRT became a space for articulation and coordination of the program. At that time, the CRT had, in fact, the field of education and training, responsible for the educational campaigns, information campaigns to the public in general, providing training to the network staff, and organizing training events. The epidemiological surveillance, jointly with the *Hospital Dia* (an ambulatory in the health center) was transferred to the CRT, jointly with all patients. At that the time, there was no hospitalization in the CRT, and it did not provide services on STD, only on AIDS. The three fields: Prevention, assistance and epidemiological surveillance, provided training to a huge number of individuals. The period from 1988 to 1991 was intensive in training. In 1991, the Health Secretariat leadership changed once again, and the Programme Coordinator (Paulo Teixeira) left it. At that time, the program had no coordination, and the CRT lost its function, i.e., the mission of supporting the coordination. The field of prevention was fragmented;

a part was assembled in the Secretariat's office and another in the CRT. The epidemiological surveillance remained working, training and articulating. The CRT field of assistance lost its programmatic feature, and became more assistance-oriented. The ambulatory *Hospital Dia* that provided good quality services to patients, the major service in the municipality, also lost its role as trainer, capacity building agent, and articulator, "The program was suspended until 1994".

In 1994 the Programme returned. In that same period, 1993 – 1994, the World Bank Loan Agreement – the AIDS I, was signed, and everybody was involved in preparing pamphlets and annual operational plans.

In 1995, when the government changes again, the team that worked in the CRT since the beginning develops a lobby work and Paulo Teixeira returns and negotiates the retaking of previous CRT project. Then, he takes the CRT coordination and leadership. Since the CRT coordination was bound to the AIDS Programme Coordination, he also takes this office.

In middle 1996, CRT leadership changes. In 1998, the CRT is transferred to the Health Secretariat own building, and now has an official organizational structure: The CRT structure and staffing are redesigned. So, the coordination that used to be a division in the CRT becomes a department. The staffing is defined, and the new CRT structure is disclosed: It officially becomes, through a decree rather than a ministerial administrative rule, the headquarters to the State STD and AIDS Programme Coordination.

The director is the programme coordinator, and the set of CRT work fields are the technical fields that coordinate the actions on prevention, surveillance and assistance in the state. The laboratorial duties have always been performed by the Adolfo Lutz, as the core public health laboratory of the Secretariat, with its mission officially defined and disclosed in the Official Gazette.

Ongoing Activities

The State STD and AIDS Coordination develops actions related to the Brazilian policy on fight against AIDS since 1983, as described in the background. Formally, through a Decree issued in the Official Gazette, since 1998.

Since 1989, in São Paulo, they worked with the concept of behavior of risk, instead of groups of risk, because they consider risk situation as a result of the behaviors in relation to the life conditions.

The behaviors are individual, but are produced in and linked immediately to socialization, both in the light of behaviors and of objective conditions of life; there is a socioeconomic and cultural context that allows this conditions to happen. So, we used to work with this notion of risk situation, trying to cope with this historic and process-oriented dimension, i.e., you characterize or not these risk situations, they are concrete social constructions that generate identities and behaviors. Ultimately, they refer to human rights and citizenship.

Relationships with the Civil Society

Since 1983, the State Coordination has developed actions related to citizenship and human rights, because the program emerged as a response to the organized civil society's demand. In this sense, it results from the interlocution between state and civil society.

According to them, the tradition in the Brazilian social medicine, public health or preventive medicine – or any name that may be assigned, collective health – has always worked on the notion that health and citizenship walk hand-in-hand, or are the same thing. Almost all activists in this field bear this concept, applicable to the set of diseases in general, and to AIDS as well. But for AIDS there is a slight difference, which makes it even more interesting, i.e., the issue of poverty as an element of vulnerability. The AIDS has also brought about the issue of deviation from moral, rules, behavior or sexuality deviation that, somehow, refers to the issue of human rights, i.e., the right to exercise identities, differences, the sexuality.

I recall that, in 1989, we already used to approach damage reduction in our newsletters, we approached the respect to sexual diversity and sexual option, the sexual identity according to the individual's choice. So, I think that in our work on the issue of AIDS, we approached the most traditional issue of the Brazilian public health, the social medicine, of pursuing links among social class, health / disease process, citizenship and lack of citizenship. Health is a fight; health is a good that must be conquered. And the human rights, although I believe that, in a more consistent way, what brings it about in a more explicit and conceptual ways – I don't know if as a concept, but as a stronger notion – is the issue of vulnerability.

They also mention the Brazilian Unified Health System – SUS, “characterized as the people’s right and the state’s duty”, which has in its principles the notion of citizenship. Any health program in the SUS must work very closely to the notion of citizenship and social control, i.e., rights in general. The human rights brought about by AIDS, were followed by the feminist movement and some fields that have strong interfaces with the user, with the patient.

I think that human rights appear because of the conflict of powers, either medical power or the institutional power with population. In AIDS, this provides the opportunity for a broader perspective of human rights in dealing with prejudice, with a moralist view. In this sense, I understand that this couple, citizenship and human rights, is essential to the work on AIDS, in the perspective that we work.

Actions Concerning Access to Prevention Devices

They state that the AIDS Programme seriously comply with the SUS principle of integrality, i.e., according to the SUS the commitment towards health promotion, disease prevention, disease cure and assistance to rehabilitation. The Brazilian policy on AIDS does that, and does not choose between prevention and assistance – what is unconstitutional in Brazil. This selection would be illegal pursuant to the political referential framework set forth in the Brazilian Constitution and the SUS. Furthermore, it is less efficient in technical terms.

So, beyond an ideological issue, I believe there is a pragmatic issue in technical terms, concerning the belief that the work is better, more profitable in technical terms, leading to better results. I guess that São Paulo is among the pioneers in the construction of access to treatment, i.e., prevention has never been challenged, even because Brazil is a poor country and should do it, it should not be concerned about treatment, because we don’t have money, it is expensive and there is no competence to do it.

Actions Concerning the Access to Medication

The State Coordination started distributing the AZT in 1989, when the medication appeared. São Paulo has afforded for it since then. Although the Law Sarney dates back to 1996, the agreement on

federal responsibility for purchasing antiretroviral drugs is dated 1997. The tripartite meeting set forth that the federal area would be in charge of purchasing the antiretroviral drugs, while states and municipalities afford medications against symptomatic opportunistic infections and STD. So, in São Paulo the responsibilities of the federal, state and municipal spheres concerning the set of medications and treatment inputs for HIV and AIDS carriers are defined within the scope of the SUS. Therefore, the state manager perceives three moments: the first one, when the federal sphere undertakes the duty of purchasing the antiretroviral drugs; the second one, when the tripartite sets forth the purchase of medications as federal responsibility; and the third one, with the bipartite meeting that defines the list of medications under the responsibility of states and municipalities.

There were three moments: a moment when the federal sphere undertook, and they discussed if there would be any kind of co-participation by the states in the purchase of antiretroviral drugs, thirty, sixty or seventy percent. This discussion remained until the tripartite decided that it was under the federal responsibility and, in São Paulo, we have agreed it following the bipartite. There are two bipartite agreements, one early in 1998, following the tripartite that defined a list of medications under the responsibility of states and municipalities, and in 1992 we expanded this agreement in the bipartite, and included almost all DST medications agreed, and all those medications available for opportunistic infections. And we re-agreed on what should be under the State Secretariat responsibility, and what should be assigned to the municipality. It now varies from a state to another. São Paulo was one of the first ones to enter an agreement. Now, under the view of medications, it is pretty well, it does not guarantee it has, but we surely know who to blame in the event of shortages.

Even previously to this definition, São Paulo used to purchase antiretroviral drugs (AZT, Indinavir and 3TC) and interrupted these actions only when the federal government effectively undertook this duty, with more consistence.

Strategies to Distribute Male, Female Condoms, and Syringe

The State Coordination purchases the female preservative, additionally to those provided by the Ministry of Health: “We are

now working with two sources: We purchase it at state level, but we tend more to the federal sphere". The quantity distributed is not the same, if compared to male preservative, because of the price.

São Paulo was the pioneer state in the distribution of needles and syringes. In 1991, the municipality of Santos tried to distribute needles and syringes, but São Paulo justice impaired it. Because of this, it was also the first state that enacted a law that allowed for developing damage reduction actions. A proposal unanimously approved in the legislative assembly disclosed that public health actions, in this field did not increase the use of injected drugs. Jointly with the law, was enacted the State responsibility for purchasing damage reduction inputs. And the state should supply it to the municipalities and NGOs. The law also allows for NGOs to carry out actions on damage reduction.

The State STD and AIDS Coordination is responsible for supplying this input: *we are supplying*. They are currently facing a crisis to obtain budgetary resources to purchase the required inputs to develop actions in damage reduction.

Assessments on Possibilities and Limits

In the field of limits, there are the economic indicators, mainly income distribution that was not improved, despite the Brazilian success concerning the AIDS Programme. Surely, if the AIDS Programme did not exist, the economic indicators would probably be the same, and we would have a larger or worse gap concerning the negative social impact that AIDS, out of control, could have caused to Brazil, not to mention human suffering.

Based on this situation, the limits would be the lack of citizenship construction in Brazil, the financial capacity of reducing social unfairness and the disparity of income concentration. This last is the basic element to increase vulnerability to any disease, especially to AIDS. They argue that, regardless the good sectoral social policies, at a given time an adverse situation, such as lack of citizenship, just cannot be bet. Another limit is the Brazilian social and sexual culture.

As structural limitation, they mention the establishment of a multi-professional team, aiming at approaching the patient in a more integral way.

Concerning the SUS, the major obstacle is the incapacity of implementing, in the basic network, actions on prevention in the vertical transmission of syphilis and AIDS, integrated to women health, children health and the Family Health Planning – PSF.

Links with Civil Society

The partnership between the State Coordination and the NGOs started to develop jointly actions, whether in the field of training strategies and qualification of the health network professionals, or to prepare products such as videotapes. Whether working jointly in the person-to-person work among specific populations (sex professionals, gays, drug users), listening to them and understanding what they think, their needs. This partnership is mainly aimed at facilitating the prevention against STD/AIDS.

São Paulo has two forums. The NGO/AIDS Forum, established in 1995, which gathers over one hundred and sixty NGOs. The officer in charge of the State Coordination participates in the forum, articulating with the NGOs. Now, there is a relationship of social control, demands, discussion. This is the political moment when the Government and the NGOs articulate one to another. Another Forum is the Managers one, assembled in 1997, and now called Forum of Interlocutors and Coordinators of STD and AIDS Programs. This Forum held a meeting that gave birth to another forum, which should gather regional spheres and a downsized state sphere. Additionally to State and Municipal STD and AIDS Coordination units, the Lutz participates in this forum, representing the laboratories, and the State and Municipal Health Coordination, besides a representative of the NGOs/AIDS Forum and of the National Network of People living with AIDS – RNP, in the state of São Paulo. These last hold seat, but have no right to vote.

The current state manager is concerned about the scope of the actions, i.e., which actions are under the Coordination of the NGOs responsibility: “It demands much care to avoid employing situations specific to NGOs, like the direct access to population, and assign them the state work, saying: the NGO does it better”. On one hand it is positive, because the NGOs works are being acknowledged in

the sense of providing credit, financing, support, developing joint work, but always having in mind the respect to the responsibility of each player: “In other words, do not waive the responsibility and assign it to the NGO; the state cannot do that, I think it is dangerous”. However, it should advance in the possibility of partnership, developing joint works and activities, also with other NGOs, not limited to the most traditional NGOs/AIDS.

6.3 MUNICIPAL AND STATE COORDINATION STRATEGIES TO FOLLOW-UP AND ASSESS THE CIVIL SOCIETY ACTIONS

Concerning the follow-up and assessment of the actions developed by NGOs, the state and municipal coordination employ several strategies, mainly through reports, meetings with the NGOs, as detailed below.

Relevance of Follow-up and Assessment

The Ministry of Health understands and acknowledges the need of a local opinion for a project, and nationwide bidding. These compel the NGOs to render accounts to states and municipalities on what they are doing. In the sites that rely on Municipal and State Coordination, both Coordination units must issue their opinion. Furthermore, through the new policy of incentive, the Ministry of Health has established an assessment system, which obligates the state and municipal coordination units to review their methods.

The culture of assessment and monitoring is being implemented in Brazil, in the scope of SUS. They believe that follow-up and assessment are impossible without a planning: “if you didn’t plan, you can’t assess”. The initial step towards reaching a situation is planning the actions. First you plan, and then you start thinking about indicators, means of verification. This culture of assessment is expanding in the field of AIDS, because the World Bank used to require information on the use of the resources that they granted, what was done about it, if it worked or not.

Therefore, the World Bank agreement brought something that is very important and positive, i.e., the culture of planning and assessing within the framework of a strategic planning. In São Paulo, the program strategic planning is performed jointly with the DIR, municipalities and NGOs.

A manager points out that a regulatory determination by the National Coordination sets forth the establishment of a commission to analyze and approve projects. The commission is involved with the NGOs, the coordination, the Secretariat.

Since the creation and elaboration of political strategies and work techniques, to the issue of direct action – whether in the field of assistance or prevention – and social control, the NGOs play a core role in Brazil.

Kinds of Strategies of Control

Following, as example, are mentioned some states and municipalities which have already started the follow-up and assessment of the actions developed by the NGO, besides disclosing the different strategies employed. Even these places report difficulties in performing the follow-up actions.

For Bahia, when actions are financed by the Municipal Coordination, the NGOs have a report-based system of rendering of accounts, and that is how they monitor their activities. Furthermore, the Coordination participates in actions such as seminars, campaigns, meetings of the Bahia State NGOs/AIDS Forum, and these are the steps that proved to be effective to develop follow-up and assessment actions. Besides these actions, they also hold specific meetings between the Coordination and the NGOs, to follow-up and assess the works developed. They also follow-up through monitoring visitations, but they are infrequent. Nevertheless, they consider this follow-up as a difficult task, because they cannot be in several places: “There is no regular monitoring”.

For Pará coordination, in the beginning of the macro-mixed assessment, explained in details herein, they go to the site where a given group or a project works, checking for the impact. The macro-mixed assessment is performed by professionals, such as a

NGO representative, an activist, an expert state civil servant, and the researchers: “They develop a real work of research, about the impact of that action”.

The macro-mixed assessment was proposed by the National Coordination that held workshops with municipalities wanting to submit projects, both to NGOs and governmental organizations. Such projects should be oriented to specific populations. During the workshop, the National Coordination established the conditions, and the State participated with a project on supervision, monitoring and assessments.

Therefore, seven projects were elaborated by NGOs and governmental organizations, to the specific population of MSM and drug users; out of these seven projects submitted to the national coordination, four were approved; two are under the Belém Local Government, one on MSM and one on drugs, damage reduction; one is under the Ananindeua Local Government, and is oriented to MSM; and three are in Redenção, with drug users. (State Coordination on STD and AIDS, Pará).

For Rio Grande do Sul the municipal coordination relies on a Committee on Monitoring and Assessment for all activities developed by the NGOs. This Committee is made up by some Municipal Coordination staff members (psychologists, psychiatrists, physical therapists and an administrator, in charge of the financial area). Monitoring is performed on a monthly basis, and is endowed with a tool for follow-up and direct supervision in the field, in the NGO working area.

The Committee was assembled because of the National Coordination invitations for bidding, since the Municipal Coordination had to issue presentation letters to the NGOs and they should present the letter to the State. This was one of the criteria to approve the NGO projects.

It has also led to the establishment of a projects shop, made up by a team in duty, aiming at assisting the NGOs in the elaboration of projects coherent to the municipal policy on AIDS, and the local reality as well.

This follow-up is an advisory service because, since it is supervised, they also provide advisory, including on financial issues, and therefore qualify more and more the works developed by the NGOs. It is not a punitive supervision, or surveillance, but they care for the proper employment of resources, pursuant to the planning. However, by the end of each year, they intend to check the “before” to assess the “during” and the “after”, assessing the impact of the NGOs intervention, if any.

The first strategy employed by the State Coordination in Rio Grande do Sul to follow-up and assess the actions developed by the NGOs is to hear them, placing special attention to the feelings of those people who are developing the works. How do they feel performing this work? If they are succeeding or if they are facing difficulties. What is good, what is bad? They employ this strategy because they are naturally concerned about whether the NGOs are developing the actions in a proper and pleasant way; otherwise, the development of these actions to the population may cease. The support is not bound to success; it is conditioned to the assessment and readjustment, whenever applicable. They miss agile, dynamic, sustained strategies of monitoring and assessment.

We are just beginning – even in a hard experience, with major difficulties because of time and resources constraints, of economic resources even for displacement – yet this year, with visitations to the field, to NGOs and to the sites where they develop their works, listening to the target-population. Hearing the target-population of the projects, of the actions performed by these NGOs. There are many difficulties, this is a slow process, but it must be intensified, even because the National Coordination will change, this year, the policy on resources transfer. Now it is decentralized, the process is fund-to-fund, regardless our will, it will happen because, otherwise, it would jeopardize the process continuity. (State STD and AIDS Coordination, Rio Grande do Sul)

In the beginning, the follow-up and assessment of the actions developed by NGOs was very weak in the Municipal Coordination in Rio de Janeiro. Now, they have the opportunity of holding two annual meetings. They hold a meeting with the NGOs, one with the Community-based Associations, and other with their own Health Units that develop actions in prevention. Therefore, they

gather information to input in their database. Through this database they know, for example, how many projects are covering sex professionals, how many preservatives were distributed to each population group, having an idea on geographic coverage.

We had a notion about the gap in given areas of the city, where actions are not so present. With the process of decentralization, in the calls for proposals on projects, we intend to set a share aside to incentive actions that may fill in the identified gaps. (Municipal STD and AIDS Coordination, Rio de Janeiro)

The municipal manager in Rio de Janeiro considers positive the experience of relying on some managerial tools that allow for better quality monitoring and assessment. However, when they have the possibility of transferring resources, they do not know how the physical-financial monitoring will be. Furthermore, there are some issues that they do not intend to undertake, such as auditing postures and, therefore, they will have to establish partnerships: “There are things that we don’t want to execute, the program doesn’t want to undertake auditing, neither issues related to misuse of public resources; so, we will have to establish partnerships in these fields also”.

The strategy employed by the State Coordination in Rio de Janeiro was to assemble a technical group to work on the issue, improving their skills in the field of monitoring and assessment, financed by the Ministry of Health.

We are working with the ENSP towards developing tools, hiring a person specifically to visitations, because we can monitor through reports, but the on-site monitoring of actions should be comprised. Most projects are here in the municipality of Rio de Janeiro. If we consider the municipality of Rio de Janeiro and the metropolitan area, we shall have 80% of the projects, what is acceptable because epidemic is like that. But, taking into consideration the size of our teams, monitoring such a large amount of projects, about 120 projects in the state, is a major challenge. (State STD and AIDS Coordination, Rio de Janeiro)

Several respondents consider that the state and municipal STD and AIDS coordination remained for too long aside the process, and it delayed their involvement in the monitoring and assessment of the actions developed by projects financed by the Ministry: “We

didn't even know what the projects were doing, we had no authority to ask for information, follow-up or develop any sort of monitoring". As of the decentralization of projects selections, they now have access to projects first, and then they review the projects and the views of the NGOs that were part of the process: "Our work was not limited to issuing letters and agreeing, saying that the NGO really exists, because this was the role played by Coordination units until then. They got acquainted to the project and started undertaking monitoring and assessment".

One of the managers interviewed criticizes monitoring exclusively based on progress reports, basically oriented to financial aspects. He points out that it opens room for "The NGOs to invent whatever they want".

In fact, the monitoring performed by the National Coordination is based on progress reports and approaches the financial aspects, the notes and things like that. A Non-Governmental Organization may invent anything it wants. In my opinion, the monitoring performed by the National Coordination has never been suitable, in this sense. So, this is not what should qualify the national policy, even less the actions by NGOs and GOs. The assessment should be over the most troublesome issues in health, an assessment on the impact over the epidemic. It is just the tool on the before, the during and the after. (Municipal STD and AIDS Coordination, Rio Grande do Sul).

Furthermore, there is the possibility of holding tri-lateral agreements, agreements with other countries, with other institutions, with international funds, where the NGOs could be the executing agency, could hire and solve some issues that the GO cannot solve, at least in the short and mid terms. Some examples mentioned are: Changes in the procurement laws, and in the law for hiring personnel. "I think that an alternative would be to establish a sound partnership with the NGOs, and a more critical posture of the NGOs".

The interviewer asked about the risk of outsourcing the State actions, since the NGOs would now play the role of mobilization agent, political player and, at the same time, execute the actions. The answer is that it is an outsourcing, but they cannot wonder

about any other solution, any other alternative in the short or mid terms.

We hope things can be changed, but at this moment I don't believe in it. There is an extremely serious problem concerning damage reduction: The program is being reduced, instead of being increased. We have the ARPÃO that we could not continue, and it is the only work in Rio Grande do Sul performed in the prisons by some NGOs that work there. And it is one of the few projects of this type in Brazil. A program that received several awards – even the UN awarded it. But we can't hire personnel because there is no legal possibility of doing so. So, I think that it is an outsourcing, but I have to safeguard the technical support to the execution, which should be under the State responsibility, i.e., the state should be accountable. (Municipal STD and AIDS Coordination, Rio Grande do Sul).

Reasons for Not Performing Follow-up and Assessment Activities

According to the respondents, many state and municipal managers consider this issue as a crucial bottleneck that must be equated. The reasons for failing in following-up and assessing the civil society actions are: short staff, lack of time, lack of knowledge on the projects developed by the NGOs, and the fact that projects are not yet decentralized. Some places do not rely on strategies to follow-up and assess the actions developed by the NGOs, because they claim “lack of control”. In the view of manager interviewed, the only likely control would be within the forum scope, through mandatory participation of the NGOs and submission of their projects to this sphere. They believe that, by doing it, they would strengthen the NGOs/AIDS forums, besides taking over the control.

A manager interviewed points to the lack of systematized work. They visit and are visited by several NGOs, but they do not monitor or assess the actions because the projects are not yet decentralized.

Even lacking the required conditions to follow-up and assess the NGOs actions, they notice it is a major failure, because it is necessary, mainly taking into consideration that, after decentralization, they will have to finance projects directly.

6.4 ASSESSMENT ON THE RELATIONSHIPS WITH THE CIVIL SOCIETY

Concerning the degree of influence of the NGOs in the elaboration, execution and monitoring of public policies and programs implemented at the state and municipal levels, this power is substantiated through the participation in commissions with representation in the NGOs/AIDS Forum. In some states and municipalities, the commission and the forum are representative in the strategic planning elaboration. Concerning NGO projects, there is a work group to discuss the priorities and the resources employment. Typically, the NGOs have broadly participated in the elaboration of the Strategic Planning. Therefore, the NGOs' influence in the elaboration, execution and monitoring of public policies and implemented programs happens during the strategic planning outlining, when the NGOs are invited to the discussion. There are other channels like NGOs/AIDS Forums, the STD/AIDS commissions.

However, in some places the NGOs have not yet achieved influence on the elaboration, execution and monitoring of public policies and programs implemented at the state level. They have only participated in the Plan of Actions and Goals, referring to the civil society.

Over the last few years, the relationship between non-governmental organizations and the government have become more mature. So much so, that the NGOs participate in the health commissions, committees and councils, at the municipal and state levels. Usually, the NGOs are the elements that gather or assemble these commissions or committees. So, the level of influence of these NGOs is high, over the elaboration, execution and monitoring of public policies, "The NGOs' participation is decisive".

Concerning monitoring, most of the respondents feel a gap, failures in defining actions, because they believe that all actions should be discussed with the organizations and, then, seek for efficacy and efficiency in the resources allotment, because of the

reduced revenues. The NGOs/AIDS Forum is concerned about becoming closer to the state and municipal coordination. The State Coordination manager in Bahia says that many things are done with no previous discussion, without calling the civil society organizations – the major stakeholders that will, in the end, execute the work.

This coordination pursues opening room for discussing its actions. Now, they are preparing the Plan of Actions and Goals for Salvador, to receive the fund-to-fund incentive, granted by the Ministry of Health (transfer of resources from the National Health Fund to the Municipal Health Fund). The Ministry played its role, and asks for discussions with the civil society. They are proposing NGO participation in the discussion and elaboration of the 2004 Plan, because of the permanent need for adjustments and changes prior to the approval. In 2003 they did not rely on this participation. Furthermore, there is the Municipal Health Council – the civil society representation in the Secretariat – and the Plan is submitted for the Council's approval.

Until 2002, they asked for the NGOs participation, and they used to bring projects that were incorporated in the coordination work plan. After 2002, the Annual Operational Plan – POA was extinguished, and the Municipal Coordination had to do it; so, the participation of the NGOs happened during the elaboration. When there was not enough time for the previous discussion, the Municipal Coordination submitted it to the Council when it was ready. At the end 2003, the Coordination had to hold discussions prior to preparing the planning document for 2004. Now, the NGOs are submitting projects to ask for direct agreement with the Secretariat, but all of them have experienced a situation of short dialogue, although the civil society organizations search for spaces to be present, not only in the Council, but to hold better dialogues with the Secretariat. But the Secretariat, maybe because of its staff overload, faces difficulties in meeting face-to-face, in directly discussing with the civil society organizations.

All NGOs are invited to participate in the elaboration of the 2004 Action Plan. Previously, they used to participate through the projects submitted, but there was no forum to discuss these actions; the NGOs just submitted the projects, and the Municipal Coordination analyzed if they fitted into the structure of what should be done. If positive, they established the partnership and the project was executed.

Points of Tension and Conflict

Concerning the points of tension and/or conflict, there were more of them some years ago, when the NGOs did not understand the working and the limitations of the health system. Now, they consider it natural and even healthy to have some degree of tension and conflict between the NGOs and managers, because there are different views and perceptions concerning needs and priorities, the way in which to develop what should be developed, the speed/rate of development. In this regard, sometimes other serious issues that must be solved avoid the conflict. It must be kept in mind that government is government, and civil society is civil society, and that neither of these participants can do everything by themselves. There is also a need for the NGOs to understand a little of the bureaucratic issue, the procurement process that sometimes is long and generates tensions. For example, as regards the acquisition of condoms, “We had to purchase condoms, we allotted resources for that, but it didn’t happen. The bureaucratic deadlines that the prosecutor didn’t understand. So, sometimes this delayed administrative process generates some tension”.

A State Coordination faced problems with medication, concerning some quota of drugs, mainly those with international patents, because sometimes they had 14 drugs out of the 15 that are distributed:

But if they didn’t have the 15th, there were no drugs... And it really was a problem. I heard my colleagues saying, “I won’t prescribe according to the Health Secretariat stock, ‘don’t do it, and prescribe whatever you want. You can prescribe strychnine if you want to, but I don’t have it to give and I won’t do it’”.

As reported, sometimes the conflict was with the doctor, and other times with the NGOs, about the same issue. Also concerning the distribution of medication for opportunistic diseases, it remains an unsolved issue under the light of state and municipal responsibility.

We are agreeing on it in the bi-partite, but the Ministry of Health said, “Look, I am supplying the antiretroviral, the most expensive drugs in the treatment, so the responsibility is yours – states and municipalities”. It almost started a war. The state finances all medium-and high-complexity care. And patients are hospitalized in state hospitals; when they are hospitalized, they receive all medication required for the treatment. We used to send resources to purchase the medication to treat these infections.

So, there was no shortage of injectable Bactrin, but the Bactring tablets to be used in the ambulatory ran out. But, sometimes we were impaired by financial issues: this procedure of providing resources, the ambulatory medication is not paid for by the SUS. You will have the expense, but will have no return. And the NGOs claimed, mainly for this definition of roles that, “It is responsibility of the state, the municipality, the secretariat, we want the medicine”. (State STD and AIDS Coordination, Bahia).

Some managers try to mediate the conflicts through dialogue, “We understand that you are doing your part, but we are facing difficulties here, let’s try to find the best way for solving the issue, we never had a shortage of medicine, so don’t make a denouncement in the newspapers”. They argue that Law Sarney has strengthened the NGOs and the carriers.

The points of greater tension in the relationship with the NGOs are in the responses that the Programme was expected to provide; and it does not occur, as for example, lack of inputs, difficult access to medications – leading to lawsuits and denouncements in the press – lack of social control by the NGOs.

Another point of tension is the duties among the three levels of government. For example, the acquisition of medications is shared among these spheres. The federal government is responsible for obtaining specific medications and, therefore, the more expensive ones; the state is responsible for purchasing medications for opportunistic infections, and the municipality for purchasing STD medications.

The user and the society – I don't mean they have nothing to do with it – but they don't have to know which is the responsible party: what matters is that things get done. The three spheres should demand from one another, and undertake their responsibilities and, in the end, they should get everything solved. So, it this is a level of tension. We must improve the mechanisms to solve these issues within the SUS scope. (Municipal STD and AIDS Coordination, Rio de Janeiro).

Currently, the NGOs have clearly understanding about the health system complexity, because they became more professional. In the past, they could not understand the duties of a municipality, the existence of municipal, state and federal hospitals. However, some degree of tension still remains, mainly concerning the NGOs dissatisfaction in relation to some demands: “Sometimes we are suited by the NGOs; and this is a field of conflict, to purchase given medications, and when we submit the request to technical analysis, we find out that it is senseless in technical terms”.

Another tension that may come to occur refers to the issue of transfer or resources. The Ministry of Health will transfer resources to the States and they, in turn, will be in charge of transferring a percentage to the NGOs. “We don't have any idea about how it will be. It will be a field of tension”.

Furthermore, some NGOs have no orientation and, therefore, ask for things that are not pertinent, or ask for few things in terms of the work developed. Other managers miss greater, more systematic and long-lasting contacts with the organizations for setting policies.

A manager stresses the willingness and the interest in overcoming difficulties. For that, it would be necessary to develop cooperation, understanding the role played by each: “it is a process to be built in a joint work”.

The points of tension and conflict also depend on the moment and, moreover, on the public power availability in face of daily populations' demands, such as requests for exams, purchase of specific medications, access to diagnosis, shorten lines, service quality, quality of services provided by the public health service, qualification in assistance. The points of tension and conflict sometimes are mistaken to the consensus points, because they bring about cooperation between the government and the NGOs in the search for solutions.

Points of Cooperation and Consensus

To some managers, the technical relationship with the NGOs is very easy, there are no major tensions: The partnerships are easily established. The fights happen in the political plan.

The cooperation points are basically in the field of prevention and assistance, providing medicines, exams, and hospital beds. They also cooperate in the field of human resources, more specifically in capacity building.

There are not points of conflict, and the partnership between GO and NGOs is crucial, both in the sense of better control over public policies, assistance to the GO professionals and staff, and to exercise pressure over the government if it fails in complying with its commitments: “We don’t want consensus, because conflict generates changes and transformations”.

6.5 ASSESSMENTS ON THE DIALOGUE AMONG THE STATE AND MUNICIPAL COORDINATION, THE CIVIL SOCIETY AND THE NATIONAL COORDINATION

The NGOs take the problems to the municipal and state levels, and just when they do not receive response, or receive unsatisfactory response, they appeal to the federal level. They usually invite the coordination to attend the NGOs/AIDS Forum for clarification, to discuss difficulties, check for ongoing projects. Formally, the interlocution spaces are the inter-institutional commissions, the STD/AIDS municipal commissions, the NGOs/AIDS forums, monthly or bi-monthly meetings between the NGO and the government, and events jointly organized.

The municipal coordination in Salvador considers the relationship with the NGOs good, despite the impossibility of contemplating all of them, due to some difficulties inherent to public services, because they are not endowed with the same agility as an organization: “now, there is a zone of conflict, because they demand agility from us, and we cannot respond it”.

The Municipal STD and AIDS Coordination in Salvador maintains smooth dialogue with the National Coordination. Historically, the National Coordination used to hold a direct link to the Municipality, without passing through the State. Upon the decentralization – which is, in other words, centralization on the state – it starts working as a consultant to the municipalities: “Nevertheless, we still hold a strong partnership relationship with them, with the Ministry, with the National Coordination. The technicians support our actions; it is really easygoing”.

Concerning the relationship between the state coordination in Bahia and the NGOs, the organizations are always in contact through their representatives, in face-to-face meetings, by phone or by fax. The institutions’ representatives feel ease with the coordination, and are always promptly attended. They are invited to participate in the capacity building and training activities. All the work performed by the state coordination is oriented to the NGOs, and they demand for actions: “Everything yields fruits, everything produces results. And, for sure, they have the right to know how the work is developed”. Concerning the National Coordination, they incorporate any structure. Now, they are assessing projects jointly with the Ministry of Health. Last year, the Analysis and Prevention and Social Service personnel visited us. Other ministries came and supported several seminars. So, there is an outstanding diversification”.

A technician interviewed stresses that some municipal coordination units face difficulties because of the manager, since some are more accessible and others harder to relate.

In the Federal district, the relationship with NGOs is very difficult, with many criticisms by the civil society organizations. It is a process which shall be constructed, maybe in a way better adjusted to the state reality.

According to Pará state manager, the dialogue is still difficult, since NGOs follow two ways, one with the State Coordination and another with the National Coordination. That situation ends up generating dissatisfaction in the State Coordination.

In Rio Grande do Sul, the dialogues between the Municipal Coordination and the National Coordination have huge gaps, since perceiving the epidemic from an office in Brasilia and understanding in daily life and close to the population is quite different. And that ends up impairing the problem understanding and, consequently, the dialogues. “We are totally available to discuss, but we realize there is a gap concerning communications, because there are different points of view”.

Additionally to the systematic meetings of state and municipal commissions of STD/AIDS, the State Coordination attends the meetings when invited by the NGOs and vice-versa. Besides discussing steps to be taken with the NGOs Forum of Rio Grande do Sul, they also invite and listen to other NGOs that do not belong, no longer belong to or have never belonged to the Forum. “All projects are discussed, including now, when writing the call for bidding – which will open vacancies and select NGOs for projects – we have drafted the call for bid and we have made consultations to the NGOs. And, together, we have discussed and we have approved it or not point – by – point”.

It is a continuous construction of dialogue, guaranteed by both sides, from GO to NGOs, as well as from NGOs to GO.

The dialogues are always present and positive, comprising all municipal coordination, not only with Porto Alegre. It is more frequent with some municipalities, transcending the party affiliation of administrations, and surviving over the last four changes of government. That has allowed for the continuity of dialogues.

With the National STD and AIDS Coordination, according to some respondents, there are conflicts when they realize that “many things are imposed or come ready”. However, these disputes are considered positive, since the National Coordination limitations are understood, “having to think about a country with such a regional diversity as Brazil has”.

Concerning Rio de Janeiro, the dialogues are now more regular, since two annual meetings are held with the NGOs partners to the municipal coordination: “That is a channel, besides having a

daily channel”. There is also a direct channel with the National Coordination: “Our agent demands and is demanded”. Besides those, there is a management commission where all the Brazilian municipal and state coordination units participate in a representative way: “Currently, the State of Rio de Janeiro holds the seat and that commission is the programs voice, it’s a very interesting negotiation channel”.

In turn, the State Coordination has a broad history of integration with the non-governmental organizations. That relationship started from the fight for blood quality, the fight for the patients’ rights: “The NGOs have always been partners of the State Coordination, or of what existed at the time, not formally as coordination, but as a group of technicians who started working in this field”.

However, this close relationship did not take place in all areas of the Health Secretariat, even because several secretaries and several groups shifted because of the change of governments. There has always been the group of technicians who, upon the NGOs cooperation, continually tried to implement all issues regarding AIDS, such as treatment, access to diagnosis. In spite of all progresses, in Brazil and in the State of Rio de Janeiro, they continue with the same fight. They still face specific problems that worsen the situations in some aspects; however, the cooperation of NGOs makes them stronger to carry on: “We have a very good dialogue. Sometimes there is tension, however we have always received plenty of support, and it is a very profitable partnership”.

In the municipality of São Paulo, dialogues take place in three spheres – the São Paulo NGOs Forum/AIDS, the Municipal STD/AIDS Commission and the Organized Social movement of AIDS – with an expressive participation of NGOs. It is an equalitarian commission. With the Movement from São Paulo in the fight against AIDS – MAPAIDS, the relationship is of mutual respect.

When the Municipal Conference of AIDS summoned by the Health Municipal Council took place, a Municipal Board of AIDS

was democratically elected. Furthermore, they maintained open communications channels with NGOs/AIDS, through the Forum.

The agreement between the Municipal Coordination and the National Coordination was considered excellent in the first two years, mainly up to Municipal Conference in 2002. Initially, they depended on the National Coordination and on the State Coordination for political, financial, material support to develop actions: “in the first six months, we had no means from agreements; virtually, we could not have done anything of what was done here; depending basically on the national and on the state coordination to work”.

Nowadays, dialogues are more formal and sustained as an institutional support: “it has become much more formal than it used to be, it was much closer, and it was companion-like, friendlier. And something similar happened with the national coordination; it has also become more formal”. That formality in the relationships and the disputes with the State Coordination were more resented than with the National Coordination, since they were more present in the city of São Paulo:

They have always being active, even to supply the total absence of the municipality; so, the conflict with them was much stronger at the beginning, even when the relationship was excellent. There is a conflict on the space occupation, the state carried out actions which at that time it could no longer perform, also in the SUS, but in the AIDS it ended up doing, then there was a conflict.

With the National Coordination, the conflict takes place much more because of the political questioning on some actions, for instance, the integration with SUS, opinion divergence as for the criterion on the distribution of inputs (preservatives).

São Paulo state manager considers that “The state is between the federal arrogance and the municipal omnipotence: It is an interesting illustration because there is the story of the municipality where everything is the municipality, and it does everything, the administration is the municipality”. The state instance has to mark its

position inside SUS and build its space to act – which is a fundamental space of negotiation – since it is meaningless to have the federal sphere dealing with more than four thousand municipalities in Brazil.

São Paulo *used to fight* because they wanted to participate jointly with the municipalities to know what each municipality was executing and, therefore, prevent the overlapping of efforts and actions in the same geographical area, avoiding high resource costs. The coordinator affirms that the state *had to fight for its space* and make the state programming, and play its role as the state manager. Such situation leads to tensions.

However it is pointed out the great identity in the AIDS-specific case, in the sense of purposes, guidelines and principles that facilitate the work between the state and the federal level, at least since 1995. Another mark of AIDS is the stability and some invulnerability to the changes in the federal level administration. AIDS has always had some defense, even because if something does not work well, people go out to streets to complain. It facilitates the institutional relationships when there is a stable team in the National Coordination.

The crisis or tension which takes place is for overrunning, mainly in the relationship with the municipalities. The tensions and disputes that the State faces in its relationships with the federal and municipal level are never by omission, but by the sensation of runover or disrespected space. It is a technical, political, ideological identity in the sense of health.

6.6 PERSPECTIVES AND ACTIONS ON THE CIVIL SOCIETY'S SUSTAINABILITY IN THE FIELD OF AIDS

After reading all the interviews granted by the municipal and state managers, one can realize in most of the speeches, their willingness towards debating with the NGOs the issue of sustainability. The sustainability not only for the organizations, but also for actions. And, not necessarily actions carried out by NGOs, but actions in

STD/AIDS. The coordination units are in different levels of discussion, some with progresses, others beginning the discussion, and some of them have not yet had the chance of discussing the issue with the NGOs.

The sustainability issue is considered by all as a critical subject. Although most NGOs are working on the financial sustainability, they do not leave aside the other dimensions, i.e., political, technical and institutional. However, the financial dimension is of the most concern, since there is a dependence on resources from the three governmental levels. The NGOs do not diversify their sources of funding, just a few of them seek for money abroad or in other ministries, or in another kind of project or wider program which is not specific of STD/AIDS funds. Besides, just a few of them are aware about the possibilities, the potentialities. Therefore, it would be necessary to increase the alternatives to financial sustainability; in other words, diversify the sources of funding.

They also enlist problems on the issue, such as lack of transparency and definition about the new policy of incentive at the federal level. So much so that some coordination units rely on private partners and international agencies to work on sustainability, together with the non-governmental organizations.

As for the political sustainability, it is guaranteed, in the sense that there is a very clear space to NGOs/AIDS in the country, at all government levels.

As for the technical sustainability, they believe most NGOs are getting structured.

The Ministry of Health has made an effort in order to increasingly provide the municipal and state managers with professionalism, since there is a great turnover and huge regional differences. The NGOs also have the opportunity of becoming professional.

The training, towards increasing the NGOs technical capacity, is an action of sustainability promotion. During such training courses, they discuss how a project is made, which are the sources of funding. Besides discussing the issue of a NGO's internal administration, how

it can be or not, how the strategies are, where are the sources for resources intake, which are the potential donors, how a project should be prepared to raise money, finally, which strategies the NGOs could have to generate and assure its sustainability.

Some of them are concerned about working in the issue of legally registering the civil society organizations, since some of them are community-based associations. Therefore, there is a general concern in providing the NGOs with by-laws and regulations, legally set up, since this also guarantees the institutional sustainability.

The discussion on the sustainability problem, not only for the NGOs, but also to actions implemented by the state and municipal coordination, has already been identified as critical, and was included in the Strategic Plan. The managers disclose some degree of uncertainty concerning the change in the financing system, since they believe they are not prepared to comply with all demands assigned to them the teams in the National STD and AIDS Coordination concerning decentralization, in spite of having already learned a lot along the process.

They comment that the National STD and AIDS Coordination has invested more on NGOs, concerned about their sustainability.

Concerning whether the coordination units perceive or intend to develop room for discussion on the sustainability of actions developed by the NGOs, regarding HIV/AIDS prevention and the assistance to people already infected, we could say that: The State Coordination of Rio Grande do Sul has been doing and it intends to continue doing; it intends not only to guarantee, but also to expand the room for discussion on the sustainability of actions developed by the NGOs in prevention against HIV/AIDS, and the assistance to people already infected. An example of this is that they are elaborating the action and goal plan, and they are inviting the NGOs to participate in the discussion. The joint space is guaranteed regarding prevention and assistance, not only for HIV and AIDS, but for other STD as well. They stress that this is a cooperation and complementary work, and therefore they render voice and vote to NGOs' suggestions and opinions.

A municipal manager informs that the coordination has full availability to discuss sustainability, so that the NGOs and GOs may jointly pursue for solutions. The current concern is that the investments in Brazil are getting more and more concentrated on the assistance area. When that coordination was created, the resources assigned to assistance and prevention were, virtually, in the same amount, extracting the expense with medication. Today it is becoming much more assistance-oriented than prevention-oriented.

According to a municipal manager, today it is impossible to establish agreements with so many NGOs since they do not have yet transfer tools. Furthermore, it is not enough to have the transfer tools, if they are not connected to assessment and monitoring mechanisms.

The municipality of Rio de Janeiro has incorporated in its budget several assignments related to assistance. But, on the other hand, it has not placed the same importance to the issue of prevention-oriented actions: "I think they are more fragile. And I think that, in the perspective of near future, this is a major challenge of sustainability".

During the Strategic planning process, the NGOs and the state and municipal Coordination units have deeply discussed the sustainability issue, even because it was not clear for the government if there would be a third financing project. The financing proposal was not yet defined at the federal level, with the new policy of incentive; therefore, they all discussed the sustainability of actions at government level, as well as at the civil society level. At certain times, they had some specific debates, through workshops, focusing on sustainability projects.

Some managers believe that part of the AIDS III resources will remain, somehow, allotted to finance the NGOs project, but they think when AIDS III is through, and no other source of resources remains at the global level, there may be problems in the sustainability of actions developed by the NGOs, with negative impacts over people's health. Besides the political cost of taking away something which has been conquered by the social movement and by the Brazilian society.

At the same time, other managers do not perceive anything wrong in having a government financing for non-governmental actions. They advocate that risks are action parallelism, protectionism or the government unwillingness in undertaking its responsibility, thus transferring it to the NGOs.

The concern of an interviewed technician is the NGO's sustainability. The strategy is to guide them in the search for income management mechanisms, in the raising of resources. The guidance is not oriented exclusively to the financial issue, but also to technical and political sustainability. In the political area, by the strengthening of partnerships, both with other institutions and secretariats.

The managers of the Southeast and South regions have a wider view on the several stages of the HIV/AIDS epidemic, such as the achievements and progresses, limits and problems, as well as the current challenges arisen from the relationship between the State apparatus and the organized civil movement against HIV/AIDS, such as the NGO's actions sustainability issue. They realize that the priority now is the incorporation of AIDS into SUS, without losing the quality of progresses obtained in the fight against the epidemic.

6.7 LOCAL COORDINATION AND NATIONAL COORDINATION: DECENTRALIZATION

Practices/Financing

According to the manager, decentralization is important, rational and it is closer to the inspection and follow-up, since as the municipal and state coordination promote the competition, they have compulsorily to follow-up the projects execution, besides assessing them. The decentralization, according to several respondents, would bring more independence and, therefore, more responsibility.

Prior to the decentralization, in the field of public bidding processes, the National Coordination used to finance all projects, and the NGOs did not run after other sources of financing. Thus, for a long time the National STD and AIDS Coordination could

support with financial resources and, now, the decentralization movement is necessary since some organizations do not have the chance to raising enough resources.

The federal government held last public bidding process, and some states were qualified. The states of Ceará and São Paulo are examples, because they had huge projects.

Bahia State analyzed and concluded that, at a certain time, it would not cope with the public bidding process and, thus, they decided for the Ministry of Health to carry out the bidding process and financial auditing, while the State Coordination would follow-up the technical aspects. The State manager believes that the decentralization way is irreversible. The big challenge for the State is giving up being a manager, and basically take care of high-and medium-complexity actions, which is its role. Besides, they need to manage the municipality routine since they represent the level wherein everything happens.

The Federal District realizes the need to foster debates on sustainability, because the resources for financing projects will be reduced, leading them analyze the projects, checking for the interesting ones. Since there are so many NGOs, it was agreed that this will be defined between the NGOs Forum and the Management. They observe that a selection committee should be established to carry out the bidding process, probably through an outsourced company, since they do not consider themselves able to take over the process.

The management of the Federal District used to decentralize the process, but financing remained at the National Coordination and, since it had no institutional commission, it tried to assemble one. However, due to the lack of consensus, they did not succeed in doing so, and then the Federal District Programme was delayed.

Some coordination units intend to hold the discussion at the NGOs Forum, in order to know the projects and inform the NGOs on actions developed by the coordination, verifying the participation in the Action and Goals Plan — PAM, the projects that will be selected, the resource for that.

In the case of Pará, the issue on how decentralization is taking place, mainly in the field of public bidding processes for project financing, the manager states that the National Coordination used to develop public bidding processes for project financing, and only the National Coordination gathered resources, through the World Bank. Today, the State Coordination has started establishing partnerships, including with universities. However it does not have yet other sources for resource intake, except through the Ministry of Health. The State Coordination does not have autonomy to enter into agreements and negotiations for resources intake: it depends on the State Health Secretariat.

The National STD and AIDS Coordination of Rio Grande do Sul held several meetings last year, both in interior regions and at Porto Alegre, having the inland regions as base, the nineteen municipalities that house the regional health units. Bringing the municipalities to the regional unit and trying to touch the regional managers and NGOs, providing managers with required tools to develop their municipal plans and foster the creation, development and strengthening of NGOs, mainly now with the decentralization of resources, through fund-to-fund transfers. As for the municipal coordination, decentralization is a concern, because they do not know how projects will be selected. The NGOs will submit projects to the State Coordination, and it will set up a team to select the projects. However, they observe the need for an active participation of the Municipal Coordination's representatives to discuss the local policies.

The Municipal Coordination of Rio de Janeiro was already exercising the decentralization in the point of view of alteration. That is, it decentralized the bidding processes, preparing the invitation for bids, analyzing projects, although the resources were all granted by the federal level. Now, there will be another stage, since the resource coming from the federal government will be transferred to the state government. And in a further stage, it envisages the need for providing State and municipal resources to partnerships, rather than having the state and municipality as mere

agents to transfer federal resources. It also sees the decentralization from another point of view, which is the strengthening of relationships.

Currently, they are discussing the Municipal Plan for the new policy of incentive. The State is also discussing, because they are undergoing a change in the relationship of financing by the federal government to municipalities and states, leaving the agreement and getting into another modality, providing higher independence and, therefore, more responsibility. As for the responsibility, it alerts that, unlike the agreement where resources could be more protected because they were sealed (one can only do that), now it is fund transfers, and it is more subject to waves and political wills. They will have to have transparency and support to use the resource in what was effectively planned, and advance in innovative actions.

There is a concern about the need for a whole qualification process, for both the state and municipal coordination offices, to receive resources according to the new financing modality.

In relation to the NGOs, they pointed out the need for qualification. With qualification, the NGOs that do not have the same experience as the older ones become more competitive in the elaboration of projects. The concern is to bring the NGOs from the State inlands, to qualify them and have projects reaching such municipalities.

A remarkable limit is the number of people available to be engaged the public bidding for financing projects, since the team is smaller than they would like.

The criterion to transfer resources from the Municipal STD and AIDS Coordination to the NGOs is through submission of proposal, since they hardly deny the request by an organization. This criterion is not disclosed and, therefore, the demand is much smaller than it should be, and some organizations have learned the way and always request, others ask for little or do not even qualify. According to them, it happens so because of a non existing culture of appealing to the municipality, addressing more to the State and to the Federal Government: "There are no criteria like selecting

part of the money through project public bidding; it doesn't work exactly like that because in fact since we do not have money for that, we use much more to provide direct support".

There was a negotiation between the Forum of Managers and the São Paulo State NGOs/AIDS Forum, for the setting up of a Work Group. A manager's forum representation, a DIR representation, a representation of municipalities, an NGOs representation and also a National Network of People living with AIDS in São Paulo – RNP participate in that WG. The WG decides on issues like how should be the public bidding for projects financing, organizes the relationships between the State Coordination and the NGOs, in the light of work. It is a kind of social control, but not in the sense of political debate, rather, it is in the sense of working together. They decided not to set up an advisory committee but the Work Group: "They try to find out a solution by consensus, if they don't find a consensus they make use of the vote".

The Work Group started with public bidding issue, and today it is the technical dimension of the relationship between coordination and the NGOs/AIDS movement, in order to rule the relationships established between the GO and NGOs. Since the bidding process decentralization, the State Coordination is technically and administratively responsible for the bidding process. Therefore, the Work Group decides on the call for proposals, how many, categories, bidding rules and whatever may be decided at these spheres, since some items have already been decided, such as the amount of resources received, rules of what can be accomplished within the limit of amount subject to financing. But this group does not define technically and politically which category of project should be submitted, the limit of projects by each NGOs, the limit for the maximum value.

Interference of Decentralization on the Established Partnership

For the decentralization interference on established partnerships, all the municipal and state managers are in favor and consider that it will be profitable, because it will provide further knowledge on what

the NGOs are developing at state and municipal levels, strengthening the partnership and setting the grounds for the manager to apply for additional resources and to cover specific areas for the NGOs projects. Furthermore, they stress the need for keeping the control, since they need data and information to carry out the actions assessments.

The managers pointed out a benefit in the sense that now the project approved will be in compliance with the municipal or state policy defined in the strategic planning. Since the decentralization has to be connected to an understanding about the municipal and/or state policy, it should try to qualify the actions to have this police effectively enforced.

Another change will be the approach and dialogue at local level, because the decentralization will lead to approximation among several players, since the dialogue will no longer take place at the federal level, but at municipal and state spheres. The fear is that the competition for the main character's role comes to happen at local levels. They trust that, with the maturation process and dialogue they can deal with the situation. The decentralization is taking place faster than many managers wanted and, therefore, they fear that the approach does not happen in a smooth way, which could probably be painful at certain times. Painful in the sense of the existing relationships among the NGOs and the Ministry of Health, with the National STD and AIDS Coordination. Now the decentralization process is compelling the approach and dialogue at local level, because they will have to work as a team, talk and understand each other, outline and think policies, execute non-conflicting or parallel activities, convergent to a common goal. With decentralization, there could be turbulences in existing partnerships, what may lead to the re-adaptation and readjustment to reality.

Some municipalities and states, with short human resources, will succeed in reproducing the operation carried out by the National Coordination. With that kind of hindrance, mutual responsibility is a must. Diversifying partnerships, working with other secretariats within the municipal and/or state structure and other programs, such as the programs focused on adolescents, on women.

Furthermore, nobody is so sure of what will happen when decentralization comes, and that ends up bringing about anxieties. Another issue is the sensitiveness of this relationship, because hundreds of NGOs are financed by the public power, and at the same time should maintain their independence, to return their action as a control, and even to criticize the public power.

Another concern to managers is the resources transferred through Fund-to-Fund, because they would not like to have them worsened when they start managing, even worse than when it was under the National Coordination responsibility. For instance, they would not like to have discontinuity periods, like they use to have. That situation also generates insecurity, because they need to find mechanisms to work with it.

6.8 CIVIL SOCIETY AND SOCIAL CONTROL: PRACTICES AT LOCAL SPHERE

There are several perceptions about the performance of NGOs considered as of social control, as detailed as follows, and not only the participation in Commissions, Committees, Councils and Forums. They also consider a social control action the outlining of a project that is submitted to the municipal, state or national coordination, receiving approval and resources to make it feasible. It is a kind of social control, since there are projects executed with resources approved based on the problems raised and analyzed by the NGOs themselves, in the light a certain reality.

However, the legitimate discussion channels are the councils, committees and commissions, at local, state or national levels. Another rich space of political discussion for the exchange between NGOs and the government is the State Forums of NGOs/AIDS, existing in most of the Brazilian states.

The discussion on social control is important; therefore, it would be necessary to strengthen the debates within the Forum, a

space where the lines of action, selection, control and projects monitoring are defined.

The municipal coordination in Belém intends to build an agenda on discussion, bringing the NGOs/AIDS Forum not only for the social control issue, through STD/AIDS, but also to health units in general. They are also discussing the election of the managerial council, discussing with the CTA and with Casa Dia. With that, they intent to have a general social control on the Managing Council and the Forum.

According to the São Paulo State manager's perception, the NGOs have long exercised one of the SUS' principles, i.e., social control. Not for participating in SUS' formal instances such as the state or municipal health councils, but because they appealed to direct action, making street manifestations, the press, social pressure. This way, they have exercised the social control, and mobilized the civil society organizations, which stands for one of the successful responses the Brazilian AIDS Program:

The demands and the militancy generated political willingness within the governments towards placing relevance to the issue. You don't see other social movement discussing tuberculosis, Hansen's disease, hepatitis with such a mobilization, demand and social pressure as for the AIDS case. (State STD and AIDS Coordination, São Paulo).

However, according to a manager, the organizations fail in exercising the social control "the way they should, since they are subject to lawsuits, accusations in the press and through phone calls, due to the lack of medicines, reagents". Under that manager's point of view, the NGOs should occupy the political spaces allowed by the Health Secretariat, such as holding seat in the Health Council. Also claiming that the NGOs cannot participate in too many issues, except issues related to the civil society, such as the transfer of resources for project financing. Other issues are technical: "They really don't have to participate in the remaining issues, because they are technical terms under the responsibility

of the management. They can participate, but cannot deliberate! Because they are not the technical management, they are NGOs, and they don't understand that!"

Today the health policy area is the space with more effective social control. Some managers comment that the performance is very focused on the AIDS programs at the municipal, state and national coordination, and that the Social Action and Education Secretariats have to be squeezed and get more involved.

In a manager's opinion the organized civil society should intensify its pressure over other governmental spheres, including the private sector, so as to have them contributing and more engaged to their responsibilities in the prevention and assistance to carriers.

Social Control Practices at the Local Level

There are several coordination units that elaborate the strategic planning together with NGOs/AIDS Forum representatives.

The AIDS State Commission and the AIDS State Council of Rio de Janeiro are promoting a work to build sensitiveness among municipal Councilors in order to try to increase social control, not only at the state level, but specially at municipal level, because the pressure on municipal managers is still low, and many Councilors do not know and are not enough touchy to put on the pressure they can do.

6.9 ON THE BRAZILIAN STD AND AIDS PROGRAMME

This section presents the municipal and state managers' indications of the valuation repertoire on the program scope, relationships with the civil society, possibilities, limits and suggestions on the Brazilian STD and AIDS Programme.

In the Municipal and State Managers' view the Brazilian Programme is undergoing a moment of more possibilities rather than limitations. They observe that the support rendered by the STD and AIDS National Programme and by the Ministry of Health to

the States and Municipalities is very good and they have served as example. So much so that most of the Municipal and State STD and AIDS Programs reproduce the national model. There is an alignment of the policies built by the Ministry of Health, because since the beginning they succeed in holding broad dialogue. “A dialogue that came about not due to a hierarchical structure, but for an ideological posture”. The difference among them is that the National Program does not execute the actions, but plans and rules them.

The National Programme’s possibilities lay on the eagerness with which the regional offices, the states and the municipalities have accepted all initiatives, which proved to be inclusive and positive in the sense of learning, learning the knowledge, the resources, the possibilities offered so far, including training, capacity building, qualification.

The program moved forward and managed to comprehend all assistance areas, part of production, functional and working management with all structures, in spite of the huge size of Brazil, but there was the concern of each one towards assuring continuity. The AIDS I and II proposal was positive, so as to foster the program municipalization, i.e., put the program on the edge.

Another important point was the work accomplished at the federal level, as in international relationships, the far-reaching scope of the program, ruled on the articulation with civil society.

The National STD and AIDS Programme also moved forward in terms of assistance, treatment and break of some medicine patents. It is a program extremely respected at national level and, mainly, internationally.

In the same way some that strength is pointed out in relation to the Brazilian programs, some limits are also observed.

One of these limits, very mentioned, concerns the “bureaucratized organization of the Programme, which fails in solving the problem of the so-called ‘end’, that is, it does not solve the direct work among the population living with HIV/AIDS”. Those bureaucracies are mentioned, having in mind the agreements made. According to the survey, the agreement model is *restricted and bureaucratic*, and it is

necessary to think about replacing it by another tool, without giving up the monitoring and assessment issue, considered necessary in the light of responsibility towards investing resources.

The concern with the Brazilian STD and AIDS Programme is therefore, with the new rule established for the decentralization, in relation to resources – because they know it will be shortened – as well as regarding the issue of being bound to the bureaucracy of the Health Secretariats.

The managers emphasize the need for decentralizing actions, in a way to expand the work to other municipalities in the state inland, stressing preventive actions, in the inter-sectoral perspective. At the same time, there is the concern of somehow losing the epidemic global perspective.

They warn that the Brazilian Programme cannot contemplate the whole territory and the existing diversity in the country, due to its territorial dimension, making clear it is not due to limitation on the actions quality, but due to real limitation.

Another difficulty pointed out, at national and local spheres, is the issue of turnover and lack of investment in human resources qualification, mainly to public civil servants.

In relation to concrete activities, the limits that can become possibilities are the investment made in relation to human resources capacity building, qualification, updating of human resources, qualification towards monitoring and evaluation. Another one is the National Programme's concern along the last years in placing pedagogical didactic focus on actions in both prevention and assistance.

In spite of the National STD and AIDS Programme development terms of assistance, treatment and break of some medicine patents, it faces several difficulties in relation to the adherence to treatment, difficulties connected to the population's social and cultural situation, such as the lack of information, education (school education), food, hygiene, housing. Also the State and Municipal STD and AIDS Coordination face such situation; mainly those in the North Region.

According to them, no deep transformation in the fight of an epidemic can occur without changes in the Brazilian economic policy. The “history of human beings shows that epidemic always affects the poorest people, with less education and less hygiene”. For many, this social vulnerability is little considered in the AIDS national policies.

A state manager states that the AIDS Programme works if there is integration, something that does not happen with other existing sectors, such as the program on tuberculosis and women. However, as any other program, there are still some vertical situations, although approached by some National Coordination’s plans. An example mentioned was the Project Nascer – Project Nascer is to intervene during the childbirth, for parturient who have not been tested during the prenatal care – and the State Coordination comments the marginal involvement the planning and implementation of actions.

Some managers still consider as limitations: AIDS in prison, which is poorly supported; the issue of vertical transmission that should be developed; improve the quality of services in several places, towards working in the perspective of humanization to adherence.

According to a manager, the AIDS National Programme success, on one hand was assistance-oriented, since it did not require for much negotiations to grant the quality assistance, because there were already hospital beds, clinics, the hospital itself gave home and therapeutic assistance, believing the victory is related to that. He considers, yet, that in the prevention, it is related to the action in the media with high national impact.

They observe that the next steps depend basically on the system, that is, the integration of SUS with other social segments and articulation with other areas to strengthen actions, mentioning as example, the vertical transmission control and the supply of pre-natal exams, HIV tests. Such are the needs to sustain the AIDS Programme success and, above all, towards a real impact on the epidemic, since they do not believe, as it has been in the press that “the epidemic is under control”; what is under control are the AIDS cases.

A general limitation, not exclusive to the AIDS Program, is the managerial capacity, and for that it needs to work more with evaluation, what also implies more serious policies related to SUS quality.

Another limiting factor is the SUS capacity. On one hand, the AIDS Programme evidences that, due to some social pressure and control conditions and political willingness and some priority on financial resources, SUS works. It is so much true that the Brazilian response to AIDS was possible only because of SUS and the social pressure.

The AIDS Programme seriously follows one of SUS principles, which is the integrity, i.e., SUS says that the commitment is with health promotion, prevention of diseases, cure of diseases and assistance to rehabilitation. And the Brazilian AIDS policies do that, one cannot choose between prevention and assistance, what is unconstitutional in Brazil. It would be illegal to make this choice due to the political reference milestones of SUS and the Brazilian Constitution.

Finally, the AIDS Programs is successful, it is recognized worldwide, but it should sustain the critical view so as to assure the conquests obtained and deepen them. Otherwise, we run the risk of going backwards.

The solution would be to undertake an effort and advance in joint work, from action planning to its conclusion, letting alone some degree of passivity that sometimes exists in the states and municipalities.

6.10 THE CIVIL SOCIETY AND ITS LINKS TO THE GOVERNMENT IN THE FIELD OF AIDS

According to some managers, the Brazilian Programme has learned a lot with the actions on AIDS developed by the NGOs, because these organizations showed the way.

The managers consider that the world recognition of the National Programme on Fight against AIDS is due to the NGOs that raised

the discussion, where the NGOs are the gear motor since they are on the action edge, where the public power cannot reach. Besides, those organizations have a different profile, other than the Health Units profile. The work developed by Health Units is on basic assistance, educational work, whereas the work accomplished by the NGOs is closer to the community, closer to the patient with AIDS. Therefore, they end up by associating with NGOs, which are known to have work quality in the STD/AIDS prevention.

A municipal manager observes that the Brazilian STD and AIDS Programme is an example of construction, but still holds some centralization features, especially concerning the relationships with NGOs.

Contributions by the NGOs to the Fight Against AIDS

The managers, in general, consider as the NGOs' role as crucial, observing that NGOs are daily following-up, mainly the most vulnerable populations more hardly accessible, such as the sex professionals, drug users, homosexuals, children and adolescents and young in street situation. Since the Health Secretariats cannot send their professionals to develop field works, this role remains with the NGOs that, in turn, have an outstanding performance. Thus, NGOs complement the work of the Secretariats, and the social participation existing today within the Municipal and State Health Council allows for better dialogue and discussion on actions planning.

However, other managers point out that the NGOs really contribute, but they are disorganized and only a few know the legislation and SUS operational working, observing that if NGOs had better knowledge about SUS, they could improve their contribution. Another difficulty is the creation of an Inter-institutional Commission.

It is mentioned that the main contributions by the NGOs to the fight against AIDS have been in the field of popular participation, health concepts, participation of AIDS patients, social control, health promotion, citizenship issues, human rights, advocacy.

They also point out the contribution of NGOs, especially those working with specific population groups (homosexuals, sex professionals, damage reduction), in the sense that these can handle with the situations, besides being more acquainted to the group language; therefore, they have more access to these groups than the Coordination, which is a strictly technical area. Allied to the access, they also have better knowledge and are better trained to deal with the issue.

The advances obtained in the national policy to fight the AIDS epidemic in Brazil, are due to the militancy and participation of organized civil society. Currently, the NGOs are gradually losing the path, the militancy and the critical posture, because the national policy is inadequate in relation to NGOs, due to the lack of appropriate understanding about this posture, which ends up influencing the relationships between the government and the organizations.

A manager evaluating the major contributions of the NGOs in the fight against AIDS, observes that at the beginning of the epidemic, if there were no NGOs they could not face the epidemic today as they do now: "It would be larger, crueler and with social charges of human sufferings, financial and economical, I don't know... unthinkable".

Thus, the NGOs role, along the whole AIDS epidemic history, has been of paramount importance in the sense of unchaining the discussion, forcing the establishment of public policies that contemplate the diversity of vulnerabilities in relation to STD and AIDS.

Another important contribution by the NGOs to the fight against AIDS is the issue of social control, harmonized and abolishing the opposition between government and society, towards a necessary and profitable understanding: "the criticism, surveillance and demand must be constant, but solidarity-based partnership is basic for both sides, because they allow for a dynamic and more complex response, as in fact demanded by AIDS". The AIDS issue has to be dealt jointly with the complexity its holds, and the NGOs allow for and make

possible those actions, as they establish unusual partnerships, setting different languages and providing feedback to all experiences. The other issue is related to assistance. The NGOs render service to improve the lives of people living with HIV/AIDS; many of them manage Shelters, adhesion projects, deal with issues related to human rights and legal issues. All this support is vital and it would not be possible without the NGOs participation. Also, many talents from the NGOs have already contributed to the government and vice-versa. According to them, this peculiarity could be transposed to and learned by other areas.

The health system, as it has been conceived, with social control and participation of society, relying on the civil society's representation at the Municipal and State Health Council, is the best example of the contribution by the work developed by NGOs in the fight against AIDS. Furthermore, the NGOs are crucial to the identification of problems and cooperation in the elaboration of public policies.

Therefore, the main contribution by the NGOs to the fight against AIDS is the social control, because without social control there is no progress, neither the achievements are guaranteed.

Coverage of Local Needs, Through Projects Developed by NGO

In a general way, the several interviewed managers' perception is that the NGOs fail in meeting local needs through developed projects, due to the epidemic's and vulnerable populations' profile. One of the reasons for that are the specific actions exclusive to the public power responsibility, such as increasing people's access to tests, to treatment. This increase in the access is an action that the NGOs do not cope with, so the Public Power has to undertake the responsibility. Another argument is that the actions are still very centered on the capital and on the metropolitan area, and on certain population groups. There is the need of spreading them to inland regions. Furthermore, the populations covered by the NGOs in the capital do not exist in inland regions and, thus, the coverage is below expectations.

If compared to the covering of specific populations, sex professionals, lesbians and carriers are far more focused by the actions, and the same does not happen to populations in settlements, movements such as the Brazilian Landless Movement – MST, Indigenous populations, truck drivers. The populations in poverty and imprisoned are considered completely unattended, because they do not have anyone to defend them. In relation to adolescents out of school, the Coordination has supported actions developed by the NGOs.

Other managers believe that some NGOs play their role, mainly the ones working in areas where STD and AIDS Management do not reach, such as specific populations of homosexuals, sex professionals, drug users and truck drivers. At the same time that they allege that the NGOs do cover, they observe that there are too many populations to work with, and they lack human resources.

One Municipal Coordination considers that NGOs do not assist the same public as they do, because the Coordination addresses its actions to extremely poor people. Depending on the point of view that situation can be considered positive, taking into account that there is no overlapping of actions, but complementarily.

The manager of Rio Grande do Sul State observes that NGOs play a very important role in relation to some populations in some risk or with specific vulnerability (sex professionals, transgender, transvestites, transsexual and Indigenous population), because the State virtually has no direct action, except through NGOs: “it is a local need that NGOs are successfully meeting. It is true that upon our support, the support of the GOs. The institution out there in the field, interacting with the population, is the NGOs. The experiences brought by the NGOs to GOs are priceless”.

The state and municipal programs have matured, but they could not embody evaluation instruments and forms, and not even the diagnosis of the NGOs’ action coverage scope in their planning, in their situation diagnoses. They point out that it would be necessary to have more information and data in order to have an accurate idea. Through monitoring and evaluation, they expect to come to

know coverage in terms of vulnerable population, to which extent these populations are covered by actions on preventions, which are being funded within the projects by NGOs and GOs, if there are enough resources, if they are well employed, how many individuals are assisted, how many individuals need coverage. Thus, only when assessment tools are in place, they can say whether the NGOs are covering local needs or not. For that, it is also necessary to move forward in the integration of NGOs with services.

Furthermore, they suggest investments towards qualifying evaluation of what is accomplished, in monitoring and readdressing of actions, because that helps resources intake, as well as in its optimization, valuing the resources they have that, usually, are not recognized.

The Government Relationships with NGOs and Vice-Versa

From the observations learned from the several interviews with municipal and state managers, regarding the relationships between the governmental and the non-governmental organizations, it is noticed the need for expanding the spaces for *unarmed* political discussion aiming at interaction, carrying out actions that allow for dialogue, avoiding the idea of mutual enemies, but partners. The term *unarmed*, due to the background, is that the players know before hand that such institution will be attacking, questioning. This situation only takes place at the political level, when they are acting as municipal or state representatives, because at the technical area the relationship is harmonic.

This relationship can always move forward, in the sense of mutually knowing better the work accomplished, proposing instruments at the government and civil society levels, providing spaces to hear, understand the other's view and thus improve interaction.

Some reports make clear the close partnership between the government and NGOs/AIDS, even when carrying out bidding processes for project funding, deciding together which areas and which populations will be benefited.

A technician interviewed suggests increasing sensitiveness-building actions among managers, because the government relationship with NGOs and vice-versa depends on this player, since the politicians sometimes do not have any idea about the work developed in the base. The advancement of governmental relationship with NGO also undergoes the reduction of bureaucracy in the accomplishment of actions, providing quicker responses to the requests by these organizations.

In spite of acknowledging the important role played by the NGOs and their partnerships with the state and municipal coordination, and of how much the technicians have learned with this contact, one could observe some degree of difficulty (or intimacy lack) between some coordination units and NGOs, be in the safeguard of initial difficulties in dealing with the NGOs, be in the recognition of existing conflicts among the associations, be in the repeated references to the non-participation of NGOs in the Strategic Plan elaboration.

The issue of space delimitation in STD and AIDS prevention actions, between the Municipal and State Coordination and the NGOs, is controversial, delicate and, sometimes, constraining in the public authority point of view. Some of them think it should be outsourced, and the public power should supply financial resources. Some Coordination offices have the clear purpose of undertaking prevention as a governmental problem – not exclusively to government, but also the government'. Keeping the support to organizations and working in an articulate way, avoiding overlapping actions.

It is worth mentioning a manager's report, whereby he explains the non-interaction with the NGOs calls, alleging that the coordination reproduces locally the situation faced in the National Coordination. In other words, he comments that at the National Coordination there is neither integration relationship among the areas, nor with the NGOs. That manager does not comment on the positive and negative sides of the relationship, but justify them.

Another manager pointed out the concern about the research area. The performance of NGOs in Brazil is still very bashful, when

compared to the United States and Brazil. According to that manager, the NGOs do not rely on installed capacity; they do not have enough power to apply for investments of public resources in AIDS research. It is an area that needs to be strengthened, through better integration among researchers and civil society, to provide the NGOs the capacity and knowledge about what the researchers are doing. Together, they can identify those needs and, therefore, empower NGOs even more.

It should be mentioned a kind of discomfort concerning the social control issue. Many times, the favorable speech by Salvador municipal coordination manager, acknowledging the work developed by the NGOs and their successful role in the partnership with the governments for the epidemic control, became reticent concerning the specific situation of municipal arena. Thus, its silence is observed regarding the episodes of the year 2002, when the municipal administration dissolved the Health Council, imposing another format to this sphere, with the withdrawal of several civil society's representations, clearly contrary to that administration. Although the coordinator has never made any explicit reference to that situation, some answers point out the limits in closer relationship between NGOs/Municipal Government, still marked by that fact.

A technician from Bahia State Coordination constantly refers to the fundamental role played by the NGOs, emphasizing the profitable work with these entities; however, he points out the challenges of narrowing that relationship.

The Federal District's management believes that the relationship with NGOs has improved, but there is still a long way ahead for the construction of this relationship. There is the AIDS Forum and, recently, the AIDS Commission was set up; however, the social control exercised by NGOs is still very poor. The state does not have clearly understood the NGOs role in social control and the relationship that should be established with the government spheres, and the National STD and AIDS Coordination should encourage this discussion.

In Pará, the huge difference among institutions is the understanding about and respect to the NGOs; except for the disputes municipality *versus* state, especially previously to January 2003, when the new state governor starts trying to smooth the controversies.

6.11 REFLECTIONS SUGGESTED BY THE MANAGERS

1. The issue of financial decentralization, with incentives, is seen with concern because of its potential impacts, due to internal bureaucracy of some coordination and resulting obstacles.
2. The obstacles to assembling a team with qualified and skilled personnel to deal with the AIDS issue, since they have faced many difficulties due to values, faiths and behavior of people who worked in the area, having shocks and incompatibilities with the assisted population.
3. The conditions of the physical space occupied by some state and municipal coordination offices are another limiting factor, as well as the relationship difficulties among people.
4. It considers that the access of public power to populations and places is not easy, because it does not have knowledge and experience in dealing with the structure and profile of all the added risk populations. Therefore, the partnership with NGOs should promote the capillarity that, otherwise, would not be possible.
5. The rupture of actions through the decentralization is presented with concern, indicating that the AIDS movement suffers some kind of parallelism, since this is the health area with more effective social control, whereas it is not totally integrated to SUS.

6. The agreement model is considered restrictive – extremely bureaucratic – and unfeasible, according to some people, because it is not enough to have the transfer tools, but they should be linked to monitoring and assessment mechanisms.
7. It is necessary to find out mechanisms to deal with resources transferred through Fund-to-Fund, avoiding the discontinuity periods that lead to insecurities.
8. The role of other institutions is highlighted, that is, other ministries, municipal and state secretariats in the epidemic's organization and facing. They advocate that social control exclusively in health is not enough. At some places the AIDS issue is separate from other policies.
9. There is no pressure at municipal level; the power of managerial councils remains unknown.
10. The managers are favorable to decentralization, and consider it profitable because it is expected to bring broader knowledge on what the NGOs are doing in states or municipalities, reinforcing the partnership and providing basis for the manager to apply for additional resources and cover specific areas for NGOs projects.
11. With decentralization, the approved projects will be compliant with the municipal and state policies set forth in the planning.
12. The decentralization process will provide for approach and dialogue, locally and between the government and the civil society organizations, in the sense of jointly thinking, planning and executing activities for a common objective and mutual responsibility.

13. To diversify partnerships, working with other secretariats within a municipal and/or state structure and other programs, such as the programs oriented to adolescents, to women.
14. The managers emphasize the need for decentralizing actions, so as to expand the work to other municipalities in the state inland region, emphasizing preventive actions, under the intersectoral perspective. At the same time there is the concern about losing, to some extent, the epidemic global perspective.
15. The lack of investment in human resources qualification was pointed out as a hindrance at the national and local level.
16. The State and Municipal STD and AIDS Coordination, mainly the ones located in the North Region, identify difficulties in relation to the treatment adherence in relation to the population's social-cultural situation, such as the lack of information, education (school education), food, hygiene, housing.
17. They observe that there cannot be deep transformations in the epidemic fighting without changes in the Brazilian economic policy. The "history of mankind shows that epidemic always affects the poorest people, with less education and poorer hygiene". For many people, this social vulnerability is little considered in the AIDS national policies.
18. According to a state manager, the AIDS Programme works integrated, something that doesn't happen to other sectors, such as the programs on tuberculosis and women. However, as any program, there are vertical situations, surprising by the National Coordination's plans. An example mentioned was the Project Nascer. This State Coordination was involved in a marginal way into the planning and implementation of actions.

19. To some managers, there are limiting factors: AIDS in prisons, which is poorly assisted; the issue of vertical transmission that must be developed; improved quality of assistance at several places, so as to work under a more humanized adhesion perspective.
20. They defend the integration of SUS with other social segments and the articulation with other areas for strengthening the action, mentioning as example the control of vertical transmission, the supply of pre-natal exams and the supply of HIV tests.
21. It is necessary to keep a critical view on the AIDS Programme, in the sense of assuring the conquests and enhance them. Otherwise, we run the risk of going backwards.
22. The solution is to move forward in the joint work, from the planning up to the action.

7. FINAL REMARKS AND RECOMMENDATIONS

7.1 FINAL REMARKS

The previous chapters have been based on the representation of the members from civil society entities and from state and municipal sectors (managers/ administrators). These players highlight the positivist aspect of the Brazilian model in its fighting against AIDS, particularly in terms of governance – the partnerships among government and other organizations which compose the heterogeneous world called civil society, as well as besides a centralized system at the federal level with a considerable and effective local presence – , and the democratization of the assistance services and the availability of the necessary medications to HIV/AIDS patients, additionally to the appropriate respect and solidarity to the victims of the epidemic.

Beyond the challenges posed to the National Programme for the Sexually Transmitted Diseases (STD) and AIDS – also shared by all its partners – the HIV/AIDS policy in the country is based on a tripod consisted of: health programs, health assistance and respect to the human rights of those who lives with HIV/AIDS. Therefore, it is important to point out that the reference itself is a HIV/AIDS National Programme which takes place in a moment that both national and international scenarios are affected by structural questions and more restricted conjunctures. That is why it is a model to fight against the AIDS which, at the time of its full implementation, is subject to several types of resistance.

Despite of the positive factors, such as the incidental participation of the NGOs/AIDS in the reformulation, elaboration and social control of the public policies directed to the epidemic, it is necessary to enhance, on the other hand, that the difficulties found to the implementation of the Unified Health System – SUS is a process marked by the country own tensions in searching responses to health problems, social problems and effectiveness of democracy.

For this reason, there are many tensions at the states and municipal levels for the decentralization of the epidemic control. There are problems in understanding the best way to dialogue with the organized society which deals with the Brazilian epidemic.

In light of those initial considerations, this chapter is composed by the complementation of the main future challenges, both in national and international fields. In first place, we may emphasize the documentation produced after the first field research in 2004, where the organizations of the civil society exposed their concerns in regard to the obstacles in the direction of the AIDS Programme in Brazil. Prior to those references, we may think about the major obstacles found in the international scenario. At last, in the recommendations section, we bring back the basic research material, focusing on the suggestion of public policy actions referred by the players (during interviews) and the authors that collaborated with this study.

7.1.1 CURRENT CHALLENGES: REFLECTING ABOUT THE NEW PANORAMA OF A NEW ERA OF THE AIDS EPIDEMIC

The last five years have been of great relevance for the global discussion about the AIDS pandemic. In those the international political scenario consisted itself as a propeller to change the scientific conception priority in relation to the approach to the pandemic, to that which should incorporate the implications of a new model of development economically preponderant, and, in special in Latin America and the Caribbean, where new structural adjustment policies generated several government reformulation

that reflected drastically in health. Furthermore, and besides, those countries have been affected by the tensions and contends generated in consequence of a new political alignment at the present international order leading spheres.

In light of this, the pandemic have been thought from a new paradigm and a new concept of problems, either those related to global initiative for the control of the HIV/AIDS dissemination or those inputs to prevent other segments not directly affected by the Syndrome.

The world has been living with HIV/AIDS pandemic for the last 21 years and, during the last two decades, there were significant changes in relation to global responses for fighting against the HIV/AIDS pandemic at different fields and levels.

Further to the changes on the epidemiologic profile, which marked the beginning of the 90's, and with the arrival of the epidemic at the contingent of women and young people, the utilization of a new perspective focusing on the concept of vulnerability to the HIV infection showed the implications of the structures of 'social exclusion', in the context of the dynamics of the virus dissemination. It refers either to the damages raised from the cultural aspects (e.g. stigmatizing) or those related to life conditions (social and economic). This new understanding left clear that the absence of mechanisms to guarantee the non-exercise of the human rights is one of the principal factors responsible for the pandemic. Since then, the association between the promotion and the protection of the human rights is considered the key, at a world level, to obtain responses for the AIDS, taking in consideration that the political and economic context in Africa, Latin America and the Caribbean is contributing to increase social inequality and poverty in those continents.

The consequences of the model of social and economic development in the dynamics of the AIDS pandemic became totally exposed when the declaration of the scientist David HO (who is responsible for the development of the associated anti-retroviral therapy, announced at the International Conference, in Vancouver, in 1996), during one of the plenary sessions at the Geneva Conference (1998), pointed out that the effectiveness of the

utilization of the “ cocktail “ to interrupt the mortality of patients with AIDS, should depend on people good life conditions directly affected by the HIV, besides the access to the medications used in the therapeutic consensual procedures, as well as to drugs that treat the opportunistic infections that raise in close relation to the immunodeficiency caused by the Syndrome.

In effect, the passage to the new millennium was marked by several and decisive events for the control of the epidemic. Among them, the signing of the UNGASS/AIDS Declaration of Compromises (2001), which, among other important commitments to fight against the epidemic, as previously mentioned before, enforces the recognition that the access to medications is fundamental to achieve the full right of all persons to mental and physical health. It also establishes the compromise of facing the factors that affect the supplying of anti-retroviral drugs, such as availability and price. Another innovative aspect of the text of the Declaration refers to the measurements to support the creation, in an urgent basis, of a world fund for HIV/AIDS, with the main objective of financing responses to pandemic. South Africa and other countries with high risk of contamination are top priority. A special appeal to donors countries (G8), foundations, and the business community including pharmaceutical groups, private sector and others, was emphasized. This fund was effectively created in July, 2001 as a Global Fund to fight against AIDS, tuberculosis and malaria.

The signature of the Declaration carried out a substantial change in the XIV AIDS International Conference Declaration (Barcelona, 2002).

In this aspect, the Conference in Barcelona was considered, by the governments representatives and activists groups worldwide, as one of the most important international discussion forum about the HIV pandemic since 1986, when the first International Conference on this theme, took place in Atlanta. The Barcelona event hosted besides politicians and government authorities, 4,228 delegates from Europe, 4,374 delegates from North America, 713 delegates from Latin America and Caribbean, 1,064 delegates from Asia and 1960 delegates from Africa.

The opening speech of the Executive Secretary of the UNAIDS (United Nations AIDS Programme), Mr. Peter Piot, emphasized the necessity of committing to political compromises and radical changes, against the pandemic. According to Piot, the steps to take actions in different countries should depend on the effective commitment and dialogue among politicians, pharmaceutical industries and the society, as whole. He also pointed out that the AIDS theme should be inserted in the political agenda of different countries as a priority, and that in his opinion, the main obstacle in fighting against AIDS resides in the economic aspect.

After two decades, we can see that the control of the pandemic is beyond the health sectors, growing in importance as a challenge in the social and economic development plans of different continents. It was also stated the relevance of an integrated discussion in human rights and the necessity of emergencies in fairly social policies in order to manage the economic impacts related to the current context.

So, it is important to state the present situation that emerges as a challenge either in a global level – the implementation of the Declaration of Compromises UNGASS/AIDS – or at a national level, that intimidate the maintenance of the quality of prevention and assistance in the HIV/AIDS services in the country, as well as the legitimacy of the Brazilian Programme as a model for fighting against the epidemic. They are:

7.1.2 FREE ACCESS TO MEDICATIONS FOR THE TREATMENT OF THE HIV/AIDS AND OPPORTUNISTIC DISEASES. THE INTERNATIONAL RULES AND REGULATIONS OF THE INTELLECTUAL PROPERTY

One of the principal tensions that have been acting as an opposition to a global alliance to control AIDS pandemic and in special, is mobilizing the activists of the national fight movement against AIDS in Brazil, is related to TRIPS – either in the world concept – and in the context of the World Trade Organization (WTO) – and in the Europe Union or in the regional context –

ALCA; and the agreements among the USA and different countries of Latin America and Caribbean (principally the Andean countries, through bilateral agreements); and in the Central America, through the Central America Free Trade Agreement – CAFTA.

The Agreement on the Rights of Trade Intellectual Property (TRIPS) deals with the protection of two aspects in the field of the Intellectual Property: a) The industrial property which refers to the right of patents, trade marks and unfair competition; b) Authors rights: literature and arts among others.

However, it is in the field of the industrial property, especially those related to the drugs patent that the most exacerbated combats take place, nowadays. The exacerbated competition occurs only in order to benefit the big industrial corporations, in special the pharmaceutical ones in opposition to the questions related to public health policies world wide.

This change led to a great impact on the question involving access to treatment of patients with HIV/AIDS. The pharmaceutical industries have become one of the most powerful corporations in the field of the intellectual property due to the fact that their products are essential to life, the medications. This is the main reason those industries may exercise their power. The TRIPS is, as matter of fact, an agreement that allows those industries increase substantially their financial earnings as well as improves a certain degree of protection resulting from their association, which is invalidating the treatment of serious diseases all over the planet, in special to the poorest countries.

Nearly 97% of the number of patents granted, belong to the industrialized countries. On the contrary, the number of persons with HIV /AIDS lives in countries in process of development. From the moment that the discussion about the rights of the industrial property were taken into consideration within the WTO, and the consequent acceptance of the pressure on hard contents of TRIPS rules and regulations imposed to developing countries, it consisted itself in one of the most serious offense to the humanity. A situation

like that left countries, such Africa, Asia, Latin America and the Caribbean locked up in the obligation of having to patent all products and processes referring to medications and, as a matter of fact, being unable to follow the abusive prices practiced in the international market. Consequently they faced many difficulties in keeping the treatment of patients with HIV/AIDS in their population. It means that the access to the acclaimed combined therapy which stops the AIDS virus multiplication in the human body became a privilege and not a human right. It is also known that 80 % of the patents granted to developing countries belong to an enterprise or to individuals resident in a developed country.

In Brazil, for example, until 1996 it was possible to public laboratories to produce the medications used in the HIV/AIDS combined therapy, due to the fact that the eligibility of a sector to be granted a patent was made by the government. In this concept patents were denied to the sectors of medications and food. This allowed, until that year, to follow-up the pharmaceutical innovations and the medications availability for AIDS treatment into the Public Health System. Furthermore, after the incorporation of a new law envisaging the adequacy to the TRIPS, Brazil cannot reproduce the new medications that appeared after 1996, and it is now must purchase them in the international market. Consequently, a hostage of the abusive taxes imposed by the foreign laboratories. Brazil produces eight of the fifteen drugs used in the treatment of the HIV/AIDS, and is compelled to expend a large sum of resources to purchase the remaining seven drugs.

Based on this, the Brazilian government appealed to a provision in the Agreement – the compulsory license – and in August 2001, decided, after six months of negotiating, to intimidate by breaking up the patent of one of the medications used in the treatment of persons living with AIDS.

The Brazilian initiative inflamed more than fifty countries that supported the inclusion in the agenda of the WTO Doha Meeting, held in November, 2001, in Catar, a proposal to discuss about granting drugs patents and access to health. The USA and Japan did

not endorse the above said proposal. Brazil had full support from national and international NGOs.

The text approved in the 4th WTO Conference (Doha Meeting), says that the countries members of the World Trade Organization will no longer be subject to interpretations that may result in retaliations against internal decisions taken by a member, to protect the public health sector and the human rights. The countries will have more autonomy to make decisions on the expanded access to health.

The new text gives the necessary tools to negotiate with the laboratories which have been granted a patent. Besides, the legitimate concession of a compulsory license (this clause allows the breaking up of patents) in favor of local laboratories to produce medications whenever it is necessary, and besides in case of abusive prices. The new text also gives the opportunity of an open space for the presentation of new actions to guarantee the access to health and the use of the medications. It also makes clear the delegation to each country in defining the rules to issue the compulsory license as well as in defining criteria which will determine what is a condition of national emergency in the public health field.

According to the OXFAM evaluation, the TRIP keeps going on its policy of knowledge monopoly and increases the differences between rich and poor emphasizing the interests of the big corporations in the opposite of the public interest.

The huge disparity between industrialized and developing countries weakens the arguments that commercial agreements to IP (Intellectual Property) contribute towards promoting development. In fact, according to the OXFAM document, the Agreement favors the concentration of the economic power of industrialized countries, damaging the interests of developing countries.

In this sense, the issue involving access to medications reveals, in practice, the negative consequences of a commercial agreement on IP, based on the interest of major companies.

More specifically, at a global level, the discussions about the TRIPS Agreement bring a new set of worrying contents for the Latin

America. One of those tensional questions refers, not only to the intellectual property and its correspondent inclusion in the hemisphere investments agenda but also for the fact that the monopoly of processes and production were increased from twenty to twenty-seven years by those who granted a patent (TRIPS PLUS). This new period of time, and even the previous one stated on the TRIPS Agreement at the WTO, avoids any possibility of transference of technology. Considering that the technological changes occur rapidly, it is easy to figure that countries in process of development will not be able to acquire medications, at a reasonable price for its population who lives with HIV/AIDS.

It is also advisable to consider that the MERCOSUL will be of extreme importance to the countries of South America in the meaning of acting as a compact cooperation block, and also for the new emerging alliances throughout the world.

An agreement signed by Brazil, Russia, Ukraine and Nigeria during the 15th International Conference on AIDS held in June, 2004 in Bangkok , created a network for the transference of technology on AIDS. In this Conference, the Brazilian government committed itself in exchanging information about the manufacturing of condoms, medications, and in improvement of lab tests and scientific cooperation on vaccines research. The network utilization is expected to allow all countries involved to exchange technology and to improve the local input production and to facilitate the importation and exportation of generic medications. According to Grangeiro, in an interview given to the “Brazil Agency” during the Conference: “This Agreement is very important to Brazil. It is the first time that we sign an Agreement under such dimension. There are so many populous countries where the AIDS epidemic is inserted into a public health sector” Grangeiro also states that the next step is to create a technical work group with the representatives of each one of the five countries. “A diagnosis will be made to evaluate and identify the potentiality and the needs of each one of those countries and later on, to establish specific areas for technical cooperation”.

7.1.3 THE UNIFIED HEALTH SYSTEM – SUS, THE STATE REFORM AND THE CHALLENGE OF THE DECENTRALIZATION OF THE ACTIONS TO HIV/AIDS

The health as a right, as a priority matter and as subject of public relevance for the State, was an important focal point to build a Brazilian Citizenship, – the promulgation of the Federal Constitution, in 1988 – our “citizen constitution”.

It may be stated that the formulation of the Unified Health System – SUS was one of the most important political achievements under the social movement flag in the fight for human rights. It resulted from the articulated actions of different social players. The SUS brings new directions and principles that affirmatively endorse the political scenario as the legal one to discuss questions related to public health.

The SUS was conceived to finish the major inequality existing on population health assistance. The previous public health assistance system, under the responsibility of the INAMPS (National Institute for Medical Assistance and Social Security), now extinguished, could only assure medical assistance to employed workers officially registered, through their *Carteira de Trabalho* duly signed by the employer. Those who were out of the formal work market, but in good financial conditions, went for private medical assistance. Nevertheless, to those out of the work market and without financial conditions to pay private medical assistance, the only option left was the free assistance furnished by non profitable Institutions such as “Santa Casa”, local health centers and even school hospitals. The part of the population who needed to use those services, and it is true to say that they were the biggest part of the population, were treated like indigents.

The creation of the SUS generated actions to install global health assistance and determined that health assistance must be public and free to any person. This determination is supported in the article 198 of the Federal Constitution promulgated in 1988.

The public health actions and services integrate a regional and hierarchic network and constitute a unique organized system according to the following directions: I – Decentralization, with a unique direction to each government sector. II – Full attendance – preventive actions must be a priority but not in detriment of the assistance services. III – Community participation.

Decentralization is an organizational method that permits the redistribution of funds resources as well as encourages sharing responsibilities among the Union, the States and Municipal regions. The main principles of the decentralization are grounded on regionalization and hierarchy. Both regionalization and hierarchy are ways for the organization of a system that permits making the public health services and the funds administration more effective. Besides, they are also important elements for planning and actions execution. As complementary directions to regionalization and hierarchy it was stated that: a) full access to health services in all assistance levels: all persons, without discrimination, has the right for free public health assistance; b) equality in health assistance: the same kind of attendance must be available to all persons, without prejudice and privileges; c) equality in funds distribution: More funds must be allocated to the poorest regions with minor capacity to fulfill the needs of their population except in case of specific considerations (NOBs and NOAS); d) services problems resolution: The capability in solving the population health problems.

Therefore, the decentralization, to the managers of NGOs interviewed for this research, by the end of the Project AIDS II, pointed out some certain understandings such as: (1) Among most structured NGOs the understanding of the importance of having different partnerships beyond the Ministry of Health, to build and consolidate their sustainability which is understood as financial, political and technical (private sector, universities, external resources funding); (2) unclear assignment of roles to the NGOs and the government – the concept for the government is that the NGO is merely a service supplier. In real, the NGOs still have a very strong dependency to the General Coordination of the DST/AIDS and do not delimit their actions by demanding more action from the

governmental counterpart; (3) the importance of going on playing their role in the social scope as a controller, to be assured that all actions already reached do not be reverted and also follow-up the transfer, fund-to-fund.; (4) the main concern is that many NGOs will adopt the decentralization for not having the necessary representation besides the government and the civil society (damages reduction, marginal populations); (5) the main concern is that the AIDS services should be incorporated to the SUS leading to a poor quality attendance; (6) the importance of interacting with other sectors to increase actions for the organization of the civil society in its fight for health and other rights; (7) the main concern is that full and free access to health and anti-retroviral drugs be maintained; (8) to lesser extent, consider the government actions not effective and emphasize the importance of the government sustainability by promoting interactive actions among its various sectors (education, justice, public security) on preventive matters and epidemic assistance.

In the document called “The development of a Unified Health System: Advances, challenges and reaffirmation of its principles and directions”, produced by the National Health Council (2003), some political impacts may be considered, as a result from the adjustment and the State Reform in the effectiveness of the SUS.

The continuous growth of areas of hunger and misery and the continuous growth of the violence in the field and in town still paint a dramatic picture that shames the nation, principally when the economic growth indicators are compared to the human development indicators.

Many important population health policies, such as basic sanitation, did not grow up at the desired level to attend the needs of water supply and sanitary sewage.

It is clear that this scenario impacts the present conditions of life and health of the population. Study cases considering newly-born and children in the first years of live nutritional profiles reveal deep inequalities. Eight percent of all children born below standard weights belong to developed regions like Rio de Janeiro, São Paulo and the Federal District.

The national and regional data on people assistance and access to health services do not show up the accomplishment to the universal and constitutional

precepts. When trying to evaluate the quality and the capability for solving problems, this distance increases.

The main picture of the social and economic inequalities that characterizes the Brazilian society is basically expressed in the health area either in the epidemiologic cases and in the conditions of access to actions and services.

In the document about the thematic axes of 12th National Health Conference held in Brasilia, from 7 to 11 December 2003, the Minister of Health, Humberto Costa states that: “The effectiveness of the Right to Health depends on providing social and economic policies that assure a sustainable economic development and the inputs distribution”. The SUS main task is to promote, protect and recover the health to individuals and collectivity, equally.

The Minister of Health also points out some obstacles in this aspect: the extended agenda to be accomplished to consolidate the right in many aspects such as the quality and the integrality of the attention to health. The services of low quality and the difficulty in accessing those services are still problems that obstruct the SUS principles of integrality and universality.

The Minister also affirms that the organization for the attention to health, the co-participative administration, the work in health and the SUS financial resources are obstacles and, consequently, are big challenges to be won for the full implementation of SUS and to guarantee the right to health.

Nevertheless, it is important to note that the viability and effectiveness of the direction taken by the SUS are being intimidated due to political, structural and administrative changes that have been occurring in the states due to the strategies being adopted for the reform of the state, principally in health sectors. It is also because of some problems found in the relationship between the state and the municipal authorities related to the administration of the public health sector.

The state reform is continuously reflecting in the plan of attention to health and has provoked in some states of the country, in special those where it was effectively established. One of the consequences is the common practice of hiring personnel in a temporary contract basis and/or from private third parties employers. Those procedures lead, most of the times, to services of low quality, to poor work

relations, to the discontinuity of the actions in health sectors and to a minor capacity building of the available human resources. Another relevant question is about the incorrect, or even more, the non applicability of the normative contents of the NOAS⁴⁹.

The non compliance of the NOAS contents is seriously worrying the Municipal and state AIDS coordinators and those involved in the national movement for the fighting against AIDS.

The state and municipal departments of health are not yet fully capable to deal with the decentralization of the fund resources to implement projects in partnership with the NGOs. The absence of an internal forum to discuss the resources in a fund-to-fund basis and besides, the absence of appropriate instruments to follow-up and evaluate the actions to be taken starting from the resources in a fund-to-fund basis. Absence of incoming resources to improve prevention and also of diagnosis kit. Absence of human resources capacity building.

On the other hand, there are complains of the National Movement for Fighting Against AIDS, in its mobilization for 12 Brazilian states, in August 26, 2004 called *Cadê o Melhor Programa de AIDS do Mundo?*⁵⁰, claiming:

In the Federal District, the NGO that works with HIV/AIDS published an open letter addressed to the Secretary of Health of the Government of the Federal District, called “*Cadê o Melhor Programa de AIDS do Mundo, no Distrito Federal?*” In this letter those NGOs informed that during the process of decentralization there

⁴⁹ Edited and reviewed in 2002. The NOAS shares the responsibility of management and administration of the health sector between the state and the municipal regions for the attendance services. In this way, each municipal region receives the resources according to its capability. Most of them have an important task in providing total attention to health sectors which includes the reception of the people from other municipal neighborhood which are not able to attend cases of medium complexity, whenever is possible. This means to make work the reference and counter – reference in the reduction of overpopulation in the capital city health services.

⁵⁰ All open letters were disclosed by the AIDS Brazilian Agency, on 27/08/2004.

were less progress and more problems, due to the fact that the state and municipal authorities are not acting in accordance with the terms agreed with the National Programme of Sexually Transmitted Diseases and AIDS of the Ministry of Health, according to the established by SUS. This letter also reveals that more than R\$ 1.300.000,00 (One million and three hundred thousand reais) allocated by Ministry of Health through the Plan of Actions and Goals /PAM – DF is available for more than one year at the Secretary of Health without being used for the appropriate programme actions. The letter also reports failure in the acquisition of male and female condoms preservatives and lubricant gel, educational materials, kits to make free anti HIV tests, medications for STD and opportunistic diseases as well as beds for seropositive persons an AIDS patients in the general hospitals of the Federal District. The letter also states the absence of actions among different public sectors involving other important policies such as education, social assistance and humans rights an also the difficulty in accessing lab exams and/or complex lab exams that are of relevant importance in monitoring the opportunistic diseases prophylaxis.

The Bahia State Forum on NGOs/AIDS (FOBONG) also published an open letter addressed to the Municipal Health Secretariat in Salvador, complaining against the transfer of the allocated resources in a fund-to-fund basis. It also states the absence of specific medications for opportunistic infections. Besides, the absence of an appropriated place for testing and counseling is leading to a congestion of persons in the state referential hospitals for more complex cases.

The open letters from the states of Londrina, Porto Alegre, Rio de Janeiro, São Paulo and Pernambuco, among other things, contains the same references to the absence of actions among different public sectors of the State and Municipal Secretariats and the NGOs, in respect to the transfer of the allocated resources in a fund to fund basis. They also point out the absence of essential medications to treat opportunist diseases, anti retroviral drugs, beds for those more complex cases and the absence of basic inputs to preventive action.

The decentralization of actions in the STD/AIDS Programme is one of the main components of the last agreements signed with the IRDB. However in light of its context, there are still some problems to be solved in the scope of the Brazilian Public Health System in order to avoid discontinuity of the assistance quality and of the AIDS preventive actions when direct interlocution with the STD/AIDS National Programme is involved.

7.1.4 THE SUSTAINABILITY OF THE ACTIONS IMPLEMENTED BY THE BRAZILIAN NGOS/AIDS

The new international financial and political scenario, as a matter of fact, has demonstrated a great incidence in the global responses to AIDS epidemic. As explained before, there is a conjunction of facts in the international order unknown to most of those militants that generate changes in daily life, either in the State actions than in the social movements and in non governmental organizations.

According to Armani (2001:14), considering the new economic and political context, the new challenges faced by the NGOs consist of being confident to their actions viewing and to their legitimacy and political responsibility. In this regard, the author enhances some aspects such as political actions and positive relationship with the media, direct communications with the target people and the establishment of partnerships with different sectors (the public power, the universities etc). Those actions are necessary to strength the sustainability of the different social segments and the different NGOs.

In order to achieve those goals it is important to give special attention to the organizational efficiency, to the capacity of creating modern and innovative actions and to the social impacts that may arise in different social sectors.

Nevertheless, its advisable to think that both the social movements and the NGOs have been compelled to enhance their capacity of working and besides, in converting themselves into real mechanisms to facilitate the articulation within local and regional problems in light of

the changes occurred in the international scenario. As a matter of fact, those needs lead to the creation of health networks and partnerships to expedite communications and political mobilization. That is why the big organizations in the civil society have been created effective strategies to improve and empower their HR capacity building and to intensify their proposals among their partners and the government. In Brazil, most of the different social movements and NGOs strongly take part in the specific spaces of the social control. They are ready to denounce and make resistances, whenever required. Its is a peculiarity.

In light of this, the national movement for fighting against AIDS, despite of its extended political agenda, can be considered in its total concept as one of the social movements with major focus on actions proposition.

However, when examining the different segments that compose the national movement for fighting against AIDS, we note significant differences. For example, if the focus are on the possibilities of access to media, or on political viewing and on funding possibilities, some of those movements linked to damages and damage reduction, to the legalization of prostitution and to the homosexuality, are seen, under the optics of the social reactions of discrimination and prejudice. It affects, inclusive, the funding resources Agencies that do not consider those fights as a priority for funding purposes.

Based on this, we may even consider that in light of the restructuring of the international cooperation in Brazil and the present demand of resources outgoing the country in the belief that the epidemic is already controlled, the NGOs rises as the organizations that have the best chances of still being sustainable.

Nevertheless, Armani (2001:16) brings the attention to the fact that the Brazilians NGOs are being challenged to go deep into institutional development, spreading and consolidating strategies on articulated interventions by diversifying its resources fund (capitation of national, public and private resources) and building solid argumentation in defense of their causes and purposes, reinventing methods and forms that gives credibility to their contributions in strengthening democracy and country development.

7.2 RECCOMENDATIONS

In accordance with the collected information for this case study, such as interviews with managers and administrators of the NGO and state and municipal managers and administrators of the STD/AIDS in Brazil; from the national literature on AIDS; from the experience of the STD/AIDS National Programme, and particularly from UNESCO in Brazil. The intended interlocution is not limited to the Agency and to players in Brazil but must be widely promoted to enable full cooperation within other countries, the following recommendations are based in practices and policies that are currently in use or that have been adopted by different agencies all over the country. It is recommended to give emphasis to these ones, while the others are only wills and concerns with the improvement of the Brazilian system of responses to the AIDS challenge and with the continued materialization of principles such as decentralization, actions integrality, health services universal access, social control exercising and dissemination of an equalitarian culture against intolerance.

7.2.1 GENERAL RECOMMENDATIONS

- Taking into consideration the importance of the international community, the global efforts on the pandemic and particularly the acquired knowledge, it is recommended:
 - The Implementation and monitoring of the commitments assumed in UN AIDS Special Assembly – UNGASS/AIDS, 2001.
 - The Implementation of the Doha Declaration (2001), increasing the discussions about the existing safeguards in the TRIPS Agreement that enable continuous free access to the Anti – Retroviral Combined Therapy (Spontaneous Licenses, Compulsory Licenses and Parallel Importation)
- It may be considered that the multifaceted actions network, its coordination and evaluation, contribute more than the specific thematic areas, for a well succeeded system in prevention,

education, (even sexual and against prejudice), gender, activities involving groups of risk, assistance and treatment, among others. In light of this, the replication and the documentation of such studies is fully recommended and that the best practices found in politics, strategy and technology, even those collected in the schools fronts, health services, working places, the media and others, be internationally disseminated as it is being promoted and suggested by UNAIDS⁵¹.

- The State, the international community, the private sector and the Nation as a whole, have the responsibility to assure that the advances obtained in Brazil in the prevention field – including newly born babies, pregnancy diagnosis and prevention against mother/son HIV transmission, the guarantee of free access to preservatives, the free and universal access to anti-retroviral drugs, diagnosis and treatment including medical/hospital follow-up to those persons living with AIDS, be sustainable by means of various funding sources.
- It is recommended, in special to the financial international agencies to adopt a more critical and reflexive position in relation to linear associations between the success achieved by the country and the need for international cooperation i.e., to review the concept that Brazil has totally granted universal access to health and to medications and that the National Programme is completely structured and therefore, it is no longer necessary to count on international investments in the field of health and AIDS, particularly. So, it may be considered that to either the sustainability of a model which is going on successfully than to the need of facing new challenges, it matters counting on international funding.
- It is recommended more investments in the areas of prevention, diagnosis and treatment. In some segments of the population such as women, young people, people living in regions far way

⁵¹ See: <http://www.unaids.org/bestpractice/index.htm/>.

from the big cities, in the rural area and the poorest ones, the contamination by the HIV/AIDS have been increased. It is also recommended keep supporting the actions and projects related to those populations traditionally living under a major risk situation and with major risk of infection, considering the principle of damages reduction.

- To better improve the resources intake for developing projects in areas such as prostitution, homosexuality, drug users, and marginal populations. The funds allocated to those programs are basically from the Ministry of Health and from very few international agencies.
- It may be considered that youth, education and communications are dimensional multiplication factors either to the prevention, and the formation of a culture for human rights to those who lives with AIDS, than how living ethically with the diversity on sexual orientation and various social relations. In light of this, we should insist on the UNESCO strategy in association with the National STD/AIDS Programme, and also in the importance of counting on national and international resources to develop the following actions:
 - To improve the strengthening of the young, adults, workers in education and health areas, non governmental organizations and professionals from social communications area to deal with epidemic challenges in order to minimize the negative impacts over the persons, the institutions and the societies.
 - To improve information broadcasted in the media about HIV/AIDS prevention, since the media impacts at national levels.
 - To disseminate legislative practices and public policies of excellence to avoid discrimination and stigmatization of those who live directly or indirectly with the HIV/AIDS.
 - To advocate in favor of the preventive measurements among the main opinion formers (congressmen, journalists, youth and businessmen for example)

- To establish partnerships with other countries to replicate the Brazilian successful practices in the epidemic contention in both regional and national context. (in UNESCO 2003 – folder)
- In the education area it is recommended the adoption of the UNESCO proposal of investment in the horizontal communication, peer education, young people teaching young people mainly through the media chosen by them, debating themes linked to sexuality, gender, changes of behavior, sexual education in schools, prejudice, and public policies focused in human rights for youth.
 - Reference is made to researches involving young people about sexuality and AIDS (see RUA and ABRAMOVAY 2001) – the potential to incentive changes of behavior (behavior changes) through education by focusing the young people)
- Taking into consideration the school strategic paper for preventive measurements, for sexual education and formation of an equal culture without prejudice, we may enhance the importance of a co-participative action between the Ministry of Health and the Ministry of Education, in producing educational materials and programs in AIDS prevention at schools.
- Taking into consideration the importance of expanding the partnerships in the fight against AIDS and the political representatively of congressmen, UNESCO created the Parliamentarian Front of support to the fight against AIDS in 2002, which congregates politicians around the theme and stimulates the creation of laws and the reformulation of the pertinent legislation in regard to the human rights of those persons who live with AIDS. It is also recommended to continue the expansion of those tasks together the legislative assemblies to implement the creation of a Parliamentarian Front of Mercosur, to promote the exchange among the affiliated countries and conjunct actions for the fighting against AIDS.

- Attention and investments from different agencies are recommended to improve the collecting data system on HIV/AIDS information in the National Health Information System. The system should adopt the UNAIDS recommendations in the identification by race/ethnic to cooperate in the follow-up of the health situation of the afro-descendents population.
- It may be highlighted the initiative of the National STD/AIDS Programme (PN) in putting together subjects like preservatives availability and educational actions oriented to the young people. It is recommended to insist on this strategy as well as on the methodology of programs evaluation. In the recently established partnership between PN and UNESCO those practices are in use.
- To improve the population access, preferentially the young people, to information and to free preservatives.
- To improve the advertising of female preservative to facilitate its acceptance. To work in a daily basis and build awareness among women concerning the negotiation on the use of preservative.
- To unify the AIDS Programme preservative distribution schedule with the Women's Programme, Family Health Programme and Adolescent Health Programme.
- To enhance articulation among the Ministries of Health, Justice and Education in the human rights field; creation of programs to fight against adolescents and children sexual exploitation; prison population; actions against damages and losses in the frontiers areas, promoted by the epidemiologic vigilance sector. It is also recommended the analysis of these and other programs envisaging its improvement, continuity and dissemination.
- The professionals from the health area at all levels, as well as the professionals from education and justice areas should be encouraged and well trained to understand the necessity of

implementing actions to reduce damages. It is also recommended the capacity building to health professionals, education and public security areas; and partnerships with treatment services for drugs abuse.

- To improve attendance to drugs users in the health public services and to develop strategies to avoid discrimination to the chemical dependent in many public services.
- To give more support to the NGOs that deal with programs for damage reduction, bearing in mind their less knowledge on this matter and the discrimination they suffer when negotiating for funds.
- To pay attention to the social conditions of the target-population, such as social exclusion and the low school capital, investing in the democratization not only of the information about the epidemic, but also in the democratization of living in a diversified culture, giving emphasis to social relations such as gender and the human rights of the homosexuals. Such misunderstandings and the reproduction of a stigmatized culture contributes to the vulnerability, particularly, for those excluded persons and communities, who have a major risk of being infected by the HIV virus.
- To emphasize the actions of the National Programme (PN) which compels the society to avoid discrimination of specific groups commonly associated to groups with high levels of AIDS prevalence, such as the homosexuals, the drugs users and the sex professionals.
- In the scope of the Ministry of Health is outstanding the transversality of HIV/AIDS concerning interventions related to women health, tuberculosis and mental health, for example. It is recommended the systematic evaluation and the detailed analysis of different projects like it has been done with the Program Nacer Maternidade, which deals with pregnant

women as well as to such other programs of singular social value, e.g. the Programa de Agentes Comunitários da Saúde/ PACS e o Programa Saúde da Família⁵².

- To promote the development of activities in units that have programs of tuberculosis, hepatitis B and C, because those diseases may be associated with AIDS.
- The Brazilian Government orientation for the transfer of the resources to start actions and programs at the regional level of the administration may strength and enhance the system overview in the field of AIDS, but it requests investments on its institutional implementation. As a part of this implementation, the recommendations are:
 - Capacity building to state and municipal managers and administrators of the DST/AIDS and NGOs that work with HIV/AIDS to the management and social control of the decentralization of resources that will be transferred to state and municipal authorities;
 - Advisory action with the cooperation of various agencies in formulating specific methodology for planning, follow-up and evaluation of the administration of resources in a fund-to-fund basis – either in the scope of the centralized coordination and the local agencies of the civil and political society.
 - To increase human resources in the state and municipal health secretaries to fulfill ongoing actions in monitoring activities in DST/AIDS

⁵² “The capillarity of both programs justifies the priority given to the basic network health assistance. In 2002, the PSF was installed in 71 % of the Brazilian municipalities. This number rises to 88.0% in the case of the PACS. The insertion of the Health Agents in your community makes possible the dissemination on HIV/AIDS information and respecting its social and cultural specificities and strengthening its preventive strategies. The PSF acts directly in the assistance to seropositive persons and to those with AIDS, promoting diagnosis and supporting for the improvement of the adhesion to treatment and to prophylactic regime to prevent opportunist diseases, besides the following – up to those patients in domicile attendance. We also may enhance that the articulation with the states and municipal authorities is fundamental for the PACS and PSF.

- To invest in human resources capacity building, qualification and updating in the scope of the agencies in the State and in the organizations of the civil society at local and national levels for monitoring and evaluation purposes in the field of AIDS.
- To invest in the professional level of the state and municipal managers and administrators as well as the NGOs. The common practice is the turn over and the regional differences when refers to instructional resources.
- To invest in adjustment of premises of the state and municipal coordination to improve the activities development. Present premises are inadequate for the actions intended.
- The acquisition of goods and equipment must be decentralized from the Health Secretariats to the State Coordination.
- To expand the installed capacity of the health network, increasing the number of health basic units and laboratories as well as the purchasing of to improve treatment and attendance to the population with DST/AIDS.
- To provide full support to the state and municipal health councils, which in Brazil those councils are composed almost solely by women and acts as a controller of the health services, placing priorities and suggesting actions on administration. This existing social and controlling participation should be more fomented, especially on the AIDS field. Half of the council staff is composed by person who uses the health services, 25% of health professionals and the others are managers and/or administrators of health services. It would be an asset if persons linked to AIDS (persons who live with AIDS, activists and specialized health professionals) could be invited to take part in those councils.
- It is recommended taking into consideration the consensus that the success of the Brazilian model is grounded for almost 21 years by the civil society engagement in fighting against AIDS, and

its participation with agencies in several levels such as international cooperation and government, and also considering that its political, financial and technical sustainability demands for sharing resources and for joint work among professionals and activists:

- Full cooperation in strengthening those socially legitimated NGOs both technically and financially. Particularly in the adoption of efficient administrative models and resources administration techniques as well as in searching for funding diversity and communications strategy, and enhancing contacts in local communities and at the government high levels – basic requisites to its political sustainability – cooperating (with the equation) to improve activism and professionalism. The main criteria to this recommendation are the respect to the autonomy of the civil society entities, that lunders the clear assignment of on the political roles between the government and the organized civil society.
- To implement mechanisms of resources transference linked to monitoring and evaluation. It is also recommended to consider local complains about the agreement bureaucracy and limitation. In case of necessity, it may be examined the possible substitution of the mechanism into another, without throwing away monitoring and evaluation concepts which are basic in for the administration of the resources fund.
- To improve dialogue between the committees and the commissions composed by the representatives of the National Movement on Fight against AIDS in the government and National Health Council levels.
- Capacity building to inland NGOs in projects formulation, implementation and evaluation, since the competition for public funds is unfair if compared to the metropolitan capital cities.
- It may be highlighted the recommendations of the National STD/AIDS Programme Coordinator in his inaugural address. (Pedro Chequer 2004).

- Strengthening strategies in partnership with the SUS envisaging the NGOs sustainability.
 - Adoption of adequate and innovative strategies in accordance with current and future epidemic demands.
 - Adoption of adequate and innovative strategies to improve both the quality of services rendered by SUS and the access to it.
- Taking into consideration the scope of an AIDS program in health quality it is recommended among others, the following:
 - To implement health professional capacity building to improve services to those patients who lives with AIDS, focusing in humanistic and solidarity.
 - To promote potential synergies in the several programs of the Ministry of Health and among the different Ministries and local Secretariats.
- Taking into consideration that the AIDS system depends on such a knowledge that aggregates social responsibility, technological modernization and intimacy with differentiated perspectives, it is recommended the emphasis on evaluation, extensive and comprehensive researches either instrumentals or related to programs follow-up and evaluation such as those of large temporal spectrum to diagnosis tendencies and affective and effective engagement of different people.
- To incentive agencies in producing knowledge in the DST/AIDS researching area. It is also advisable the generation of more alternatives actions in self-promotion and funds financing, which may enable the engagement of new and recognized researchers in this field.
- To incentive enterprises to implement, inside their own premises, preventive actions in DST/AIDS directed to a healthy population and particularly to those workers that rarely appears in the enterprise health service department.
- To strength the understanding that AIDS is not only a problem of public health but also a problem that affects the country development and embraces human rights principles.

7.2.2 SPECIFIC RECOMMENDATIONS

State and Municipal Management

In the AIDS field, among others governance principles, is the principle of the decentralization that suggests the importance of the actions focused on the state and municipal management and administration, as a Brazilian response to the control of AIDS. State Secretariats and municipalities, as well as local councils interact with civil society entities and with federal sectors generating tensional situations which demands qualification and funds from different sources. It is then recommended the emphasis on public – private – community partnerships (meaning enterprises and civil society institutions engagement) and the implementation of a diversified institutional apparatus to be supported by hybrid instruments not necessarily restricted to the State, such as:

- The creation of committees to monitor and evaluate NGOs/ AIDS activities at local levels;
- To promote major communications between DST/HIV/AIDS state and municipal managers and local NGOs.
- To promote major communications between the higher government levels and those NGOs that develop transversal public policies with AIDS, adding efforts to build co-responsible and collective actions;
- To increase actions that will permit to follow-up the preventive inputs supplying and assistance at the SUS.
- To improve, through the public power, the acquisition of specific medications, the access to diagnosis and the attendance time shortening to face the population daily demand for exams solicitation, as well as improve attendance and assistance in the public health services;
- To expand access to free exams and allow lab tests being made by more laboratories. There is nowadays, a higher number of requests for HIV exams.

- To expand access to testing, treatment and diagnosis, directed to places located far from the metropolitan areas. This will increase the population coverage.
- To implement the decentralization of the access to diagnosis in favor to the health centers and the basic health units, in order to guarantee in a regular basis the access to exams and tests, primarily for pregnant women.
- To bring into attention the vulnerability of the target-audience in questions related to the use of drugs and alcohol, self respect, socioeconomic situation, non-use of preservatives, cultural values a lack of information.
- To insist in the partnerships with other programs of the Brazilian Government, such as the Program on family planning and the Program on adolescent health, to inform about contraceptives methods, preservatives distribution, sexuality, pregnancy prevention and Sexually Transmitted diseases in special at schools and local health services.
- To develop actions in the area of damages reduction by implementing the distribution of syringes in health units, allied to educational actions. To create a health unit with this profile, to work closer to community agents and promoting their training. Those agents will be trained to approach other drugs users trying to sensitize them to adhere treatment.
- To develop actions closer to young people who are out of the school, with legal problems, probationers, and also together the population in prisons.
- To guarantee the humanization of the services by training health professionals to deal with the reality. To supervise those professionals working in the services and being assured of their articulation with the civil society to create an administrative council to supervise the attendance quality.
- To implement actions in the basic network to prevent vertical transmission of syphilis and AIDS. The actions must be integrated to the program on women, children and adolescent health, and the program on family health.

- To be careful to avoid duplication of actions developed by the government and NGO in the same geographic region, to avoid double costs.

NGO, Networks and Forum

The NGOs dynamics in various thematic areas is affected by several changes. Some of them do not depend on their own ethics and solidarity engagement to the cause even it is to a basic purpose. Many restrictions may affect the budget, the quality of the human resources and the wide scope of the work. Many NGOs had to reduce their working level, and others simply closed the doors. Furthermore, many others remained working and several are well recognized by their services in AIDS field. Many challenges suggest various recommendations, and many of these recommendations require the cooperation of other agencies, like the State and international organizations, while others depend only of the own organization. Taking into consideration the Brazilian experience with the NGOs/AIDS, it is recommended:

- The implementation of a dialogue communication with the communities in the local scenario and searching for a diversity of communications to sensitize a large number of players and agencies, to avoid the communication be restricted to the networks in the field of the civil society in relation to AIDS.
- To give attention to the organizational institutional development even though facing administrative challenges, taking care of professional capacity building, strategic planning and capitation of resources and political sustainability which is the base of its social legitimacy; keep civil society informed of the NGOs activities. In light of this it is recommended to emphasize, among others: the necessity of planning, execution and evaluation of all activities involved; also empowering its beneficiaries; to participate in the organization not only a beneficiary of the services rendered but also in planning and

evaluating the organization. To emphasize the humanitarian characteristics of the services and its participation in the community; in the efficiency of the services and promoting partnerships.

- To accomplish, as much as possible, the prevention activities directly inside the community. This methodology may guarantee the frequency of the participants who, in general, would not be able to participate by funding themselves with travel expenses to the NGOs place.
- Taking into consideration the importance of the humanization of the health services, particularly in the AIDS field, we may insist in the attention to be given to the insertion of the beneficiaries into special context where they feel safety, where they can talk and work the their self-respect, discuss about their sexual and reproductive rights, about the access to health services, about inputs for prevention, about prevention alternatives, about human rights and in this context having conditions to exercise their citizenships.
- To take care in searching the political sustainability to enable the NGOs to exercise social control in public policies and in State actions.
- To take into consideration the financial sustainability, the internal capacity building and through the network of other organizations to search alternative resources funding, and in case it is necessary, requiring inclusive, resources from public donors in a different approach.
- To insist in enhancing the strategic value of educating for equality, prevention and treatment and also the exchange of experiences in this area by participating in events such as EDUCAIDS and/or by local actions in schools, making use of the artistic and cultural and diversified pedagogic methodology.
- Capacity building and modeling composition, functioning and limitations of the SUS.

- To be ready to follow-up and to point indicators and evaluation about the local, regional and international context about incident policies in the HIV/AIDS epidemic control.
- To implement and strengthen technical capabilities to dialog with research agencies and to be used in the capitation of public resources for HIV/AIDS studies and evaluation.
- To increase knowledge on international mechanisms, for example, the UNGASS/AIDS as well as being prepared to follow-up the assumed compromises of the organized civil society.
- To contribute for the strengthening of the network/forum of the NGOs/AIDS exercising social control, exchanging experiences and social viewing.
- To participate, in a partnership basis, of the international cooperation, specially the South/South.

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ANNEX I

GLOSSARY AND ACRONYMS⁵³

ABC: Brazilian Cooperation Agency

ABONG: Brazilian Association of NGOs

ACES: Community Association on Social Action

ADT : Domestic Therapeutic Assistance

Advocacy: Defense of Rights

AIDS: Acquired Immunodeficiency Syndrome

ALERTA: Acronym in Portuguese that stands for the Association of Friends Freely Involved in AIDS Reeducation and Treatment.

ANS: Brazilian Health Agency

ASICAL: Acronym in Spanish that stands for Integral Health and Citizenship in Latin America.

CAASA: Acronym in Portuguese that stands for the House of Support and Assistance to AIDS Carriers.

⁵³ Glossary in Portuguese and acronyms extracted from:
GAPA/RS. AIDS Library. Leia antes de escrever. Available at:
<http://www.gapars.com.br/biblioteca.htm>. Accessed on 11/Aug/2004
MINISTRY OF HEALTH. Virtual Health Library. Thematic Areas BVS MS. STD and AIDS. Available at: <http://dtr2001.saude.gov.br/bvs/aids/glossario.htm>. Accessed on 11/Aug/2004.
MINISTRY OF HEALTH. National STD and AIDS Coordination. Available at www.aids.gov.br. Accessed on 12/Nov/2004.

CAFTA: Central America Free Trade Agreement

CAPS: Psycho – social Care Center

CDC: Centers for Disease Control

CE: State Coordination on STD/AIDS

CES: State Health Council

CETAD: Center for the Study on Alcohol and Drugs

CIB: Bipartite Inter – managers Commission

CID: International Classification of Diseases

CIDAP: Integrated Center of Development and Settlement of small – size Agriculture Workers

CIRH: Inter-sectoral Human Resources Commission

CIT: Tripartite Inter-managers Commission

CMDCA: Municipal Council on Children and Adolescents Rights

CMS: Municipal Health Council

CNAIDS: Brazilian Commission on AIDS

CN – DST/AIDS: National Coordination on Sexually Transmitted Diseases and AIDS/MoH

CNS: Brazilian Health Council

COAD: Center of Guidance Support and Serological Diagnosis – CTA

COAS: Centers of Guidance and Serum Support, current CTA – Advisory Center

CPTT: Center of Prevention and Treatment to Drug Addicts

CREAIDS: State Reference Center on AIDS

CRIA: Integral Reference Center for Adolescents and Children.

CRN-AIDS: National Reference Centers on AIDS

CRT: Training Reference Center

CTA: Test and Counseling Center

CT-DST: Training Centers on Sexually Transmitted Diseases

DFID: Department for International Development, Great-Britain

ENONG: National Meeting of NGOs

ERONG: Regional Meeting of NGOs

ESF: Family Health Strategy

FIOCRUZ: Oswaldo Cruz Foundation /Ministry of Health

FNS: Brazilian Health Facilities

FTAA: Free Trade Area of the Americas. Idealized by the United States, it foresees custom tax exemption for almost all commerce items among associated countries. Free trade is expected to start in 2006. All countries of the three Americas are part of it, except for Cuba. Altogether, there are 34 nations.

FUND-TO-FUND: transfer of resources from Brazilian Health Facilities to Municipal or State Health Facilities.

GCTH: Horizontal Technical Cooperation Group. Group established by AIDS National Program aimed at formulating cooperation programs among the Latin American countries.

GEEF: Group *Estudar e Evitar a Fármaco – dependência*

GEPAB: Habilitation for Expanded Basic Management

GTZ: German Cooperation Agency for Development

HD: Hospital Dia

HDS: Hospital Dório Silva

HIV: Human Immunodeficiency Virus

HRS: Hospital Roberto Silvaes

HSH: Men who have Sex with Men [MSM]

IBASE: Brazilian Institute on Social and Economic Analysis

IESP: State Institute of Public Health

ILGA: International Lesbian and Gay Association

INMETRO: Brazilian Institute of Metrology, Ruling and Industry Quality

IRDB: International Reconstruction and Development Bank.

ISER: Institute of Studies on Religion

LACEN: Laboratório Central

MAPAIDS: São Paulo Movement of Articulation for Fighting AIDS

MAPH: Movement of Human Support to HIV/AIDS Carriers

MoH: Ministry of Health

MRE: Ministry of Foreign Affairs

NAPS: Centers of Psychosocial Care

NDI: Center of Infectious Diseases

NEPAIDS: Center of Studies on AIDS Prevention

NGO: Non-Governmental Organization

NOAS: Operational Rule for Health Care

NOB: Basic Operational Rule

OSC: Civil Society Organization

OSCIP: Civil Society Organization of Public Interest – Law 9.790, of 23 March. Synonymous to NGO (Non – Governmental Organization)

OUT REACH: reaching target-audience

PACS: Program of Community-based Health Agents

PAHO: Pan-American Health Organization

PAISM: Program of Integrated Care to Women Health

PALOPs: Portuguese-speaking African Countries

PAM: Plan of Actions and Goals

PN DST e AIDS: National Program on Sexually Transmitted Diseases and AIDS/MoH

POA: Annual Operational Plan

PRD: Project on Losses Reduction

RNP+: National Network of People Living with HIV/AIDS

SAE: Service of Specialized Care to HIV/AIDS carriers

SAS: Health Actions Bureau

SEJUS: State Justice Secretariat

SEMUS: Municipal Health Secretariat

SES: State Health Secretariat

SESA: State Health Secretariat

SICLOM: National System on Medication Control

SIMOP: Projects Monitoring System

SISFAF: Fund-to-Fund Transfer System

SMS: Municipal Health Secretariat

STD: Sexually Transmitted Diseases

SUS: Brazilian Unified Health System

TAVR: Antiretroviral Therapy [HAART]

TRIPS: Trade-Related Intellectual Property Rights Agreement

UBS: Basic Health Unit

UDI: Injected Drug Users [IDU]

UN: United Nations Organization

UNAIDS: Joint United Nations Programme on HIV/AIDS

UNESCO: United Nations Educational, Scientific and Cultural Organization

UNFPA: United Nations Population Fund

UNICEF: United Nations Children Fund

UNODC: United Nations Office for Drugs and Crimes

USAID: United States Agency for International Development.

WHO: World Health Organization

WTO: World Trade Organization

ABRINQ: Abrinq is a non-profitable “child-friendly” organization, established in 1990, when the Statute of the Child and Adolescent was enacted. It aims at promoting advocacy and exercise of children’s and adolescents’ citizenship. Every work developed by Abrinq foundation is guided by the International Convention on Children’s Rights (UN, 1989), the Brazilian Federal Constitution (1988) and the Statute on the Child and Adolescent (1990).

ACCOUNTABILITY: Rendering of Accounts. This expression leads to another core element in resources mobilization. Considered in broader sense, instead of merely financial sense, it means the capacity of proving works developed, changes attained and use of generated and raised resources. This capacity should be an obligation for all – OSC, State and corporations – to reach the desired transparency and confidence (Lório, 2001:53)

ADDICTED TO ALCOHOL: A person that meets the criteria for alcohol addiction, pursuant to 10th Review of International Classification of Diseases– ICD – 10.

ADHESION (ADHERENCE): This term is broadly used in any therapy to chronicle diseases. However, it became particularly relevant in the field of HIV/AIDS along the last few years, as antiretroviral therapy (see specific definition) efficacy substantially

increased, leading to favorable impacts on extension (technically called outlive) and quality of life to individuals living with HIV/AIDS. Due to therapy efficacy and chronicle nature of HIV/AIDS infection, any break in treatment could bring adverse consequences, like the emergence of strains (variants) resistant to HIV. Adhesion is extremely complex in HIV/AIDS field, since therapy is always combined (involving different drugs, in different dosages and with different effects) and typically causes jeopardizing adverse effects.

ADOLESCENT: Adolescents are individuals ranging from twelve to eighteen years old.

AIDS CARRIER: Expression used to identify AIDS – diseased individuals. In Brazil, ONG/AIDS and CN – DST/AIDS fight against the use of such term and disagree with it, for the pejorative and discriminatory feature now associated to it.

AIDS CASE: Individual in most developed stage of infection, due to high compromising of immunological system.

AIDS impoverishment: Epidemiological concept that describes a change in HIV dissemination in Brazil and worldwide. It is characterized by increasingly spread of HIV among low-income and low-education layers, more vulnerable to dissemination due to poor information, hard access to preventive means and concurrent investment of energy and time in other priorities, urgent and absorptive, as food and housing.

AIDS FEMINIZATION: Concept originated in epidemiology, describes a shift on HIV Dissemination pattern in Brazil and worldwide. It means gradual increase in the number of infected and/or diseased women along the observation period.

AIDS FEMINIZATION: Term applied to HIV infection profile, where is observed a trend towards increased number of infected and/or diseased women. In Brazil, women currently represent 25% of total

cases reported. This trend may be measured through sex ratio, 3:1 along the last few years, meaning 3 cases in men for every 1 case in woman. (Ministry of Health. National Coordination of STD/AIDS).

AIDS I: First World Bank Loan Agreement.

AIDS II: Simplified designation of the second World Bank loan to Brazilian Program on AIDS Control. The first loan was named AIDS I, and in July 2003 the third loan, AIDS III, was negotiated.

AIDS INTERIORIZATION: Trend of cases occurrence in medium- and small-size municipalities.

AIDS: Acquired Immunodeficiency Syndrome. Identifies a viral process that attacks the human immunologic system, destroying cells that defend the organism against infections. When it happens, the diseased person becomes vulnerable to a broad range of serious diseases, like pneumonia, tuberculosis, meningitis, Kaposi's sarcoma and other kinds of cancer. These are opportunistic infections that may lead AIDS diseased individuals to death. It is caused by the HIV (Human Immunodeficiency Virus), which has already been isolated in different concentrations of organic materials or fluids: Blood, sperm, vaginal secretions, saliva, and urine and breast milk. Nevertheless, no infection through saliva or urine has been proved. However, it has been proved its transmission through blood transfusion, shared use of syringes and/or needles, and through sexual intercourse. A mother carrying the virus or diseased of AIDS may transmit the HIV to her child during pregnancy, delivery of breastfeeding. Some drugs have been used for fighting HIV, in a relatively successful way. However, no cure has been discovered to this disease, and immunization is far from becoming reality. In Brazil, the first cases were reported in 1980, and about 120 thousand cases were recorded as of November 1997. In French, Portuguese and Spanish, the corresponding acronym is SIDA. In Brazil, AIDS is most broadly used. Please see HIV, Retrovirus, Kaposi's Sarcoma, Safe Sex and Vertical Transmission.

AIDS: AIDS is a clinical disease, resulting from immunodeficiency caused by HIV (HIV-1 and HIV-2, where this last is not epidemiologically relevant in Brazil). It is characterized for severe suppression of mediated immunity, mainly T cells, resulting in opportunistic infections, secondary neoplasia and neurological diseases. HIV (AIDS virus) is transmitted through: sexual contact, transmission of virus from infected mothers to fetus or newly born, and through blood (like in transfusions of blood and blood by-products, or shared use of injected drugs).

ANTI AIDS COCKTAIL: Term broadly used to the associate use of two or three antiretroviral drugs. It is characterized by consumption of too many pills or tablets a day. Typically, two inhibitors of reverse transcriptase and one proteases inhibitor are combined.

ANTIRETROVIRAL THERAPY: General denomination to the set of drugs used for treating infection by HIV, which is a retrovirus.

ANTIRETROVIRAL: Generic designation for drugs used in treatment of HIV infection, which is a retrovirus.

ARC: AIDS-Related Complex. This expression was broadly used in the 1980's to characterize intermediary clinical stages of HIV (AIDS virus) infection, in patients who used to present a set of signs, symptoms and laboratory alterations but that, nonetheless, do not clear characterize clinical syndrome of immunodeficiency (acquired immunodeficiency syndrome – AIDS), with opportunistic diseases.

AZT: Acronym for azidothymidine, a pharmacological compound. Also known as zidovudine, this antiretroviral drug belongs to the groups of reverse transcriptase inhibitors, used in the treatment of HIV infection. It was the first medication used to treat patients with HIV/AIDS infection.

CATEGORY OF EXPOSURE: Term that replaces previously terminology “groups of risk”, which is technically unclear, besides having strong prejudice and stigmatizing load. Category of exposure translates the likely way how each individual or group was exposed to HIV, giving rise to infection.

CD4: Is a receptor mainly present in T-assistant lymphocytes (thus named Lymphocytes-T CD4+), whereto HIV connects to start infecting these cells. Other molecules found in Lymphocytes-T play auxiliary role, but relevant to this process of Lymphocytes-T linking, and are named co-receptors.

CDC: Centers for Disease Control and Prevention, agency of the United States government, in charge of promoting health and health security. Have partnership with several countries worldwide, including Brazil.

CENTER OF TESTING AND COUNSELING IN AIDS: Units belonging to the Brazilian Unified Health System (SUS) basic network. Its general objective is to induce the adoption of safe sexual practices (primary prevention), expand assistance provided by Specialized Assistance Services (SAE) to HIV-infected individuals (secondary prevention).

CENTER OF TESTING AND COUNSELING IN AIDS: Units of Brazilian Health System (SUS) basic network, aimed at inducing adoption of safe sexual practices (primary prevention) and leading HIV-infected individuals to seek for assistance at Specialized Assistance Services (SAE) (secondary prevention).

CENTERS OF GUIDANCE AND SEROLOGICAL SUPPORT:
See Center of Testing and Counseling in AIDS.

CIVIL AND POLITICAL RIGHTS: Are those that ensure the right to equality in face of law, granting that no one can be discriminated or impaired of fully enjoying rights set forth in the federal constitution. They comprise: right to birth certificates (civil

registration of live birth); right of prisoners; right to fair judgment; prohibition of torture and slavery; right to come and go, freedom of opinion and thinking; right to associate to and participate in political life; right to vote, join political parties, rung to public offices.

COLLECTIVE COUNSELING: Targets to provide users the opportunity of re-dimensioning difficulties by sharing doubts, feelings and knowledge. Group dynamics also allows individuals to perceive their own demand, acknowledge their knowledge and feelings, thus inducing their participation in further individual sessions.

TUTELARY COUNCIL: Responsible for receiving denouncements, verify, forward and provide guidance in the event of violation of the rights of children and adolescents. It may act in the event of threat, risk or when violence has already occurred.

COUNCILS OF DEFENSE OF RIGHTS OF CHILDREN AND ADOLESCENTS: These are institutions devoted to discuss and follow-up policies for fighting violence practiced against children and adolescents.

COUNCILS ON WOMEN RIGHTS: These are established based on an initiative of municipality or state women, jointly with government. They prepare proposals and promote policies towards abolishing discriminations, harassment to women, and overcoming unbalanced opportunities for men and women.

COUNSELING – Approach aimed at providing individuals with conditions for assessing their risks, making decisions and meeting realistic ways for facing their STD/HIV/AIDS-related problems.

COUNSELING: Process of actively hearing, individualized and focused on client. It requires for capacity of establishing trustworthiness relationships between interlocutors, aiming at recovering clients' internal resources and, then, lead them to acknowledge their core role concerning their own health and shift.

d4T: Also known as estavudine, it is an antiretroviral drug, belonging to the group of reverse transcriptase inhibitors (similar to AZT, ddC and ddI), used in treatment of HIV infection.

DAMAGE REDUCTION: Model of investment focused on individual, its social network and community, where pragmatic strategies are adopted aiming at reducing damages caused by the use of drugs. Some of the most relevant damages to be avoided concern infection by HIV and other infectious agents, as agents of infectious hepatitis, mainly among users of injected drugs, vulnerable to double risk of sexual and blood transmission. Proposals on damage reduction do not require for abstinence as leading criterion for participation of target-population, despite playing crucial role in “attracting” this population to programs on treatment of drugs abuse. Action on damage reduction include provision of inputs, such as sterilized syringes and needles and preservatives, aiming at reducing shared use/reuse of contaminated syringes and needles, besides favoring safer sexual practices.

ddC: Acronym to dideoxycitidine. Also known as zalcitabina, it is an antiretroviral drug belonging to reverse transcriptase inhibitors (similar to AZT), used in treatment of HIV infection.

ddI: Acronym to dideoxiinosine. Also known as didanosine, it is an antiretroviral drug, belonging to the group of reverse transcriptase inhibitors (similar to AZT and ddC), used in treatment of HIV infection.

DECLARATION OF ALMA – ATA: The International Conference on Health Primary Care, held in Alma – Ata on 12 September 1978, disclosed the need for urgent actions by all governments, those working in the field of health and global community development, towards protecting and promoting world peoples.

DNA: Acronym for deoxyribonucleic acid, i.e., the genetic material responsible for memories on structures and functions of a cell, and its conservation in future generations. During replication, HIV

nucleic acid becomes part of lymphocytes' DNA, where it is multiplied until restarting the infection cycle on another lymphocyte.

ELISA (Enzyme Linked Immuno – Sorbent Assay): Acronym for enzyme immunoassays that allow determining if an individual is infected by an agent. For HIV, it detects the presence of antibodies to the virus in blood. A reagent ELISA test does not mean that an individual is diseased. Other tests should be performed to validate ELISA results.

EMERGENCY CONTRACEPTION: Use of some kinds of contraceptive pills, in emergency situations, to avoid pregnancy after unprotected sexual intercourse – where woman may get pregnant.

EPIDEMICS: Infectious disease or any aggravating factor to health that rises suddenly and spreads rapidly, concomitantly reaching a great number of individuals, in a given place or region.

EPIDEMIOLOGY: Study on how a disease is spread and propagates in several population groups. Epidemiological studies allow for identifying factors that facilitate or impair the disease dissemination, thus contributing towards prevention and/or control.

FEMALE PRESERVATIVE: A polyurethane-made tube, with a closed extremity and another open, coupled to two flexible rings, also made of polyurethane. The first ring remains free in the tube, and assists in inserting and fixing the preservative in the vagina. The second ring serves as external ring to the preservative and, when preservative is properly used, covers part of the vulva. The product is lubricated and should be used only one time.

FUNDAÇÃO NACIONAL DE SAÚDE (FUNASA): Executive body of Brazilian Ministry of Health. Its mission is to serve as an agency for the promotion and protection to health, through integrated actions on education and prevention and control of

diseases and other aggravating factors. Furthermore, it is in charge of providing integral health services to Indigenous peoples, aiming at improving the population quality of life.

GAY: Term used as synonym to man who has sex with man or male homosexual.

GENOTYPIC ASSAY: Allows the identification of resistance of HIV virus to antiretroviral drugs in each patient. This test, named genotypic assay, is important in assessing AIDS treatment, as results may assist doctors in re-orienting therapy, replacing only the drug that became inefficient. This measure means reduction in expenses with inefficient drugs and, for patient, elimination of unnecessary side effects.

GENOTYPIC ASSAY: Genotypic assay is performed to survey the kind of mutation, eventually responsible for therapeutic failures in AIDS carriers, determining the emergence of resistance to different drugs. It is worth to notice that several mechanisms, not necessarily bound to virus structure and replication – including non-adherence (adherence) to proposed therapeutic schedules, poor chemical absorption of drugs, metabolism problems, drugs excretion, etc. – may determine therapeutic failure.

HEALTH AGENDA: Managerial tool used by federal, state and municipal governments to set, justify and detail health policy priorities. (It is a participation-based tool, resulting from negotiation and consensus among managerial bodies, health councils and inter-managerial commissions). It plays decisive role in the integrated planning of health actions, since it focuses on transparency and simplicity in elected objectives and indicators.

HEALTH CENTER: Is the unit devoted to render health services to a given population, staffed with permanent interdisciplinary health team, with general practitioners and/or specialist doctors. Its complexity and physical dimensions vary according to characteristics of population assisted and health conditions.

HEALTH CONFERENCE: Every four years, the Health Conference holds meetings with representatives of several social segments for assessing health status and proposing guidelines to formulate health policy at corresponding levels, convened by the Executive Power, or extraordinarily by the Health Conference itself or the Health Council.

HEALTH COUNCIL: The health Council is a permanent and deliberative collegiate body, made up by representatives of government, service providers, health professionals and users. It works in the formulation of strategies and control of execution of health policy at corresponding level, including economic and financial aspects. Decisions made thereby are to be ratified by the head of legally constituted power at each governmental sphere.

HEALTH FUNDS: Specific accounts comprising any resource addressed to federal, state, municipal health sectors, as donations and proceedings that should obligatorily be used in health-related actions and services.

HEALTH MANAGER: Responsible for SUS management at each governmental sphere: health systems at municipalities, states, the Federal District and national levels.

HOSPITAL ACCREDITATION: Method for building consensus, rationalizing and ordering hospital institutions. Above all, it aims the permanent education of hospital professionals, expressed by means of a voluntary, periodic and reserved procedure for assessing institutional resources, which trends towards guaranteeing services quality, pursuant to pre-established standards.

IMMUNODEFICIENCY: Condition where immunological system is weakened, and fails in protecting the body, thus facilitating the development of several diseases.

IMMUNODEPRESSED: Individual whose immunological system is weakened.

IMMUNOLOGICAL SYSTEM: Organic system responsible for the defense against potentially harmful agents. It is made up by cells and cell substances (antibodies and cytoquines). HIV infection may lead to gradual destruction of immunological system, thus favoring emergence of opportunistic complications, characteristic to the disease.

IMMUNOLOGICAL WINDOW: Time from infection until initial production of specific antibodies, i.e., time from infection by virus and serum-conversion (when antibodies can be detected in blood and serological tests become positive). Typically, this period lasts some weeks and the patient, despite the presence of infectious agent in his/her body, presents negative results in tests to detect antibodies against the agent. If test is performed during “immunological window”, result is likely to be false-negative, although the individual is already infected by HIV and may transmit it to other persons. It is a common sense that, after a risk situation, tests should be repeated to detect antibodies anti-HIV in six months, due to accuracy of existing tests. There are very few cases of late serum-conversion, lasting more than 6 months.

INCIDENCE (RATE, COEFFICIENT): Is the expression of the number of cases of a given disease or group of diseases, in specific population, along specific period of time, divided by the number of individuals of that population, for the same time span specified.

INDIRECT IMMUNOFLUORESCENCE: Is a test for determining the presence of antibodies, through fluorescence microscopy.

INFORMATION SYSTEM OF ASYMPTOMATIC HIV SEROPOSITIVE INDIVIDUALS (SIHIV): SIHIV is an information system complementary to SINAN, used in some places to assess HIV infection trends and behavior, thus providing subsidies to refine the organization of preventive and assistance activities promoted by the STD/AIDS Programs at municipal, state and regional, municipal and state levels.

INFORMATION SYSTEM ON THE NOTIFICATION OF AGGRAVATING FACTORS (SINAN): System that allows for collecting, transmitting and disseminating routine data generated by the Epidemiological Surveillance to support processes of investigation and analysis of major diseases and aggravating factors that are subject to mandatory notification.

INJECTED DRUGS: Are intra-venous or intra-muscular substances, which may be diluted and injected, whether intravenous or subcutaneous (like cocaine and heroin). The custom of sharing syringes and needles among users increase risks of being infected by HIV.

INTER-MANAGERIAL COMMISSION: Aims at ensuring shared management among municipal, state and federal governments, in order to avoid duplicity or omission while executing actions, besides building room where managers of technical health system may permanently negotiate, decide and celebrate agreements.

INTERNATIONAL COOPERATION PROGRAM (ICP): Project whereby Brazil provides therapeutic assistance and distributes antiretroviral drugs to Latin American and African countries.

INTER-SECTORAL COMMISSIONS: Inter-sectoral commissions are aimed at articulating policies and programs relevant to health, where executions are not comprised within Brazilian Unified Health System scope.

MALE PRESERVATIVE: A latex-made sheath that covers the penis during sexual intercourse, retaining sperm during ejaculation, thus impairing contact with vagina, besides impairing the contact of vagina's microorganisms with penis, or vice-versa.

MANAGEMENT REPORT: Aimed at systematizing and communicating information on results achieved and SUS managers' probity, serving as tool for rendering of accounts, since it

establishes correlation among goals, results and resources application. This tool allows for monitoring compliance of resources application to approved schedule.

NATIONAL COUNCIL OF MUNICIPAL HEALTH SECRETARIES (CONASEMS): A non-governmental organization that virtually represents all the Brazilian municipal health secretaries, serving as official interlocutor of the Ministry of Health in issues related to health policy. Law 8.142 of 1990, dealing with social participation in SUS, defines CONASEMS as the representative of municipalities at National Health Council. CONASEMS is member of the Tripartite Inter-managerial Commission. It was established because of a municipality-based health movement, within the very same context that gave birth to SUS. This movement was preceded by several national and regional meetings of Municipal Health Secretaries, since 1978, following Brazilian re-democratization process.

NATIONAL COUNCIL OF STATE HEALTH SECRETARIES: Organization that represents state health secretaries as official interlocutor of the Ministry of Health, in issues related to health policy.

NATIONAL NETWORK FOR HIV-1 GENOTYPIC ASSAY (RENAGENO): Project on laboratory network to monitor patients with therapeutic failure to antiretroviral drugs, thus allowing for assessing resistance to therapies. Reference laboratories are in the following States: Bahia, the Federal District, Minas Gerais, Pará, Pernambuco, Rio Grande do Sul, Rio de Janeiro and São Paulo.

NATIONAL PLAN ON ANTI-HIV/AIDS VACCINATIONS: Comprises virological and immunological studies, clinical and epidemiological studies, social-behavioral studies, besides development and production of input and vaccinations.

NGO/AIDS: Acronym for Non-Governmental Organization (NGO) working in HIV/AIDS. These NGOs play crucial role in Brazil and worldwide, in the sense of informing on and preventing HIV dissemination, assist treatment and support individuals with HIV/AIDS, besides promoting and protecting their basic rights.

NORMA OPERACIONAL DE ASSISTÊNCIA À SAÚDE (NOAS): This rule is aimed at facilitating agreement and procedures among municipalities, thus enhancing SUS implementation.

OPPORTUNISTIC DISEASES: Diseases caused by agents with low pathogenic capacity – which usually does not cause diseases in individuals whose immunity is preserved – that occurs in immunodepressed and weak patients in general, due to reduced immunity capacity. Usually, they are of infections nature, but several neoplasias are considered opportunistic disease.

OPPORTUNISTIC INFECTIONS: Infections caused by microorganisms that usually do not cause disease in persons with normal immune system. When immunological system is weakened or destroyed (as happens in HIV infection), opportunistic infections may prevail.

OTHER HEALTH CONFERENCES Following Ottawa Conference, other conferences were held in different countries, such as Conference of Adelaide, Australia (World Health Organization, *Adelaide Recommendations*; 1988); of Sundsvall, Sweden (World Health Organization, *The Sundsvall Statement*; 1991). These conferences have set the idea of creating healthy spaces, both at small scale and schools of health, healthy hospitals, basic health units and healthy prisons, besides at more ambitious projects, such as healthy cities that, in Brazil, are called healthy municipalities. The Conference of Jakarta, Indonesia (World Health Organization, 1997) was pioneer in the developing countries and in including

private sector in discussions on health promotion. During that conference, all principles on health promotion were restated, and the importance of the elderly health was emphasized. The fifth Conference held in Mexico (World Health Organization, *Declaration of Mexico*, 2000), besides reinforcing key-elements in health promotion, underlined the relevance of scientific, social and political aspects in health promotion. Furthermore, it emphasizes the need for reducing unbalances between groups and countries and role played by women in health policies development. Due to Latin American peculiarities, added to the need of discussing strategies to face regional problems, the Colombian Ministry of Health, jointly with the Pan-American Health Organization (PAHO), have organized the Conference of Bogotá, in 1992 (Pan-American Health Organization, *Health Promotion Program*, 1992). Later, in 1993, the *Caribbean Chart for Health Promotion* was prepared, during the 13th Meeting of Caribbean Ministers in charge of Health, held in Port of Spain, Trinidad and Tobago.

OTTAWA CHARTER: According to *Ottawa Charter* actual health state demands several pre-requisites, including education, proper income, social justice and equity. In order to effectively reach such conditions, health promotion movement must convert inter-sectoral action into a more tangible practice. For that, it should establish consistent inter-disciplinary alliances and develop community-based movements strong enough to influence public policies. *Ottawa Charter* emphasizes five areas of action that provide required grounds to promote health, including development of healthy public policies, creation of sustainable environment, strengthening community participation, developing personal skills and re-orienting health services.

PANDEMIC: Epidemic of a disease that affects people in different countries and continents, in a given time.

PLURI-ANNUAL PLAN (PPA): At regional level, sets guidelines, objectives and goals for public administration, concerning capital expenses and other related expenses, besides those concerning continuous programs. It is an Executive Power initiative, held at every 4 years.

POST-TEST: Counseling session held by occasion of delivery of test result, where the individual receives proper emotional support. In these sessions, risk perception, adoption of preventive practices concerning HIV and other STD, and adherence to treatment for individuals infected by HIV are reinforced.

PRESERVATIVE: Also known as condom, it is made of latex and covers the penis during sexual intercourses.

PRE-TEST: Counseling session where exchange of information on HIV/AIDS, risk situations, preventive measures and the result of a test to detect infections by HIV, assists the individual in deciding for undergoing the test.

PREVALENCE: The number of cases worldwide of a given aggravating factor in a specific geographic area at a given time.

PREVENTION: For AIDS, prevention means preventing an individual to be infected by HIV; avoid HIV infection to develop to clinical syndrome (AIDS) and avoid re-infection (new infection) of infected individuals. Re-infection almost always worsens previous infection and hinders treatment.

PREVENTION: Measures oriented to hold back the spread of agents of an aggravating factor to health. For AIDS, it is about HIV spread. As there is no vaccination against HIV, prevention is the most efficient measure. In order to fully achieve prevention, it is necessary to implement systematic and continuous educational intervention actions, with population in general and most vulnerable groups.

Psychosocial assistance centers: Services to patients holders of mental disturbances, as alternative to conventional hospitalization. These centers work 8, 12 or even 24-hour a day. Among routine duties, these centers provide therapeutic and preventive workshops in relation to STD/HIV/AIDS, inclusively by providing counseling and anti-HIV test. Furthermore, they assist monitoring adhesion to antiretroviral drugs for users with HIV/AIDS.

REINFORCEMENT TO REGIONALIZATION OF BRAZILIAN UNIFIED HEALTH SYSTEM (REFORSUS):

Implementation of strategic actions oriented to enhance the Brazilian Unified Health System (SUS), contributing towards granting universality, integrality of assistance, and equal access of population to health goods and services. It intends to improve SUS capacity and efficiency, through physical, technological and managerial recovery of existing services networks. Another SUS goal is to promote institutional development to health sector, through actions oriented to increase the system managerial capacity.

RETROVIRUS: Kind of virus that, for reproducing, uses a process of reverse conversion of its genetic material, using specific enzyme (reverse transcriptase) and other enzymes of the cells of infected individual. HIV is a sample of retrovirus.

RETROVIRUS: Refers to a family of virus, many of which relevant to human or veterinary pathology, capable of replicating inversely to what is usually observed in nature. It means that viruses are capable of producing copies of DNA (deoxyribonucleic acid) from RNA (ribonucleic acid), when most living beings follow opposite way, i.e., produces RNA from DNA. To carry on replication with information transcribed inversely to usual direction, retrovirus use an enzyme called reverse transcriptase. Some retroviruses induce uncontrolled multiplication of cells, and may give rise to tumors. In opposition, HIV determines the destruction of specific cells, as lymphocytes T CD4 and, therefore gradually destroys body's defenses, given the crucial role played by those cells in immunity.

RISK: Situations where people are more vulnerable to contracting AIDS virus.

RITONAVIR: One of the protease inhibitors used to treat HIV infection.

SAFE SEX: Sexual intercourse where both partners are protected. Self-masturbation, mutual masturbation, use of preservatives, monogamy, mutual fidelity of healthy partners, among others, are considered safe sex strategies.

SERONEGATIVE: Refers to individuals without anti-HIV antibodies, or whose levels are not yet detectable.

SEROPOSITIVE: Expression used to identify HIV and AIDS carriers, regardless if they are symptomatic or not.

SEROPOSITIVE: Refers to individuals with anti-HIV antibodies in detectable levels.

SEROPREVALENCE: Is the number of seropositive individuals (to HIV infection) in a given population group, in a given time and place.

SERVICE HUMANIZATION: Mutual accountability between health services and community, and closer relationship between professional teams and population.

SEX PROFESSIONALS: Men and women rendering sexual services for money, valued goods or any other kind of payment.

SIDA: French, Spanish and Portuguese acronym corresponding to AIDS, in English. In Brazil, AIDS is the most broadly used term.

SOCIAL CONTROL: Organized civil society controls the State in all social segments.

STD: Acronym that designates sexually transmitted diseases, i.e., infectious diseases caused by micro-organisms transmitted through

sexual contact. Among the STD, there is syphilis, AIDS, gonorrhea and chlamydiosis. STD is popularly known as venereal diseases.

SUS MANAGEMENT: Duty assigned to Federal Government, states, the Federal District and municipalities that, through their managerial bodies, use several management tools to ensure and improve health system work.

SYMPTOMATIC CARRIER: Individual infected by HIV, who presents AIDS symptoms.

SYMPTOMS: Any phenomenon or change in a body, caused by illness and that, described by patient, assist in greater or lesser extent to establish a diagnosis.

SYNDROME: Set of signals or symptoms.

SYSTEM OF CONTROL OVER LABORATORY EXAMS (SISCEL): Laboratory network to perform viral load assays and CD4 test, among others.

SYSTEM ON DRUGS LOGISTIC CONTROL (SICLOM): System that allows following-up distribution of antiretroviral therapies to patients countrywide.

T4 CELL: Auxiliary lymphocyte, also known as T-auxiliary cell. CD4 particle, whereby HIV connects to the cell and weakens immunological system, can be found at T4 Cell.

T8 CELL: Lymphocytes that produce antibodies, and are capable of destroying infected human cells.

UNIFIED HEALTH SYSTEM (SUS): The set of health actions and services, provided by public bodies and institutions at federal, state and municipal levels, of direct and indirect administration and foundations sustained by Public Power, make up the Unified Health System.

VIRAL LOAD: The viral load test is a methodology that allows for measuring the quantity of HIV in given fluid (usually blood, although it is possible to measure viral load in semen and vagina liquid) in the body of an infected person.

SEROLOGICAL TEST: Determination, through laboratory tests, of presence or absence of anti-HIV antibodies in an individual's blood (or, alternatively, in urine or saliva).

COUNTING OF POSITIVE T CD4 LYMPHOCYTES TEST: It is a methodology that allows counting the number of T lymphocytes with CD4 receptor. As more advanced HIV infection, as lower the number of these cells, thus indicating failure of patient's immunological system.

QUICK TEST: Serological test held in less than 30 minutes.

SIMPLE TEST: Serological test that waives the use of equipment for its execution.

SEROLOGICAL TESTS: Used to determine the presence of antibodies against a given antigen. For example: HIV virus.

SEX WORKER(S): Men and women who render sexual services for money or valued objects.

VERTICAL TRANSMISSION: HIV transmission from mother to child. It may take place during pregnancy, at delivery or during breastfeeding.

TRANSSEXUAL: A male person, who undergoes a surgery to change sex. Transsexual individuals have female psyche, dressing and behaving like a woman.

TRANSSEXUALISM: Condition where an individual, despite having normal organs of one sex, feels like as if he/she belonged to the

other sex. Transsexualism holders frequently define themselves as men imprisoned in a female body, and vice-versa. Transsexualism should not be confused with homosexuality.

TRAVESTISM: Condition where an individual feels pleasure in using clothes of the other sex. Although it may be associated to homosexuality, they cannot be confused, since travestism also occurs in heterosexual individuals.

TRAVESTY: A travesty is physiologically a man, but who also assumes a female identity, dressing and behaving like a woman, but admits his male genitals, living his sexuality.

TRIPS: Agreement on Intellectual Property Rights, aimed at controlling HIV/AIDS epidemics.

UNIVERSALITY: One of the principles of Brazilian Unified Health System, consisting in granting access to health services to population as a whole, at all levels of services, with no prejudice or privileges of any nature.

VIRUS: Microscopic agents that may cause infectious diseases. Viruses reproduce only within the cells. For HIV, its reproduces in T4 cells.

WESTERN BLOT: Laboratory tests performed in blood samples, to determine if the person had contact with the virus that causes AIDS. Because it provides very accurate results, it is usually used for validating a result obtained with trial tests.

ANNEX 2

LIST OF NGOS ACCORDING TO STATE⁵⁴

ACRE

- REDE ACREANA DE REDUÇÃO DE DANOS

AMAZONAS

- ASSOCIAÇÃO AMAZONENSE DE GAYS, LÉSBICAS E TRAVESTIS – AAGLT
- CARITAS ARQUIDIOCESANA DE MANAUS – CENTRO DE CONVIVÊNCIA DOM JACKSON DAMASCENO RODRIGUES
- MOVIMENTO EM DEFESA DAS CRIANÇAS E ADOLESCENTES SOROPOSITIVOS E FAMILIARES DO ESTADO DO AMAZONAS – MECASFEA
- REDE AMIZADE SOLIDARIEDADE ÀS PESSOAS COM HIV/AIDS

BAHIA

- ASSOCIAÇÃO DAS PROFISSIONAIS DO SEXO DE FEIRA DE SANTANA – APROFS
- ASSOCIAÇÃO DE MORADORES UNIDOS DE COSME DE FARIAS

⁵⁴ Comprises only the NGOs that answered the questionnaire. Further information on the NGOs are provided in Chapter 5.

- ASSOCIAÇÃO DE MULHERES PROFISSIONAIS DO SEXO DA BAHIA – APROSBA
- ASSOCIAÇÃO DE TRAVESTIS DE SALVADOR – ATRAS
- ASSOCIAÇÃO DOS MORADORES DE PLATAFORMA – AMPLA
- ASSOCIAÇÃO NÚCLEO DA MULHER
- ASSOCIAÇÃO RURAL DO SACO CAPIM – ARSC
- CARITAS DIOCESANA DE ILHEUS
- CASA DE APOIO E ASSISTÊNCIA AOS PORTADORES DO VÍRUS HIV/AIDS – CAASAH
- CENTRO BAIANO ANTI-AIDS – CBAA
- CENTRO DE EDUCACAO E CULTURA POPULAR – CECUP
- COLETIVO DE MULHERES DO CALAFATE
- COMUNIDADE DE ALIANÇA SANTA CECÍLIA
- FEDERAÇÃO NACIONAL DO CULTO AFRO-BRASILEIRO
- FUNDAÇÃO LUZ PARA LIBERTAÇÃO
- GRUPO DE APOIO À PREVENÇÃO À AIDS – GAPA/BA
- GRUPO DE APOIO ÀS MULHERES POSITIVAS DE SALVADOR – GAMPS

- GRUPO GAY DA BAHIA – GGB
- GRUPO GAY DE CAMAÇARI
- GRUPO LÉSBICO DA BAHIA – GLB
- GRUPO PALAVRA DE MULHER – GPM
- SOCIEDADE 1º DE MAIO

CEARÁ

- ALIANÇA LUZ
- ASSOCIAÇÃO BREJOSANTENSE DE APOIO À FAMÍLIA – ABAF
- ASSOCIAÇÃO COMUNITÁRIA DO BEM-ESTAR DO ALTO LUMINOSO
- ASSOCIAÇÃO COMUNITÁRIA MENINO JESUS DE PRAGA
- ASSOCIAÇÃO DAS PROSTITUTAS DE RUSSAS – ASPROSTIRUS
- ASSOCIAÇÃO DE APOIO AOS CARENTES DE PACAJUS – AACP
- ASSOCIAÇÃO DE APOIO, DEFESA E CIDADANIA AOS HOMOSSEXUAIS – AADECHO
- ASSOCIAÇÃO DE CINEMA E VÍDEO DE QUIXADÁ – ACVQ

- ASSOCIAÇÃO DE MULHERES RUSSANA
- ASSOCIAÇÃO DE TRAVESTIS DO CEARÁ – ATRAC
- ASSOCIAÇÃO DE VOLUNTÁRIOS DO HOSPITAL SÃO JOSÉ
- ASSOCIAÇÃO DOS MORADORES DO RIACHO DOCE – AMORDOCE
- CASA DE APOIO SOL NASCENTE E LAR DA CRIANÇA – OSNSG
- COMUNICAÇÃO E CULTURA
- FEDERAÇÃO DAS ENTIDADES COMUNITÁRIAS DO CRATO – FEC
- GRUPO DE APOIO À PREVENÇÃO À AIDS – GAPA/CE
- GRUPO DE RESISTÊNCIA ASA BRANCA – GRAB
- GRUPO DE APOIO ÀS COMUNIDADES CARENTES – GACC
- GRUPO DE RESISTÊNCIA FLOR DE MANDACARU – GRFM
- INSTITUTO DE PROJETOS E INVESTIGAÇÕES EM SAÚDE E DESENVOLVIMENTO SOCIAL – ISDS
- NÚCLEO DE INTEGRAÇÃO PELA VIDA – NIV
- UNIÃO MUNICIPAL DOS ESTUDANTES SECUNDARISTAS DE CAUCAIA – UMESCA

DISTRITO FEDERAL

- AGÊNCIA NOTÍCIAS DOS DIREITOS DA INFÂNCIA – ANDI
- ASSOCIAÇÃO REGIONAL DE COOPERAÇÃO AGRÍCOLA – ARCA
- CENTRO FEMINISTA DE ESTUDOS E ASSESSORIA – CFEMEA
- ESTRUTURAÇÃO – GRUPO HOMOSSEXUAL DE BRASÍLIA
- FUNDAÇÃO ATHOS BULCÃO
- GRUPO DE APOIO À PREVENÇÃO À AIDS – GAPA/DF
- INSTITUTO ATTITUDE – DIREITO E CIDADANIA PARA HOMOSSEXUAIS
- INSTITUTO DIVERSIDADE BRASIL
- NÚCLEO DE ESTUDOS E ATENÇÃO À EXCLUSÃO SOCIAL – NATEX
- SERVIÇO SOCIAL DA INDÚSTRIA / DEPARTAMENTO NACIONAL – SEI

ESPÍRITO SANTO

- CONVENÇÃO BATISTA DO ESPÍRITO SANTO
- GRUPO ESTUDAR E EVITAR A FARMACODEPENDÊNCIA – GEEF
- MOVIMENTO DE APOIO HUMANO AOS PORTADORES DE HIV/AIDS – MAHP

GOIÁS

- ASSOCIAÇÃO GOIANA DE GAYS LÉSBICAS E TRAVESTIS – AGLT
- CENTRO COMUNITÁRIO DO VALPARAÍSO DE GOIÁS
- COMUNIDADE HERDEIROS DA LUZ
- GRUPO PELA VIDA/GO
- GRUPO TRANSAS DO CORPO
- ORGANIZACAO DAS VOLUNTÁRIAS DE GOIAS / CONDOMÍNIO SOLIDARIEDADE – OVG
- SOCIEDADE OÁSIS – INFORMAÇÃO PREVENÇÃO E INTERVENÇÃO AO HIV/AIDS

MARANHÃO

- GRUPO SOLIDARIEDADE E VIDA
- MOVIMENTO NACIONAL DE MENINOS E MENINAS DE RUA/MA

MATO GROSSO

- AMPARO À VIDA – ASSOCIAÇÃO DO MOVIMENTO DE PESSOAS COM HIV/AIDS
- ASSOCIAÇÃO DE EDUCAÇÃO E ASSISTÊNCIA SOCIAL NOSSA SENHORA DA ASSUNÇÃO – ANSA
- ASSOCIAÇÃO ESTADUAL DE COOPERACAO AGRICOLA – AECA

- CASA DE APOIO AOS AIDÉTICOS – CASA DE SOLIDARIEDADE (FORMER CASA MÃE JOANA)
- CASA DE APOIO AOS PORTADORES DO VÍRUS HIV
- CENTRO DE APOIO À PREVENÇÃO DO HIV/AIDS DE SINOP – CAPAS
- DIOCESE DE RONDONÓPOLIS – PASTORAL DA MULHER MARGINALIZADA – PMM

MATO GROSSO DO SUL

- ASSOCIAÇÃO COMUNITÁRIA DE EDUCAÇÃO E ASSISTÊNCIA SOCIAL DE NOVA ANDRADINA – ACEASNA
- ASSOCIAÇÃO ESTADUAL DE COOPERAÇÃO AGRÍCOLA – AESCA
- ASSOCIAÇÃO DAS TRAVESTIS DE MATO GROSSO DO SUL – ATMS
- DIOCESE DE CORUMBÁ
- FUNDAÇÃO BIÓTICA
- FUNDAÇÃO DE PROTEÇÃO À CRIANÇA E AO ADOLESCENTE
- INSTITUTO BRASILEIRO DE INOVAÇÕES PRÓ – SOCIEDADE SAUDÁVEL DO CENTRO OESTE – IBISS
- MITRA DIOCESANA DE DOURADOS

MINAS GERAIS

- ASSOCIAÇÃO CASA VIVA
- ASSOCIAÇÃO METODISTA DE AÇÃO SOCIAL DE POÇOS DE CALDAS – AMAS-PC
- ASSOCIAÇÃO MISSÃO RESGATE
- CLÍNICA NOSSA SENHORA DA CONCEIÇÃO
- GRUPO DE APOIO À PREVENÇÃO À AIDS – GAPA/MG
- GRUPO DE APOIO À PREVENÇÃO E AOS PORTADORES DE AIDS – GRAPPA
- GRUPO DE APOIO AO SOROPOSITIVO – GASP
- GRUPO SOLIDARIEDADE/MG
- GRUPO DE INTEGRAÇÃO SOCIAL, APOIO AO PORTADOR DE HIV/AIDS E INFORMACOES GERAIS – VHIVER
- MOVIMENTO DO GRAAL NO BRASIL
- MULHER E SAÚDE – MUSA

PARÁ

- ASSOCIAÇÃO DE MORADORES BRASIL NOVO
- CENTRO DE ESTUDOS AVANÇADOS DE PROMOÇÃO SOCIAL E AMBIENTAL (PROJETO SAÚDE E ALEGRIA) – CEAPS

- CENTRO DE PREVENÇÃO TRATAMENTO E RECUPERAÇÃO DE DEPENDENTES (NOVA VIDA)
- FEDERAÇÃO DAS MULHERES DO ESTADO DO PARÁ – FEMEPA
- GRUPO DE APOIO À PREVENÇÃO À AIDS – GAPA/PA
- GRUPO DE APOIO VIDA E LUZ – GAVEL
- GRUPO DE EDUCAÇÃO EM SAÚDE E TRABALHO – GESTOS
- GRUPO DE MULHERES DA ÁREA CENTRAL – GEMPAC
- MOVIMENTO DE MULHERES DO CAMPO E DA CIDADANIA DO ESTADO DO PARÁ
- MOVIMENTO HOMOSSEXUAL DE BELÉM – MHB
- PARAVIDDA – GRUPO PARAVIDDA
- SINDICATO DOS TRABALHADORES DOMÉSTICOS ARRUMADORES E CAMAREIRAS – SINTDAC

PARAÍBA

- AÇÃO SOCIAL ARQUIDIOCESANA – ASA
- AMAZONA – ASSOCIAÇÃO DE PREVENÇÃO À AIDS
- CENTRO ACORDA MULHER
- GRUPO DE APOIO A VIDA – GAV

- REDE NACIONAL DE PESSOAS VIVENDO COM AIDS – NÚCLEO JOÃO PESSOA
- REDE NACIONAL DE PESSOAS VIVENDO COM AIDS – NÚCLEO CAMPINA GRANDE

PARANÁ

- ADE FIDAN – CASA DE VIVÊNCIA “SAARA SANTANA”
- ASSOCIAÇÃO AFRO-BRASILEIRA DE DESENVOLVIMENTO SOCIAL – ABDS
- ASSOCIAÇÃO CULTURAL E BENEFICENTE NOSSA SENHORA DE SIÃO
- ASSOCIAÇÃO DE COOPERAÇÃO AGRÍCOLA E REFORMA AGRÁRIA – ACAP
- ASSOCIAÇÃO LONDRINENSE INTERDISCIPLINAR DE AIDS – ALIA
- ASSOCIAÇÃO SOLIDÁRIOS PELA VIDA – SOVIDA
- CASA DE MARIA – CENTRO DE APOIO A DEPENDENTES
- CENTRO PARANAENSE DA CIDADANIA – CEPAC
- GRUPO AMOR À VIDA – GAV
- GRUPO DE TEATRO THESPIS
- GRUPO DIGNIDADE
- GRUPO ESPERANÇA – CONSTRUINDO CIDADANIA

- GRUPO REVIVER – ASSOCIAÇÃO REVIVER DE ASSISTÊNCIA AO PORTADOR DO VÍRUS HIV
- GRUPO VOZ PELA VIDA
- INSTITUTO DE DEFESA DOS DIREITOS HUMANOS – IDDEAH
- INSTITUTO DE ENSINO PESQUISA E ASSISTÊNCIA MATERNO – INFANTIL – IPAMI
- NÚCLEO DE AÇÃO SOLIDÁRIA À AIDS – NASA

PERNAMBUCO

- ARTICULAÇÕES MOVIMENTO HOMOSSEXUAL DO RECIFE E ÁREA METRO – AMHOR
- ASSOCIAÇÃO DAS RÁDIOS COMUNITÁRIAS E LIVRES DO ESTADO DE PE
- ASSOCIAÇÃO DE AÇÃO SOLIDÁRIA – ASAS
- ASSOCIAÇÃO ESTADUAL DE COOPERACAO AGRÍCOLA DO ESTADO DE PERNAMBUCO – ACAPE
- CAIS DO PARTO – CENTRO ATIVO DE INTEGRAÇÃO DO SER
- CENTRO DE PREVENÇÃO ÀS DEPENDÊNCIAS
- DIACONIA – CASA DE APOIO
- GRUPO DE ASSISTÊNCIA SOCIAL SEMPRE VIVA
- SOS CORPO – GÊNERO E CIDADANIA

PIAUÍ

- COLÔNIA DE PESCADORES DE BARRAS – Z 11

RIO DE JANEIRO

- ASSISTÊNCIA FILANTRÓPICA À AIDS DE ARARUAMA – AFADA
- ASSOCIAÇÃO BRASILEIRA DE GAYS, LÉSBICAS E TRAVESTIS (SEE ARCO-ÍRIS) – ABGLT
- ASSOCIAÇÃO BRASILEIRA DE PÓS-GRADUAÇÃO EM SAÚDE COLETIVA – ABRASCO
- ASSOCIAÇÃO BRASILEIRA INTERDISCIPLINAR DE AIDS – ABIA
- ASSOCIAÇÃO CARIOCA DE REDUÇÃO DE DANOS
- ASSOCIAÇÃO DE GUIAS LOCAL DE PARATY
- ASSOCIAÇÃO DE MULHERES DO MORRO DOS TELÉGRAFOS
- ASSOCIAÇÃO DE PAIS E AMIGOS DOS DEFICIENTES DE AUDIÇÃO/APADA NITERÓI – APADA
- ASSOCIAÇÃO DOS MORADORES E AMIGOS DA VILA MIMOSA – AMOCAVIM
- ASSOCIAÇÃO DOS MORADORES MORRO ESTADO – AMME
- ASSOCIAÇÃO IRMÃOS DA SOLIDARIEDADE

- ASSOCIAÇÃO MORADORES E AMIGOS DO BAIRRO BARCELOS – AMABB
- ASSOCIAÇÃO VIVER
- BANCO DA PROVIDÊNCIA
- CASA DA MULHER TRABALHADORA
- CASA DE INTEGRAÇÃO DA MULHER – CIM
- CENTRO DE ATENÇÃO E ATENDIMENTO À AIDS – CAA-AIDS
- CENTRO DE EDUCAÇÃO SOCIAL – CEDUS
- CENTRO DE ESTUDOS E AÇÃO EM ATENÇÃO À INFÂNCIA E ÀS DROGAS – EXCOLA
- CENTRO DE PROJETOS MULHER – CEMINA
- CENTRO DESENVOLVIMENTO E APOIO A PROGRAMAS DE SAÚDE – CEDAPS
- CENTRO TEATRO OPRIMIDO
- CIDADANIA, ESTUDO, PESQUISA, INFORMAÇÃO E AÇÃO – CEPIA
- CRIAR BRASIL – CENTRO DE IMPRENSA, ASSESSORIA E RÁDIO
- CRIOLA
- CRUZ VERMELHA BRASILEIRA

- DAVIDA – PROSTITUIÇÃO, DIREITOS CIVIS E SAÚDE
- FUNDAÇÃO FÉ E ALEGRIA DO BRASIL
- FUNDAÇÃO MOVIMENTO UNIVERSITÁRIO DE DESENVOLVIMENTO ECONÔMICO SOCIAL – MUDES
- GRUPO ARCO ÍRIS DE CONSCIENTIZAÇÃO HOMOSSEXUAL
- GRUPO CHARLATH'S
- GRUPO DE APOIO À FAMÍLIA CONVIVENDO COM A AIDS – GESTAR
- GRUPO FIO DA ALMA
- GRUPO PELA VIDA/NITERÓI
- GRUPO PELA VIDA/RJ
- GRUPO SOLIDARIEDADE
- ILE ASE D'OGUM BENEFICENTE AFRO – CULTURAL SANTO. ANTÔNIO E NOSSA SENHORA VITÓRIA
- INSTITUTO AÇÃO CULTURAL – IDAC
- INSTITUTO BRASILEIRO INOVAÇÕES EM SAÚDE SOCIAL – IBISS/RJ
- INSTITUTO BRASILEIRO DE SAÚDE E MEIO AMBIENTE – IBRAST

- INSTITUTO DE DESENVOLVIMENTO CULTURAL
THEREZA MARIA DE SOUZA – IDSC
- INSTITUTO FRANCO BASAGLIA
- MOVIMENTO DE APOIO À FAMÍLIA DO PRESO –
MAFAP
- MOVIMENTO DE MULHERES DE SÃO GONÇALO –
MMSG
- MOVIMENTO ORGANIZADO DE GESTÃO
COMUNITÁRIA
- PROGRAMA INTEGRADO DE MARGINALIDADE – PIM
- PROJETO FILIPENSES MANUTENÇÃO DE
RESULTADOS
- REFAZER – GRUPO DE APOIO À CRIANÇA E AO
ADOLESCENTE
- RNP+/REDE NACIONAL DE PESSOAS VIVENDO COM
HIV E AIDS – RIO DE JANEIRO
- SER MULHER – CENTRO DE ESTUDOS E AÇÃO DA
MULHER
- SOCIEDADE CIVIL BEM – ESTAR FAMILIAR NO BRASIL
– BEMFAM
- SOCIEDADE VIVA CAZUZA

RIO GRANDE DO SUL

- ASSOCIAÇÃO DE MULHERES NEGRAS – ACMUA
- CASA FONTE COLOMBO – CENTRO DE PROMOÇÃO DA PESSOA SOROPOSITIVO
- CENTRO DE APOIO A MENINOS E MENINAS DE RUA – CEAMEM
- CENTRO DE EDUCAÇÃO POPULAR – CEPO
- CRUZ VERMELHA BRASILEIRA/RS
- FRENTE DE APOIO E PREVENÇÃO DA AIDS – FAPA
- GRUPO DE APOIO A CRIANÇA SOROPOSITIVO – MAIS CRIANÇA
- GRUPO DE APOIO À PREVENÇÃO À AIDS – GAPA/RIO GRANDE
- GRUPO DE APOIO À PREVENÇÃO À AIDS – GAPA/RS
- GRUPO DE LIVRE ORIENTAÇÃO SEXUAL – GLOS
- GRUPO ESPERANÇA
- GRUPO PELA LIVRE ORIENTAÇÃO SEXUAL – NUANCES
- GRUPO VALE A VIDA
- IGUALDADE – ASSOCIAÇÃO DE TRAVESTIS E TRANSEXUAIS DO RIO GRANDE DO SUL

- MOVIMENTO METROPOLITANO DE REDUÇÃO DE DANOS – MMRD
- NÚCLEO DE ESTUDOS DA PROSTITUIÇÃO – NEP
- PASTORAL DE AUXÍLIO COMUNITÁRIO AO TOXICÔMANO DA DIOCESE DE PELOTAS – PACTO
- REDE COMPROMISSO COM A VIDA – APOIO E SOLIDARIEDADE AO PORTADOR DA AIDS
- SERVIÇO DE ORIENTAÇÃO E SOLIDARIEDADE À AIDS – SOSA
- THEMIS – ASSESSORIA JURÍDICA E ESTUDOS DE GÊNERO
- VHIVA MAIS – GRUPO DE APOIO AO SOROPOSITIVO E PREVENÇÃO À AIDS

RONDÔNIA

- CENTRO DE EDUCAÇÃO E ASSESSORIA POPULAR – CEAP
- FEDERAÇÃO RONDONIENSE DE MULHERES – FEROM

RORAIMA

- REDE NACIONAL DE PESSOAS VIVENDO COM AIDS – RNP+ NÚCLEO BOA VISTA/RR

SANTA CATARINA

- ADEH NOSTRO MUNDO – ASSOCIAÇÃO DE DEFESA DOS DIREITOS HOMOSSEXUAIS
- ASSOCIAÇÃO DOS PROFISSIONAIS DO SEXO VALE DO ITAJAÍ – APROSVI
- ASSOCIAÇÃO ESTADUAL DE COOPERAÇÃO AGRÍCOLA – AESCA/SC
- ASSOCIAÇÃO ESTADUAL DE MULHERES AGRICULTORAS DE SANTA CATARINA
- CASA DE RECUPERAÇÃO PROVIDA
- CENTRO DE ASSESSORIA À ADOLESCÊNCIA – CASA
- FUNDAÇÃO AÇORIANA PARA CONTROLE DA AIDS – FAÇA
- FUNDAÇÃO ESCOLA ACELINO PEREIRA – FEAP
- GRUPO DE APOIO À PREVENÇÃO À AIDS – GAPA/ CHAPECO
- GRUPO DE APOIO À PREVENÇÃO À AIDS – GAPA/ CRICIUMA
- GRUPO DE APOIO À PREVENÇÃO À AIDS – GAPA/SC
- GRUPO DE APOIO À PREVENÇÃO À AIDS – GAPA/ TUBARÃO
- GRUPO EXISTÊNCIA
- INSTITUTO DA JUVENTUDE

- INDÚSTRIA DA SOLIDARIEDADE – ISO
- VIDA EM LIBERDADE – ASSOCIAÇÃO DE MULHERES PROFISSIONAIS

SÃO PAULO

- AIDS – LUTANDO PELA VIDA
- ASSOCIAÇÃO ALIANÇA PELA VIDA – ALIVI
- ASSOCIAÇÃO AMOR EXIGENTE DE FERNANDÓPOLIS
- ASSOCIAÇÃO APOIO A PORTADORES DE AIDS ESPERANÇA E VIDA – AGAEVI
- ASSOCIAÇÃO CIVIL ANIMA
- ASSOCIAÇÃO COMUNITÁRIA MONTE AZUL
- ASSOCIAÇÃO CRIANÇAS DE BELÉM – ACB
- ASSOCIAÇÃO CULTURAL CORRENTE LIBERTADORA
- ASSOCIAÇÃO CULTURAL MIX BRASIL
- ASSOCIAÇÃO DA PARADA DO ORGULHO DE GLB E TRANSGÊNERO
- ASSOCIAÇÃO DE MULHERES DE CAMPINAS
- ASSOCIAÇÃO DE PAIS E AMIGOS DOS EXCEPCIONAIS DE OLÍMPIA – APAE

- ASSOCIAÇÃO DE PROMOÇÃO E INCENTIVO A SAÚDE – APIS
- ASSOCIAÇÃO DE USUÁRIOS, FAMILIARES E TRABALHADORES DE SERVIÇO DE SAÚDE MENTAL
- ASSOCIAÇÃO ECUMÊNICA DOS PORTADORES DE HIV DE AMERICANA – AEPHIVA
- ASSOCIAÇÃO FIQUE VIVO
- ASSOCIAÇÃO FRANÇOIS XAVIER BAGNOUD DO BRASIL
- ASSOCIAÇÃO LIBERDADE COM AMOR E RESPEITO À VIDA – LAR
- ASSOCIAÇÃO NOSSA CASA DE ACOLHIDA
- ASSOCIAÇÃO PARA PREVENÇÃO E TRATAMENTO DA AIDS – APTA
- ASSOCIAÇÃO PAULO VI
- ASSOCIAÇÃO RESPLENDOR CASA DE APOIO AOS PORTADORES DO VÍRUS HIV
- ASSOCIAÇÃO SANTISTA PESQUISA, PREVENÇÃO E EDUCAÇÃO ASPPE
- ASSOCIAÇÃO VIDA POSITIVA
- ASSOCIAÇÃO VOLUNTÁRIOS NO APOIO AOS PORTADORES DE AIDS – AVAIDS

- BARONG – INSTITUTO CULTURAL INTERSERVICE
- CASA CRIANÇA QUERIDA (ASSOCIAÇÃO)
- CENTRO DE CONVIVÊNCIA É DE LEI
- CENTRO DE CONVIVÊNCIA JOANA D'ARC
- CENTRO DE EDUCAÇÃO E ASSESSORIA POPULAR – CEDAP
- CENTRO DE EDUCAÇÃO PARA A SAÚDE – CES
- CENTRO DE INTERVENÇÃO E REABILITAÇÃO DE DEPENDENTES QUÍMICOS – ORION
- CENTRO DE INVESTIGAÇÃO DR. A. CORSINI
- CENTRO ESTUDOS AUGUSTO L. AYROSA GALVÃO
- CENTRO SOCIAL NOSSA SENHORA BOM PARTO (CASA VIDA II)
- CENTRO VOLUNTARIADO RIO CLARO
- CENTRO VERGUEIRO DE ATENÇÃO À MULHER – CEVAM
- CÍRCULO DE AMIGOS DO MENOR PATRULHEIRO DE ITANHAÉM – CAMP
- COLETIVO DE FEMINISTA LÉSBICA DE SÃO PAULO

- COLETIVO FEMINISTA DE SEXUALIDADE E SAÚDE
- COMITÊ CIVIL DE APOIO E PREVENÇÃO À AIDS
- COMUNIDADE SÃO FRANCISCO DE ASSIS
- COORDENAÇÃO REGIONAL DE OBRAS PROMOÇÃO HUMANA
- DROGAS CONSCIENTIZAÇÃO E APOIO – DCA
- ECOS – COMUNICAÇÃO EM SEXUALIDADE
- FALA PRETA
- FEDERAÇÃO DE OBRAS SOCIAIS
- FEDERAÇÃO DOS TRABALHADORES NAS INDÚSTRIAS QUÍMICA E FARMACÊUTICA DO ESTADO DE SÃO PAULO
- FÓRUM DAS ONGS AIDS DO ESTADO DE SÃO PAULO
- GRUPO AMIZADE – CASA DE APOIO A PORTADORES DO HIV/AIDS
- GRUPO CONVIVER E VIVER
- GRUPO DE AMPARO AO DOENTE DE AIDS – GADA
- GRUPO DE APOIO À PREVENÇÃO À AIDS – GAPA/BAIXADA SANTISTA
- GRUPO DE APOIO À PREVENÇÃO À AIDS – GAPA/RIBEIRÃO PRETO

- GRUPO DE APOIO À PREVENÇÃO À AIDS – GAPA/SÃO JOSE DOS CAMPOS
- GRUPO DE APOIO À PREVENÇÃO À AIDS – GAPA/SP
- GRUPO DE APOIO À VIDA – GAVI
- GRUPO DE APOIO E SOLIDARIEDADE AO PACIENTE COM AIDS – GASPA
- GRUPO DE EDUCAÇÃO À PREVENÇÃO À AIDS EM SOROCABA – GEPASO
- GRUPO DE INCENTIVO À VIDA – GIV
- GRUPO DE ORIENTAÇÃO E ASSISTÊNCIA À SAÚDE – GOAS
- GRUPO DE TRABALHO/PESQUISA EM ORIENTAÇÃO SEXUAL – GTPOS
- GRUPO ESTRELAS ASCENDENTES
- GRUPO HIPUPIARA INTEGRAÇÃO E VIDA
- GRUPO PELA VIDA/SP
- IDENTIDADE – GRUPO DE AÇÃO PELA CIDADANIA HOMOSSEXUAL
- INSTITUTO BENEFICENTE VIVA VIDA
- INSTITUTO DE ESTUDOS E PESQUISAS EM AIDS DE SANTOS – IEPAS

- INSTITUTO DIET – DIREITO, INTEGRAÇÃO, EDUCAÇÃO E TERAPIA
- INSTITUTO KAPLAN – CENTRO DE ESTUDOS DA SEXUALIDADE HUMANA
- INSTITUTO NEGRO PADRE BATISTA
- LAR ESCOLA NOSSA SENHORA DO CALVÁRIO
- LAR INFANTIL MARIA MARCONDES
- MISSÃO ATOS
- MOVIMENTO DE APOIO AO PACIENTE COM AIDS – MAPA
- MOVIMENTO ITAPECERICANO DE LUTA CONTRA AIDS – MILCA
- MOVIMENTO VESTINDO A CAMISA – MOVECA
- NÚCLEO DE ESTUDOS E PESQUISAS SOBRE AS SEXUALIDADES
- NÚCLEO DE ESTUDOS PARA A PREVENÇÃO DA AIDS – NEPAIDS
- OBRA SOCIAL NOSSA SENHORA DA GLÓRIA – FAZENDA DA ESPERANÇA
- PROJETO ESPERANÇA DE SÃO MIGUEL PAULISTA
- PROJETO SAMARITANO SÃO FRANCISCO DE ASSIS

- SOCIEDADE AMIGOS DE VILA MARA
- SOCIEDADE DE APOIO ÀS PESSOAS COM AIDS DE BAURU – SAPAB
- SOCIEDADE PADRE. CONSTANZO DALBESIO – CASA SILOE
- SOLAR EUNICE WEAVER
- SOS – AÇÃO MULHER E FAMÍLIA
- TABA – ESPAÇO DE VIVÊNCIA E CONVIVÊNCIA DO ADOLESCENTE
- TODOS UNIDOS MUDAREMOS O MUNDO – TUM
- UNIÃO BRASILEIRA DE MULHERES – UBM
- UNIÃO MUNICIPAL DOS ESTUDANTES SECUNDARISTAS – UMES

SERGIPE

- ASSOCIAÇÃO SERGIPANA DE PROSTITUTAS – ASP
- FEDERAÇÃO DAS MULHERES DE SERGIPE
- GRUPO DE APOIO À PREVENÇÃO À AIDS – GAPA/SE

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