

## Building the foundations for the response to HIV/AIDS in Brazil: the development of HIV/AIDS policy, 1982 – 1996

Richard Parker<sup>1</sup>

<sup>1</sup> Professor and chair, Department of Sociomedical Sciences, Mailman School of Public Health, Columbia University  
Director and President, Brazilian Interdisciplinary AIDS Association (ABIA)  
E-mail: rgp11@columbia.edu

### INTRODUCTION

Over the course of the past two decades, the HIV/AIDS epidemic in Brazil has emerged as one of the most serious public health problems facing the country. By early 2002, as many as 215,810 cases of AIDS had been reported to the Brazilian Ministry of Health (MINISTÉRIO DA SAÚDE, 2002). Equally worrisome, official estimates suggest that as many as 597,000 Brazilians have been infected with HIV, virtually guaranteeing that AIDS will continue to be a major social policy and public health challenge for the foreseeable future (BRASIL, 2002; PARKER, GALVÃO; BESSA, 1999; PARKER, 2000).

While the sheer weight of numbers, in Brazil as elsewhere, may offer some sense of the potential importance of HIV/AIDS, particularly with regard to the public health system, it is clear that the broader social im-

pact of the epidemic extends far beyond what the numbers, in and of themselves, can tell us (JONSEN; STRYKER, 1993). It has by now become apparent, in countries around the world, that the impact of AIDS, the social, cultural, political and economic transformations produced by the epidemic, and, perhaps most important, the diverse responses that have increasingly emerged in the face of it, have taken shape as an especially complex field of analysis – and that a fuller understanding of this field is crucially important if we are to be able to respond more effectively in the future to the dilemmas that AIDS has posed (MISZTAL; MOSS, 1990; KIRP; BAYER, 1992; MANN; TARANTOLA; NETTER, 1992; PARKER, *et al.*, 1994). In Brazil, as in other countries, the study of HIV/AIDS policy, broadly defined to include not only public policies and programs, but the wider range of social and political re-

sponses to the epidemic that have emerged from diverse sectors of society (RAU 1994), has taken shape as a crucially important priority in seeking to build a more coherent and effective response in the future.

This is perhaps particularly true in the case of Brazil, where, over the course of recent years, international attention has increasingly focused on the multidimensional range of HIV and AIDS prevention and control activities developed in Brazil by governmental AIDS programs and non-governmental AIDS-service organizations and other sectors of civil society. Funded both through a series of major loans by the World Bank to the Government of Brazil, as well as by a significant commitment of resources from the Brazilian National Treasury, and supported through a broad-based and apparently far-reaching process of social and political mobilization, what has come to be

described by some as a “Brazilian model” for the response to AIDS has been suggested not only as perhaps the most successful experience yet realized in any developing country, but perhaps anywhere. It has increasingly been identified as a model that other middle and low income countries might seek to emulate or replicate in their own national efforts. While the Brazilian model has thus played a crucially important role in many recent debates (offering hope and optimism concerning the possibility of successful responses to the epidemic in a context otherwise characterized by few success stories), the actual content of this model has often been characterized only superficially, and the extent to which it might actually be transferred to other social, cultural and political settings has never been specified.

The need to more clearly specify the characteristics of the Brazilian response to AIDS, as well as the historical and political conditions which gave rise to it, is thus a key step in being able to more adequately assess the extent to which this model (or at least the lessons learned from the Brazilian experience) might be adapted elsewhere, in relation to other societies facing the impact of the HIV/AIDS epidemic. It is with this broad goal in mind – in order to examine the policy responses to the epidemic that have emerged in different sectors of Brazilian society, and, through such an analysis, to

help provide the basis for increasingly effective responses in the future, in Brazil as well as in other countries – that the current analysis has been developed as part of an ongoing series of studies carried out over a number of years now and reported on in a series of publications (DANIEL; PARKER, 1993; PARKER, *et al.* 1994; 1999; PARKER, 1994; 1997; 2000; PARKER; CAMARGO, 2000).

Particularly because of the attention that has focused in recent years on the unique HIV/AIDS antiretroviral treatment access program, initiated on a broad scale in 1996, and because the effectiveness of the Brazilian response to AIDS has been most widely acknowledged – and the very idea of a “Brazilian Model” for responding to the epidemic has drawn greatest attention – in the years since the implementation of this treatment access program, in this essay I have sought to return to what might be described as “the early history” of the response to HIV and AIDS in Brazilian society. The primary goal has been to examine the foundations of the Brazilian response that has been so widely (and, in my opinion, justly) recognized for its effectiveness and its potential leadership in the international community. In the pages that follow, I will try to analyze the ways in which this response took shape historically, *prior* to 1996 when widespread treatment access was extended to anti-retroviral therapies – as a way of suggesting, first,

that the roots of a successful program were constructed over a long period of time by a wide range of social actors working sometimes together and sometimes in conflict, and second, at the time that the treatment access program was extended in 1996, the successful outcome that has been widely recognized in recent years was by no means guaranteed.

My hope is that the analysis developed here will help to provide a foundation for a more adequate understanding of what has emerged, in recent years, as a truly “integral” (or at least “integrated” [PINHEIRO; MATTOS, 2001]) response to HIV and AIDS in Brazil, involving treatment and prevention as central to a uniquely Brazilian model for responding to the epidemic – a model rooted in the tradition of an “integral” public health system originally championed by the progressive sanitary reform movement of Brazilian public health, and perhaps most fully achieved (not without great difficulties) in the Brazilian response to AIDS.

#### THE SOCIAL, ECONOMIC AND POLITICAL CONTEXT

Before turning to the more detailed discussion of HIV/AIDS and AIDS-related policy, for readers who may not be altogether familiar with the complex reality that is contemporary Brazilian society, it is important to situate these issues within the wider social, cultural, political and econom-

ic context within which the epidemic has taken shape in Brazil. What is most immediately striking is the country's remarkable diversity, together with the specific historical moment in which the AIDS epidemic emerged. Brazil is an immense country, with a territory of more than 8,500,000 square kilometers, and with a population of approximately 165,000,000 according to the most recent census. Traditionally divided analytically into five major "macro-regions" (known as the North, Northeast, Center-West, Southeast, and South), and divided administratively in 27 states and federal districts, the country is marked by a high degree of regional diversity, and by highly varied regional subcultures (BASTIDE, 1978; PAGE, 1995; WAGLEY, 1968). The long-term interaction of European, African and Native American cultural traditions, followed by various waves of migration from diverse points of origin, have produced an especially complex quilt of ethnic and religious diversity (BASTIDE, 1978; PAGE, 1995; WAGLEY, 1968). More recently, the rapidly accelerating processes of modernization, urbanization, and social and economic change taking place throughout the country for decades have taken place quite differently in different regions and among diverse sectors of society. In large part as the result of such complex interactions and processes, Brazil was described some years ago by Roger Bastide as a "land of contrasts"

in which the divisions of class, race, and gender are constantly apparent (BASTIDE, 1978).

The many contradictions that seem to characterize Brazilian life have become even more striking in recent decades as the result of a series of social, economic and political changes that seem to have produced a range of new social and economic divisions which have stretched the fabric of Brazilian life. Rapid urbanization and industrialization transformed what was once largely a rural society, creating the so-called "Brazilian economic miracle" with an average annual growth rate of 8.6% in the early 1970s (SMITH, 1995). Yet the political economy of debt and dependence soon produced a series of severe economic crises, resulting in a deeply-rooted and especially long-term recession by the late 1980s and early 1990s, with a rate of inflation running as high as 45% per month in early 1994. While the introduction of a new monetary and economic plan in 1994 managed to cut the rate of inflation to only 1.5% to 2.5% in mid-1995, and has offered some hope of future growth and prosperity, the long-term consequences of this model of development in Brazil are succinctly summarized by the fact that the richest 10% of the Brazilian population still enjoy 53% of the national income, while the poorest half of the population divides only 10% (SMITH, 1995). In short, in spite of the growth of the

Brazilian economy and the industrial sector, the vast majority of the Brazilian population has nonetheless faced the effects of increasing poverty over the course of the past 15 to 20 years, and the social and public welfare services that would be necessary to meet the needs of the poor have in fact deteriorated as resources have increasingly been directed to servicing the national debt and supporting structural adjustment.

Linked to this economic situation has been the evolution of Brazilian politics over the course of the past three decades. Following a period of instability and uncertainty in the early-1960s, a military takeover of civilian authority in 1964 initiated a period of 20 years of authoritarian rule, under five different military governments, which only finally came to an end in 1984 with a gradual return to democratic rule – first through indirect presidential elections held in 1984 and then finally through direct presidential elections in 1989. This slow, and often painful, process of redemocratization was further complicated by the impeachment of the country's first democratically-elected president on charges of political corruption in 1992, followed by the establishment of an interim government through the end of 1994, when only the second direct presidential election in 30 years was held a new chief executive to a four-year term beginning in 1995.

Taken together, these social, economic and political factors provide a backdrop that is crucially important in seeking to understand both the impact of and the response to the HIV/AIDS epidemic that began to emerge in Brazil in the early 1980s and to spread rapidly over the course of the next decade. The serious deterioration of the public health system, like all social welfare services in Brazil, that had taken place during the authoritarian period from 1964 to 1984, continued to worsen during the extended economic recession that accompanied the return to civilian rule in the late 1980s and early 1990s, limiting the country's capacity to address its many already existing health problems, and conditioning the ways in which it might respond to the emergence of a new socially, culturally, and epidemiologically explosive infectious disease (DANIEL; PARKER, 1991, 1993; PARKER, 1994a; 1994b; WORLD BANK, 1998). In addition to this significant deterioration of the public health system and the decline of social welfare services, the extended period of authoritarian military rule, followed by the frustratingly gradual return to democratic government in the mid to late 1980s, also seems to have undermined the legitimacy of many political institutions, and to have posed a series of political dilemmas that have only gradually been resolved through the process of redemocratization which was ini-

tiated at almost the same historical moment when the HIV/AIDS epidemic began to emerge in Brazil (DANIEL; PARKER, 1993; PARKER, 1994a; 1994b). It provided the political context in which the HIV/AIDS epidemic began to take shape in Brazil, and helped to condition the ways in which the epidemic developed, as well as the ways in which Brazilian society sought to respond to it over the course of its first decade (DANIEL; PARKER, 1993; PARKER, 1994a; 1994b). While the complex problems that this context posed in seeking to address the issues raised by the epidemic are perhaps insignificant when compared with some countries (such as Haiti, the former Zaire, or Rwanda) in which AIDS has taken an especially powerful toll, they nonetheless raised a set of complex dilemmas, particularly when compared with the relatively more stable situations found in at least some of the countries (like the majority of the industrialized democracies) that have faced the impact of the epidemic (DANIEL; PARKER, 1993; PARKER, 1994; 1997; 2001; PARKER *et al.*, 1994; 1999; MISZTAL; MOSS, 1990; KIRP; BAYER, 1992).

#### PUBLIC POLICIES AND PROGRAMS

If the rapid spread of the HIV/AIDS epidemic in Brazil has posed a wide range of challenges for virtually every sector of Brazilian society, nowhere has this been more true than for the public sector, which has been

charged from the beginning of the epidemic with the difficult task of mounting an organized governmental response to a problem that many individuals and institutions would have preferred to ignore. In Brazil, as in almost every other country in the world (MISZTEL; MOSS, 1990; KIRP; BAYER, 1992), this response was slow to emerge – particularly at the level of the federal government, where the Ministry of Health resisted taking any action on AIDS even for a number of years after cases began to be reported in major urban centers such as Rio de Janeiro and São Paulo (TEIXEIRA, 1997; DANIEL; PARKER, 1991; 1993; PARKER, 1994a). In such centers, however, where the greatest concentration of AIDS cases has been found since the beginning of the epidemic, thanks in large part to political pressure on the part of affected communities, action gradually began to be taken at the state and local levels long before the more lethargic bureaucracy in Brasília began to perceive the potential gravity of the situation. Particularly in São Paulo, where activists from a number of gay organizations sought out the State Secretariat of Health (SES-SP) in early 1983, following the first report of a case of AIDS the previous year, a relatively early and for the most part highly progressive public health response to the epidemic began to emerge which would serve, over the long-term, as an important model for similar efforts through-

out the country (TEIXEIRA, 1997; PARKER, 1997; PARKER *et al.*, 1999).

That such a response should have emerged first in the State of São Paulo, long before any action was taken on the federal level, is surely due to a number of factors. Not only were the earliest cases of AIDS heavily concentrated in São Paulo, but it was also at the time the key center for an emerging gay liberation movement in Brazil, and thus one of the few areas with any constituency capable of applying political pressure for action with regard to the emerging epidemic. Perhaps even more important, due to a unique moment in Brazilian political history, at the height of what was known as *abertura* or opening (the term used to describe the gradual return to civilian rule, at the time being orchestrated by the last of five military governments in Brasília), São Paulo was fortunate enough to have a government that was perhaps uniquely willing to listen and respond to pressures coming from civil society. The State of São Paulo had recently elected a progressive opposition leader, Franco Montoro, as Governor – and Montoro, in turn, had appointed progressive political figures in virtually every area of his government, including the State Secretariat of Health, where João Yunes served as Secretary from 1983 to 1987. While the military government continued to rule in Brasília until an indirect presidential election gave power to

a civilian president in 1985, and the federal bureaucracy (including the Ministry of Health) continued to be characterized by a staff trained and placed in power during the height of the authoritarian period, in the State of São Paulo, on the contrary, the spirit of democracy and the forces of opposition to the dictatorship (including the sanitary reform movement in public health that had played a key role in criticizing the military regime) had occupied the most important decision-making positions. While the newly emerging gay liberation movement could hardly be considered a powerful force, whether in São Paulo or anywhere else in the country, it was thus nonetheless fortunate in this case to encounter a political context within the Secretariat of Health in which even if officials might not have been especially sympathetic to the concerns of what was still a highly stigmatized minority group, they nonetheless had little choice, if they were to maintain any kind of ideological consistency, but to respond to the demands being made by representatives of civil society.

It was largely in response to these demands from gay community representatives, then, that a working group on AIDS was formed in mid-1983 within the Division of Hansen's Disease and Sanitary Dermatology at the Institute of Health of the SES-SP, where a program focus on STD treatment was already in the process

of being developed. In its earliest deliberations and documents, this working group, which would later serve as the basis for the State AIDS Program, provided the basic tone that would characterize the best of the governmental response to the epidemic in years to come. Drawing on its previous experience with Hansen's disease, which like AIDS has traditionally been subject to high levels of social stigma and discrimination, the working group placing central emphasis on seeking to develop more effective structures for epidemiological surveillance, on attempting to guarantee adequate medical care and social support, and on working to combat prejudice and discrimination linked to AIDS. It also sought to build a more or less informal coalition between political activists from the gay community, as well as from community groups previously involved in offering support to individuals with Hansen's disease, together with the progressive sectors of the sanitary reform movement, which had come to power in the public health system in São Paulo with the election of the Montoro government in the early 1980s (TEIXEIRA, 1997).

These efforts were hardly without their critics. On the contrary, some sectors of the São Paulo Secretariat of Health itself questioned what they saw as the exaggerated importance being given to a problem of limited proportions that was per-

ceived as affecting only a small minority of the population. Faculty members from the São Paulo School of Hygiene and Public Health sought out Secretary of Health João Yunes, suggesting that concern with AIDS would draw needed resources from more serious and statistically significant health problems such as malnutrition and other infectious diseases. And even representatives of the Ministry of Health in Brasília repeatedly affirmed that AIDS failed to satisfy epidemiological criteria sufficient to determine the need for intervention on the part of the public health system (TEIXEIRA, 1997).

The general lack of concern, and, at times, resistance found among some segments within the public health system itself was present as well on the part of other sectors. In spite of repeated attempts by the State AIDS Program to develop partnerships and collaborative initiatives with other areas, little in the way of progress was made in seeking to involve sectors outside of public health. The State Secretariats of Education and Justice, for example, failed to take any significant initiatives, and attempts to jointly implement AIDS education programs in public schools and to address reports of growing numbers of AIDS cases in the penitentiary system were ultimately frustrated. Indeed, any range of other institutions outside of the public health system that might clearly have been seen to have a stake in

AIDS-related issues largely failed to take any significant action, already signaling a problematic tendency (that would later repeat itself with serious consequences at the federal level) to conceive of the HIV/AIDS epidemic as exclusively a medical or health issue with little broader social relevance (TEIXEIRA, 1997).

At the same time, in spite of the difficulties encountered in seeking to mobilize other sectors of government, the aggressive and innovative São Paulo AIDS Program nonetheless served as an important model for similar Programs in other states in which cases of AIDS had begun to be reported. Throughout the 1980s, for example, representatives of other State Secretariats of Health visited the São Paulo Program and drew on its basic organization, including its localization within Hansen's disease units, in setting up their own programs. By 1985, when the Ministry of Health finally began to move in the direction of creating a National AIDS Program, State AIDS Programs had already been established and were functioning in at least eleven of Brazil's 27 states and federal districts, and a range of important local initiatives had already been implemented through interfacing between these AIDS programs and other sectors of the health system (TEIXEIRA, 1997).

By the mid-1980s, as the number of reported cases of AIDS began to mount and AIDS began to become

an increasing concern in the international community, in light of such mobilization at the level of states and municipalities, it became increasingly difficult for the federal government in Brasília to remain silent. By 1985, following an indirect presidential election largely orchestrated by the outgoing military government, a civilian administration had finally taken office. While this new government, under the command of President José Sarney, could hardly be described as a major break with the past, and maintained many of the individuals as well as the basic policy approaches that had characterized previous regimes, a gradual process of redemocratization had nonetheless been initiated, together with the gradual turnover of staff in federal agencies. While it would never have the outspokenly progressive character of the São Paulo Secretariat of Health, the general climate within the Ministry of Health in Brasília had also begun to change, and a general spirit of reform had become widespread as many of the basic goals of the sanitary reform movement, including the implementation of a Unitary Health System nationwide with a concomitant decentralization of power and decision-making began to be implemented in the mid-1980s. Again, given these changes in the broader context of Brazilian political life in general, and of the politics of health in particular, it is perhaps no surprise that in 1985 the

Ministry of Health would begin to take initial steps in the creation of a National AIDS Program and the formulation of AIDS-related policy at a national level (TEIXEIRA, 1997).

Again, as in the case of the majority of the states that had implemented AIDS programs, the Ministry's Division of Hansen's Disease and Sanitary Dermatology played a key role in bringing together a series of meetings with specialists and program staff from around the country to discuss the structure and format for a National AIDS Program. The Program itself was finally created formally through a Ministerial *Portaria* or "Decree" (#236) on 2 May 1985, and following a further series of meetings with state AIDS Program staff, NGOs and the media, finally began to effectively function beginning in 1986. In April of 1986, a further *Portaria* (#199, issued on 24 April 1986) also constituted a National Advisory Committee, later renamed the National AIDS Commission, and including representatives of other ministries such as the Ministry of Education and the Ministry of Justice, civil society representatives such as the Association of Attorneys, and AIDS-related NGOs such as the Brazilian Interdisciplinary AIDS Association (ABIA), the Gay Group of Bahia (GGB), and the Brazilian Association of Family-Planning Organizations (ABEPF). Again, the formation of this commission was very much in keeping with the spirit

of the times, aimed at stimulating civil society participation, but within specified limits, as the Commission was always designated as an advisory body, appointed by and responsible to the Ministry of Health, whose main function should be to offer technical advice rather than to take responsibility for determining policy or for delineating areas of action (TEIXEIRA, 1997).

In terms of its basic precepts, at least during the Sarney government from 1985 through the end of 1989, the National AIDS Program would in large part adopt the basic conceptual and ideological framework that had already emerged in a variety of State AIDS Programs. In virtually all of its written documents, the National AIDS Program explicitly or implicitly adopted the emphasis on non-discrimination and solidarity that had already emerged at the state and local level. At the same time, while this general principle was clearly present, the major thrust of the Ministry's efforts were clearly more pragmatic than ideological. Central emphasis was placed on improving epidemiological surveillance, widely recognized as inadequate particularly in poorer, less developed states and regions, and a regular epidemiological report initiated in order to track the course of the epidemic. Leading state and local AIDS treatment services, particularly in Rio de Janeiro and São Paulo, were designated as National Reference

Centers, and an aggressive program of training was initiated particularly for staff from smaller or more distant states which were beginning to initiate AIDS Programs. And ongoing efforts were made, only in part successfully, through a series of Ministerial *Portarias* aimed at developing a more effective system for control of the blood supply – though it was only in 1988, after intensive lobbying on the part of NGOs and civil society representatives that the Brazilian Congress would finally pass a law (#7,649, approved on 25 January 1988) mandating HIV testing of blood donations on a national level (TEIXEIRA, 1997).

By 1987, a document titled *Estrutura e Proposta de Intervenção* (Structure and Proposal for Intervention) had been elaborated to assess the work already carried out and to set a five year plan of action for the period of 1988 to 1992 (BRASIL, 1987). This document offered a clear sense of the progressive consolidation and institutionalization of the National AIDS Program, together with its increasingly technical character. It also marked an important change in the relations between the National AIDS Program and the State and Municipal AIDS Programs.

While the previous period had been characterized by the National AIDS Program's adoption of state and local policy initiatives, based on their prior experience, beginning in 1988 the National AIDS Program,

strengthened by technical and financial cooperation on the part of international agencies such as the World Health Organization and the Pan American Health Organization, began to take a much more aggressive leadership role in seeking to define policy norms and programmatic activities that should be implemented throughout the country. Increasingly, State and Municipal AIDS Programs came to serve principally for the execution of program activities designed and coordinated from Brasília. Examples of this new trend were particularly strong in the area of AIDS prevention, with national projects such as the *Projeto Empresas* (Project Businesses), which sought to provide AIDS in the workplace training for the staff of hundreds of business around the country, largely ignoring already existing state and local initiatives along the same lines, or the *Projeto Prevena* (Project Prevent), which sought to develop centralized prevention programs for perceived 'high risk groups' around the country, without any significant consideration for local or regional differences in HIV/AIDS epidemiology or in the social organization of sexual and drug-using behavior (TEIXEIRA, 1997).

While increasing centralization clearly continued to intensify over the course of the next two years, at times creating serious tensions between the National AIDS Program in Brasília and the more experienced

of the State and Municipal AIDS Programs in other parts of the country, in retrospect it is nonetheless apparent that gradual progress was made in developing a wide-ranging policy response to the epidemic. Whatever its limitations, epidemiological surveillance clearly improved throughout the period. National education campaigns were televised on a regular basis, and although they were clearly of varying quality they nonetheless produced a high degree of concern with AIDS on the part of the general population. And a number of important laws were passed guaranteeing people with AIDS the basic benefits provided to patients with other incapacitating or fatal diseases. While non-governmental organizations and AIDS activists were often highly critical of the slow pace and inconsistency of many policy initiatives, gradual progress nonetheless seemed to be being made.

All this would rapidly change, however, in 1990, when a new President, Fernando Collor de Mello, would take office. Collor appointed Alcení Guerra, a conservative politician with a background in medicine, as his Minister of Health. One of Alcení's first acts was to substitute Lair Guerra de Macedo Rodrigues, who had coordinated the National AIDS Program since its inception. In her place, he appointed Eduardo Côrtes, a young researcher from Rio de Janeiro, who had carried out a number of early seroprevalence

studies among a range of different populations vulnerable to HIV infection. In appointing Côrtes, Alcení simultaneously called for a renewed, increasingly aggressive campaign against AIDS, and offered new hope, at least initially, to those who had criticized the excessively technical and centralized Program developed during the Sarney government (PARKER, 1994).

Unfortunately, the initial prospects for a revitalized, more intensive federal program against AIDS were never realized. On the contrary, almost from the very beginning, confusion seemed to reign not only in the National AIDS Program but in the Ministry of Health as a whole. Following the substitution of Lair Guerra, virtually the entire technical staff of the Program resigned in protest. The following period was marked by a series of attacks and counterattacks, in which it was even suggested (though never formally confirmed) that the outgoing staff had sought to sabotage the new appointment, removing key documents and seeking to undermine international relations established during the prior administration. Côrtes, for his part, was thoroughly inexperienced in the politics and bureaucracy of the Ministry of Health, and had no prior experience as an administrator. This lack of experience showed all too quickly, as one after another of the program components developed during the previous adminis-



tration was discontinued. Over the period of more than two years that Côrtes coordinated the National AIDS Program, there was never a meeting of the National AIDS Commission. The epidemiological bulletin that had been published on a regular basis was substituted by a xeroxed notice circulated on an irregular basis. Contacts with international cooperation agencies were suspended. And for more than a year, the public service educational announcements that had been a regular feature of the AIDS program from 1987 to 1990 were suspended altogether.

In one important area, the National AIDS Program during this period clearly did make important headway, adopting a policy of free distribution of specialized medicines for AIDS patients, such as AZT, Ganciclovir, and Pentamidine (TEIXEIRA, 1997). While this decision was originally justified as part of an attempt to stimulate AIDS case reporting, and was based on the assumption that patients and physicians would be more likely to report cases if this brought with it some concrete benefits, it nonetheless had the long-term effect of guaranteeing expensive medications for patients whose economic situations would otherwise make such access impossible (PARKER, 2000; TEIXEIRA, 1997). In spite of the extremely important gains that such a policy clearly brought, particularly for people living with HIV/AIDS, however, its potential political benefits were largely wasted due

to a series of other, far more shortsighted policy decisions.

When the National AIDS Program finally did begin to take up prevention activities again, for example, after a long silence, the results were largely disastrous both educationally as well as politically. In 1991, a highly touted televised prevention campaign, funded through donations from private corporations, was released which was built around the notion of fear (the motto of the campaign was summed up in the phrase, If you don't take care, AIDS will get you), and focusing on the incurability of AIDS as its key element. A heated controversy ensued, pitting AIDS activists and community-based organizations, critical of the campaign, against the staff of the Ministry of Health, which sought to defend itself from accusations of stigma and discrimination by arguing that the interests of the uninfected needed to be placed above the feeling of people living with HIV/AIDS. As this controversy deepened over the course of the following year, whatever legitimacy the new National AIDS Program might have had gradually began to disappear, and the broader social response to the epidemic became increasingly polarized between non-governmental, AIDS-service organizations and representatives of the federal government.

Much the same rapid deterioration of relations also characterized the interaction between the National

AIDS Program and the State and Municipal Programs throughout the country, as well as relations with the scientific and medical communities. While the municipalization of health initiatives generally, and of AIDS program actions specifically, was part of the rhetoric of the Ministry of Health during this period, the process of municipalization was carried out without any concern for existing structures. Municipal AIDS Commissions were created around the country, independent of whether or not Municipal AIDS Programs already existed, but the majority of these new Commissions failed to ever function. The repass of federal funds to states and municipalities, as well as funding for research and development on the part of universities and reference hospitals, which had been an important feature of the centralized actions in the prior administration, was also largely discontinued as resources for AIDS began to disappear when the new National AIDS Program failed to develop a plan of action for submission to international bodies such as the World Health Organization.

Many of these tensions came to a head in 1991, when WHO designated Brazil as a priority country for its HIV/AIDS vaccine development program. Both Eduardo Côrtes and Alcení Guerra publically denounced the WHO's decision, employing a highly nationalistic rhetoric which was almost altogether out of keeping with the normal relations be-

tween the Ministry of Health and the United Nations' system, and claiming that Brazilians would not be used as "guinea pigs" in medical experiments imported from abroad. In the ensuing outcry, the voices of activists and NGOs previously critical of prevention programs were joined by those of respected researchers and leading medical authorities, together with State and Municipal AIDS Program Staff, outraged not only by the potential loss of important financial and technical resources, but by the almost absolute lack of rational justification offered by the Ministry.

By early 1992, however, the specific tensions marking the relationship between the National AIDS Program and virtually every other sector working with AIDS in Brazil had again been largely subsumed or eclipsed by the broader political process—in this case, a widespread crisis linked to accusations of unethical conduct on the part of key sectors of the Collor government, and within the Ministry of Health in particular. Accusations of inflated contracts with under the table kickbacks had been increasing through much of 1991, with both Ministry of Health staff members and Minister Alcení Guerra as key suspects. While accusations were never directly targeted against the National AIDS Program, the general climate of suspicion and accusation clearly contributed to the already deeply-rooted perception of general incompetence and

perhaps even dishonesty (especially with regard to the real causes for breaking relations with WHO on vaccine research) that had grown up around the Program and its key staff members, and led to an almost complete immobilization of programmatic activities in early 1992.

Once again, this broader political process brought with it an important shift in AIDS policy when the Collor administration implemented a ministerial reform in early 1992 aimed at fortifying the ethical basis of the government. In the Ministry of Health, Alcení Guerra was replaced by Adib Jatene, known as the leading heart surgeon in Brazil, and greatly admired for his pragmatic administration not only of the leading center of heart surgery in Brazil, but as a past Secretary of Health in the State of São Paulo. To the surprise of almost no one, one of Jatene's first acts as Minister was to replace Eduardo Côrtes as National AIDS Program Coordinator. Yet it came as a surprise to almost everyone when he named Côrtes' predecessor, Dr. Lair Guerra de Macedo Rodrigues, to once again assume the coordination of the Program (PARKER, 1994).

In spite of a range of difficulties created by the broader context of ongoing charges of corruption leveled against the Collor government, the revitalized National AIDS Program moved quickly to reconstruct much of what had been undermined during the previous two years. New

staff members were recruited from existing State AIDS Programs and leading universities. The National AIDS Commission was recreated through a new Ministerial *Portaria*. Epidemiological surveillance was reinforced, and epidemiological bulletins were again issued on a regular basis. A series of potentially explosive crises, such as the denial of access to education for children infected with HIV, were rapidly addressed – though again, as in the past, through Ministerial Decrees rather than the passage of legislation. International cooperation was taken up again, and Brazil's formal entry into agreement with the WHO for participation in vaccine development and testing was quickly approved. Perhaps most important, in terms of its medium- and long-range consequences, negotiations were initiated with the World Bank, which had expressed interest in the possibility of developing a project loan which would provide support for AIDS prevention and control in Brazil (TEIXEIRA, 1997).

While the background of political unrest continued to create an unstable climate until late in 1992 when the initiation of impeachment proceedings against him led Fernando Collor de Mello to resign and an interim government led by Collor's Vice President, Itamar Franco, was installed, the complex process of negotiation with the World Bank occupied virtually all of the National

AIDS Program's attention. Indeed, the process of negotiation involved a wide range of specialists and institutions, far beyond the staff of the Program itself, in developing a plan that would involve support for State and Municipal AIDS Programs, projects developed by non-governmental organizations, as well as a range of training and research activities. The organization of a proposal in record time (at least in comparison with the time taken to develop and negotiate support for other programs previously developed by the Ministry of Health with support from the World Bank) required intensive action on the part of a team of consultants as well as program staff from every level of government and all parts of the country. It counted on intense support not only from the Minister of Health, but also from the Ministry of the Economy and the General Attorney's office. By the time the negotiations were finalized, in 1993, and officially signed, on 16 March 1994 (with an effective beginning date of 1 June 1994), a profound set of changes in policy and personnel had taken place in the Brazilian government, including the President of the Republic, the Minister of Health and the Minister of the Economy, yet the process of negotiation and accord between the Brazilian government and the World Bank had been carried out almost without incident in spite of such a turbulent political sea, and the Bank had

agreed to provide a US\$160 million loan which, together with US\$90 million provided from the Brazilian Treasury, would comprise a US\$250 million dollar project to be carried out over a three year period.

Understanding all of the reasons for the World Bank Project (BR 3659), ranging from the interest of the Bank to the willingness of the Brazilian government to take on a loan for AIDS prevention, as well as the political strategies that enabled the negotiation to take place successfully in spite of potential problems, is by no means an easy proposition. Clearly, one key factor must have been the interest of the Bank itself. Over a number of years, the World Bank had gradually increased its commitment to AIDS prevention and control through loans to specific countries as well as through increased participation in coordinated United Nations action. While the instability and general lack of competence in the Brazilian National AIDS Program under Minister Alceni Guerra had made the thought of support for Brazil almost impossible, the change in personnel under Minister Adib Jatene provided new openings. A loan to Brazil, like an earlier loan made by the Bank to India, would provide an important test case for the possibility of AIDS control in the developing world when adequate resources are made available – and in a social and demographic context in which HIV/AIDS, if left uncon-

trolled, might surely have explosive consequences. Precisely because of this, in the first instance, it was the Bank itself that made contact with the new National AIDS Program Coordinator in order to initiate discussions about the possibility of a loan.

At the same time, at least at the beginning of the negotiation process, it seems highly unlikely that the Bank imagined making as large a loan as was finally approved in 1994. The size and scope of the final project took on the dimensions that they did in large part due to the determination of the National AIDS Program staff, together with their remarkable capacity to build a political coalition capable of providing pressure from a variety of directions in favor of such a large-scale proposal. Perhaps precisely because of the disaster that had taken place during the prior administration, it was possible for the National AIDS Program staff to mobilize wide-spread support from AIDS activists, non-governmental organizations, and public opinion leaders of various stripes, in favor of large-scale project capable of major impact. This popular support was skillfully transformed into political capital through articulation with political leaders from diverse parties (ranging from the leftist PT and PPS to the more conservative PFL) in the Brazilian Congress, which in turn could be counted on to leverage support internally in the Ministry of Health as well as in the

Ministries of Planning and the Economy. The full details of this articulation among a range of different forces may never be completely clear, as they were carried out on a variety of fronts and no single individual, not even the Program Coordinator, was exclusively responsible. But the end result was that widespread public opinion that HIV/AIDS should be considered an important priority on the part of the Brazilian government, and that a response comparable to the dimensions of the problem should be implemented, was successfully transformed into political pressure adequate to guarantee a significant commitment of national funds, and, consequently, to build upon the good will of the Bank itself in approving what was announced as the largest AIDS control project thus far developed in any developing country.

While different documents have given slightly conflicting pictures of the exact details of the 1<sup>st</sup> World Bank Project, a useful summary of the Project is nonetheless contained in the National AIDS Program's official report for 1994 (BRASIL, 1994b). Of the total project cost of US\$250 million, 41.08% of the funds are earmarked for Prevention, 18.56% for Institutional Development, 6.48% for Epidemiological Surveillance, and 33.84% for Services. More specifically, within the category of Prevention, 36% of the total budget is directed to Counseling, 20.2% to AIDS in the

workplace programs, 16.5% to information, education and communication (IEC) activities, 9% to behavioral interventions, 8.2% to programs for injecting drug users, 6.6% to community-based prevention projects, and 4.5% to condom promotion. Within the broad category of Institutional Development, 43.9% of the funds are destined to support reference laboratories, 22.2% for training programs, 17.7% for blood control activities, 11.7% for supervision, and 4.4% for cost and economic impact analyses. Within the area of Epidemiological Surveillance, 67.4% is destined for STD/AIDS surveillance programs, 16.8% for sentinel surveillance studies, 11.1% for HIV/TB interventions, and 4.8% for mathematical modeling. Finally, within the Services category, 68% of the funds are for STD clinical services, 27.3% for AIDS clinical services, and 4.7% for community services.

While the precise ways in which one cuts and rearranges these different totals may give a certain flexibility to the picture that they paint, what is perhaps most striking is that the overall emphasis, in keeping with the World Bank's own focus, is very heavily on AIDS prevention, as opposed to treatment or care. Even a large part of the budget for Services, for example, is directed to STD treatment services, aimed at reducing an important co-factor known to increase the risk of HIV infection, and hence is in fact ultimately directed

to primary prevention of HIV infection above all else. Throughout the negotiations between the National AIDS Program and the World Bank, this emphasis on primary prevention aimed at reducing new infections, and hence the economic cost of the epidemic, was repeatedly emphasized as crucial to the Bank's goals in AIDS control, and as justifying the Bank's investment in terms of a costs/benefits analysis. Any greater emphasis on care and treatment, on the contrary, was repeatedly rejected by Bank staff, and the Brazilian government's previous decision to provide costly medications such as AZT to AIDS patients was repeatedly criticized as an example of the ineffective (at least in terms of costs) planning on the part of the National AIDS Program (TEIXEIRA, 1997).

Perhaps no less important than the programmatic areas to be supported by the World Bank Project is some sense of the ways in which the total volume of resources may impact upon the National AIDS Program, and the consequences that this may have for the implementation of the project. It is impressive to note the remarkable fluctuation in the AIDS Program's budget over time, for example. In 1989, the last year of the Sarney administration, the NAP counted on a budget of US\$11,870,000. During the Collor administration, the budget fell to US\$2,370,000 in 1990, US\$1,250,000 in 1991, and US\$2,870,000 in 1992. In 1993, prior to the loan from the Bank,

but with negotiations well underway, the Program budget jumped to US\$13,730,000. In 1994, with the signing of the Bank loan, the budget literally leaped to US\$76,134,000. Finally, in 1995, it jumped again, nearly doubling this time to US\$160,000,000. Of the US\$76,134,000 in 1994, US\$29,165,000 came from the World Bank loan. Another US\$44,859,000 came from the National Treasury, and a final US\$2,110,000 came from the federal government's Emergency Social Fund. In 1995, of the total of US\$160,000,000 budget, fully US\$94,500,000 comes from the Bank loan, while the remaining US\$65,500,000 comes from the National Treasury's matching funds (BRASIL, 1994b).

It is almost inevitable that this remarkably rapid growth should create a series of administrative problems. This is particularly true given the fact that an important part of resources provided through the project should in fact be destined for support of State and Municipal AIDS Programs as well as project activities on the part of non-governmental organizations. Indeed, 60% of the funds provided through the World Bank Project should be used at the state and local level through cooperative agreements between State and Municipal AIDS Programs and the Ministry of Health. Execution of the Project thus depends upon a high degree of administrative agility – effectively getting the money out to

a total of 27 states and 42 municipalities, as well as executing and monitoring nearly 200 contracts and agreements with NGOs, as well as National and Regional Reference Centers (BRASIL, 1994a). Yet the rapid increase in the volume of funds passing through the Ministry on their way to other institutions clearly poses the threat, frequently confirmed in the complaints of State and Municipal AIDS Programs and NGOs alike, of a bureaucratic bottleneck and administrative procedures that are unable to accompany the projected volume of resources.

These administrative and bureaucratic bottlenecks, which may easily occur in spite of the best intentions of the National AIDS Program and its staff go a hand in hand with a series of equally important problems which have thus far received little attention. The intensity of activities related to the World Bank Project poses the added risk, for example, that other programmatic actions outside of the context of this project, such as care and treatment for those individuals who are already infected and ill, and who are clearly not considered a priority within the philosophy of the World Bank Project, will suffer seriously from the intensive focus on prevention activities. Beyond this, the heavy influx of resources to the Ministry of Health has tended to reinforce the already existing lack of action on the part of other sectors – providing a

false sense, for example, on the part of other Ministries, that all AIDS-related issues are being resolved by the Ministry of Health, and that action in the areas of education, justice, social welfare and so on is therefore unnecessary. Finally, the continued reliance on relatively weak legal measures, such as Ministerial *Portarias* as opposed to implementation of legislation through the Congress, has failed to resolve what might be described as the fragility of public policy measures in response to AIDS in Brazil – the serious risk that a change in administration might easily undermine the gains made thus far, just as it did from 1990 to 1992 during the Collor administration.

These problems are far from hypothetical. Recent history suggests that the only effective long-term policy options related to AIDS in Brazil have been achieved largely through civil society pressure leading to legislative and judicial action, as in the case of the Henfil Law for control of blood quality which was implemented as part of the 1988 Brazilian Constitution through pressure from NGOs, hemophilia associations and similar civil society organizations. Without similar action, different sectors of the Brazilian government itself often ignore or violate policy directives on the part of the Ministry of Health, as has been the case in the penitentiary system of the Justice Department, which regularly tests and isolates, against Ministry of

Health directives, prisoners with HIV/AIDS. Similar practices have been employed by the Brazilian military, which has used HIV testing to monitor admissions and to mandate dismissal of military personnel, as well as by the Brazilian Congress itself, which until recently including a negative HIV test as a criterion for prospective employees (TEIXEIRA, 1997).

Ultimately, then, there is much that is positive to be said about the public policy response to HIV/AIDS in Brazil. Responding to political pressure on the part of affected communities, many state and local responses in the earliest years of the epidemic certainly compare favorably, both in their basic ideologies as well as in their concrete policy initiatives, with similar responses at the same time in other affected countries. Long before the Ministry of Health, or even international bodies such as WHO or PAHO, had taken significant action, programs such as the State AIDS Program in São Paulo had taken important steps toward providing a significant response to the epidemic. More recently, discounting the relative disaster of AIDS policy during the Collor government, the Brazilian National AIDS Program has moved rapidly to seek to implement a pragmatic and technically competent agenda for action that certainly compares favorably, as well, to similar programs in other developing countries. Unfortunately, these important steps in the right direction

have in large part not been accompanied by a more broad-based, multi-sectoral mobilization in response to AIDS. Given the lack of a National AIDS Commission as anything other than any advisory body linked to the Ministry of Health, and the general tendency to centralize both resources and action within the health sector, the broader dimensions of a public policy response, involving all relevant administrative agencies, together with legislative and judicial branches of government, has largely failed to emerge on any level. On the contrary, different branches of government have more often than not worked in contradiction and sometimes opposition to one another, and the role of political leadership with regard to AIDS has been left in the hands of technical officers from the Ministry of Health rather than political leaders in Brazilian society more generally. While the actions of many non-governmental organizations, religious institutions, and at least some private sector businesses, described below, have made some limited headway in seeking to broaden the basis of this response, a broader social and political mobilization around HIV/AIDS still remained a task for the future. Given recent trends, both nationally and internationally, such as the pauperization of the epidemic and its increasing impact on sectors that have traditionally lacked the resources necessary to mobilize social and

political pressure, the extent to which this broader mobilization would in fact be possible still remained an open question.

#### NON-GOVERNMENTAL AIDS-SERVICE ORGANIZATIONS

Together with the programmatic response developed at various levels of government in Brazil, the responses developed by diverse sectors of civil society are crucial to a fuller understanding of the ways in which Brazilian society as a whole has sought address the complex questions posed by the epidemic. While a range of institutions in civil society have clearly played an important role, such as the religious and business responses described below, perhaps nowhere has the contribution been as intensive and as important as in the case of what have come to be known (perhaps somewhat erroneously) as the AIDS NGOs – the general category that has come to be used in describing a range of cultural and organizational responses to the epidemic on the part of non-governmental AIDS-service organizations (GALVÃO, 1997b; ALTMAN, 1994). As Jane Galvão has pointed out, the category of AIDS NGOs is perhaps somewhat problematic, in part because it tends to subsume the wider range of non-governmental responses to the epidemic under a single-heading, and to implicitly associate them with what is in fact a

more nuanced set of practices and institutional arrangements. It seems to presume a specific community base, as in the English-language notion of community-based organizations, which, if it generally exists in the case of the AIDS NGOs in Brazil, certainly exists in a variety of different forms. At the same time, the category of AIDS NGOs is less specific than the notion of AIDS-service organizations, also used in English, precisely because the range of institutions often described as AIDS NGOs may or may not inevitably have the provision of AIDS-related services as their primary area of action (GALVÃO, 1997a; 2000; 2002).

Equally important, while the AIDS NGOs in Brazil have clearly been profoundly influenced by the evolving AIDS industry (PATTON, 1991), and by the AIDS-service organizations of other countries in particular, they must also be understood within the longer history of non-governmental organizations in Brazil. Once again, the heritage of the authoritarian period is fundamentally important, since the role of civil society, and of non-governmental organizations of diverse types, was clearly circumscribed in a variety of ways during the twenty years of the authoritarian period. With the *abertura* or opening of Brazilian society in the late 1970s and early 1980s, and the return of generation of political exiles, an important stimulus to the formation of non-governmental organiza-

tions working on diverse questions took place in the early 1980s. Independent of their many differences, what seemed to unite the broad range of what came to be known as the NGO movement was a common concern with the redemocratization of Brazilian society. In large part founded and staffed either by former political exiles or by members of the formal opposition to the military regime, the NGO movement as a whole was thus heavily marked, particularly in the early 1980s, by a commitment to opposition politics, and by the conviction that the organization and mobilization of civil society would be fundamental in order to further guarantee the successful return (which at the time seemed by no means guaranteed) to civilian rule under a democratically elected government (GALVÃO, 1997a; 2000; 2002; PARKER, 1994).

This wider context of the growing NGO movement in Brazil, with its otherwise significant differences in large part covered over by its general distrust of government authority and its common commitment to opposition politics, is by no means insignificant in seeking to understand the emergence of the non-governmental response to HIV/AIDS in Brazil. As has already been mentioned in discussing the formation of the earliest governmental responses to the epidemic at the state and local levels, the existence of political pressure, particularly on

the part of organizations linked to the gay rights movement in the early 1980s was fundamentally important in providing stimulus for early program development – particularly in states such as São Paulo, where the opposition to the military regime had been elected to power as part of the first round of redemocratization. At the same time, given the relatively small size and fragile structure of the gay movement in Brazil, the kind of mobilization that took place in the United States, as well as in countries such as Australia, Canada, and many of the countries of Western Europe, was almost impossible in Brazil. In these developed countries, a more well-established, politically experienced gay community was able to re-tool its organizations and much of its energy in order to confront what was perceived as a new threat to the community, and, as such, a fundamental political issue. In Brazil, on the contrary, only a handful of gay organizations existed at the time – indeed, the majority of gay groups would be founded only after the beginning of the AIDS epidemic, and the emerging gay community in Brazil has thus been profoundly shaped by the vicissitudes of the epidemic itself (DANIEL; PARKER, 1991; 1993; PARKER, 1994; 2000).

In spite of the political pressure that they were able to mobilize early on in São Paulo, and the really heroic prevention efforts that they

would lead in years to come, the gay movement in Brazil was thus hardly prepared to take on the full burden of the epidemic, or to offer the kinds of responses that the gay movement in the industrialized countries could offer. On the contrary, it would have to be constantly wary of allowing AIDS, with its immense demands during a period of relatively limited government action, overwhelm the broader agenda focused on political rights that had necessarily given rise to gay liberation. At the same time, the relatively rapid perception that AIDS in Brazil could not be dealt with as an exclusively gay issue, and that the mobilization of Brazilian society more broadly would depend upon breaking the notion of HIV/AIDS as exclusively a gay disease, led many early AIDS activists to focus on the need for a broader organizational response to the epidemic. While many of the early non-governmental organizations that would be formed in response to the epidemic were thus staffed in large part by gay men, and in some cases lesbians as well, they were highly reluctant to identify themselves as gay organizations, preferring, on the contrary, to maintain a certain distance with regard to what were perceived as gay issues, and to align themselves more directly with the broader political mobilization associated with the NGO movement more generally. And in with this broader movement, in developing a novel

approach to the HIV/AIDS epidemic, they would focus heavily on the continuing antagonism between what was perceived as a largely monolithic and unresponsive state, on the one hand, and the organization of civil society in order to pressure the state, on the other (PARKER, 1994; GALVÃO, 1997a; 2000; 2002).

These tendencies are especially apparent in the foundation of organizations such as the Support Group for AIDS Prevention in São Paulo (GAPA-São Paulo) and the Brazilian Interdisciplinary AIDS Association (ABIA) in the mid-1980s. Founded in 1985, nearly a year before the Ministry of Health's National AIDS Program was fully functional, GAPA-São Paulo brought together a number of the original gay activists responsible for pushing the São Paulo State Secretariat of Health to take action on AIDS, along with a range of health professionals, social workers, and similar community activists, most of whom had in one way or another been directly affected by the growing epidemic, either as themselves seropositive, or as the friends or loved ones of people with HIV/AIDS. From the very beginning, then, GAPA-São Paulo directed key energy to the fight for better conditions in relation to care and treatment, as well as for more aggressive campaigns aimed at raising public awareness and developing prevention programs. Staffed almost entirely by volunteers, GAPA-São Paulo developed an

effective relation with the State AIDS Program, at times working together for common objectives (such as the internment of patients otherwise rejected by both private and public hospitals), and at times in opposition when the only course seemed to be to denounce government inactivity (GALVÃO, 1997a; 2000; 2002).

Perhaps even more than GAPA-São Paulo, whose focus was initially more local, ABIA, founded in Rio de Janeiro in 1986, was from the very beginning closely associated with the broader NGO movement and focused on advocacy for more effective government policies at the local, state and federal levels. Originally comprised of a diverse range of professionals and community leaders, ABIA was nonetheless very much the conception of Herbert de Souza, more popularly known as Betinho, a hemophiliac who was himself seropositive, and whose two brothers had early on been stricken with AIDS. A progressive political activist before going into exile in the 1960s, and one of the leading figures in the NGO movement following his return, Betinho had previously founded the Brazilian Institute for Social and Economic Analysis (IBASE), one of the largest and most influential NGOs in the country, and a leading institution in the fight to redemocratize Brazilian society. In founding ABIA to specifically address the question of AIDS, Betinho and his colleagues would consciously reject any direct



role in care or treatment for people with HIV/AIDS, arguing that these functions were nothing more than the obligation of the state, and would focus their attention on criticizing government policy—or lack of it, particularly at the federal level. With unusual access to news media, ABIA thus quickly emerged as perhaps the most vocal and most influential critic of the National AIDS Program during the late 1980s and early 1990s.

With different nuances, much the same range of concerns present in GAPA-São Paulo (with its focus on pressure for local-level services and its role in providing at least some services and medications that the state failed to provide) and in ABIA (with its commitment to advocacy for more effective policy making at every level and its call for more innovative prevention campaigns), would characterize the vast majority of the other AIDS NGOs that began to form in major urban centers around the country over the course of the next five years. By the time that the 1st Brazilian Meeting of NGOs working on AIDS was held in June of 1989, for example, it would count on 30 participants from 14 different organizations. By October of the same year, the 2nd National Meeting of AIDS NGOs would bring together as many as 82 participants from 38 organizations, ranging from GAPA-São Paulo and ABIA to other independent chapters of GAPA from Minas Gerais, Rio de Janeiro, and Ba-

hia, as well as distinct organizations such as the Religious Support Group Against AIDS (ARCA) from the ecumenical Institute of Religious Studies (ISER), gay rights groups and prostitutes' associations.

From roughly 1988 to 1990, this rapid growth in the AIDS NGO movement in Brazil was accompanied by really remarkable successes in terms of its accomplishments. In virtually every major urban center in the country, at least one AIDS NGO emerged and quickly became a key point of reference for information concerning the epidemic. In some locations, particularly where government programs were newer or less well developed, these non-governmental organizations often served as the major source of information about AIDS not only for the lay public, but for more specialized audiences, such as the news media, as well. They played key roles in providing medications for people otherwise unable to afford the price, in developing home care programs and, in some instances, hospices, in developing prevention and education programs, and, perhaps above all, in advocacy work aimed at applying political pressure for better policy making. While official governmental programs had repeatedly been unable to demonstrate adequate control over the blood supply, for example, NGO pressure, led in particular by Betinho and ABIA in close collaboration with associa-

tions of people with hemophilia and other AIDS NGOs, was critically important in bringing about congressional passage of the *Lei Henfil* (named after Betinho's youngest brother, an exceptionally popular political cartoonist who had recently died of AIDS), ensuring that the commercialization of blood supplies would be outlawed in the 1988 Constitution. And throughout the late 1980s and early 1990s, NGOs succeeded quite remarkably in intervening at the level of the media and public opinion to gradually bring about important changes in the existing climate of stigma and discrimination. Far more than governmental programs, though often working in tandem with more progressive programs such as the São Paulo State AIDS Program, NGOs such as the diverse chapters of GAPA, ABIA, and ARCA/ISER were able to draw on the notion of solidarity as a key political concept, and to transform the dominant discourse of prejudice and exclusion of people with HIV/AIDS in favor of a radically different discourse based on solidarity and inclusion (GALVÃO, 1997a; 2000; 2002; DANIEL; PARKER, 1991; 1993; TEIXEIRA, 1997).

In developing this intervention at the level of public opinion, charismatic leadership on the part of individuals such as Paulo Bonfim, from GAPA-São Paulo, and Herbert de Souza, from ABIA, was crucially important, as they were able to occupy significant space in the news media,

and, in a sense, to personalize AIDS – to give the epidemic a human face, not simply as an affliction of anonymous others, but as an epidemic affecting flesh and blood individuals, leaders in civil society, who may not all have been household names, but whose human faces increasingly entered the living rooms of growing numbers of Brazilian families through the nightly news. Particularly important in this sense was the role of Herbert Daniel, a writer and political activist who had begun working with ABIA shortly after its foundation. When Daniel was diagnosed with AIDS in late 1988, he became the key figure in mobilizing the earliest organizations of people living with HIV/AIDS in Brazil, founding the Grupo Pela Vidda-Rio de Janeiro in early 1989, originally as a project of ABIA and later as an independent organization.

Once again, the broader political context was crucially important. Like Betinho, who had been a prominent political exile, as well as Paulo Bonfim, who participated actively as a member of the opposition Workers' Party (PT) and served for a time as a member of the São Paulo city council, Herbert Daniel had returned from exile abroad in the early 1980s, and had played an important role in forming the Brazilian Green Party, running unsuccessfully for elected office as one of the first openly gay candidates in the country shortly before he began working full time on HIV/AIDS.

Very shortly after the foundation of the Grupo Pela Vidda-Rio de Janeiro, with Daniel as its first president, additional chapters of the Grupo Pela Vidda had been formed in other major cities such as São Paulo, Curitiba, and Vitória, and together these organizations had begun to play a central role in focusing attention on AIDS-related stigma and discrimination, and in developing a focus on human and civil rights as central to the fight against AIDS. Legal aid programs established by organizations such as Pela Vidda-Rio de Janeiro and GAPA-São Paulo were especially important in bringing strategic lawsuits to court in defense of the civil rights (related to housing, employee benefits, and so on) of people with HIV/AIDS (GALVÃO, 1997a; 2000; 2002; PARKER, 1994).

Throughout the late 1980s and early 1990s, these advocacy activities quickly established AIDS NGOs as what might be described as the 'moral conscience' of the epidemic. In Brazil, perhaps even more than in most other countries, AIDS NGOs became the most outspoken critics of government policy, particularly in relation to the slow action taken by the federal government, both during the Sarney and, especially, the Collor governments. Indeed, from 1990 to 1992, while Alceni Guerra served as Minister of Health and the National AIDS Program languished and delayed taking action, an almost complete polarization between the fed-

eral government and the AIDS NGO movement grew increasingly antagonistic. NGOs such as GAPA-SP and ABIA that had once participated actively on the National AIDS Commission, now entered into direct and unqualified conflict with the National AIDS Program, charging it in no uncertain terms with the moral equivalent of genocide (SOUZA, 1994), and Herbert Daniel and Eduardo Côrtes (the Coordinator of the National AIDS Program at the time) exchanged diatribes in the press. Again, the broader political climate was clearly important, and it is surely no coincidence that Herbert de Souza was one of the key forces in organizing a national Campaign for Ethics in Politics, which would ultimately push the Brazilian Congress to open impeachment hearings against Fernando Collor. While the politics of AIDS, and of AIDS NGOs, clearly cannot be understood as simply a function of this broader political climate, they also cannot be understood as altogether separate from it, and late 1991, while accusations of corruption against the Collor government were growing in Brasília, surely marks the period of most extreme antagonism between the AIDS NGOs and the National AIDS Program (PARKER, 1994).

This sharply antagonistic relationship began to wane only in mid-1992, when the National AIDS Program was reorganized under the coordination of Lair Guerra de Mace-

do Rodrigues. While the ongoing tensions surrounding the crisis in the Collor government continued to create a problematic backdrop until Collor's eventual resignation in late 1992, the revitalized National AIDS Program acted quickly to renew its contacts with AIDS activists and NGOs. A number of key staff members were recruited who had historically maintained strong links with the activist and NGO communities (including this author, who had co-authored two books with Herbert Daniel, and who briefly served as Chief of the Prevention Unit at the NAP). The National AIDS Commission was recreated, again with NGO membership. NGOs were enlisted as key partners in reverting the decision to not participate in WHO-sponsored vaccine development research, and were enlisted as formal members (though without the right to vote) on the National Vaccine Commission, which was charged with monitoring the vaccine research process. And perhaps most important, NGO participation was enlisted from the very beginning in the elaboration of the World Bank Project, and key NGO representatives were hired as consultants charged with drafting initial proposals for components dealing with support for community-based initiatives, prevention programs, and AIDS in the workplace initiatives (GALVÃO, 1997a; 2002).

Over the course of the next three-year period, the elaboration, approv-

al and implementation of the World Bank Project would profoundly transform not only the nature of the work carried out by the AIDS NGOs, but also the relations between the NGO community and the National AIDS Program. Among the most visible components of the World Bank Project has been the direct financial support provided by the Ministry of Health for NGO projects. While the exact amount destined to NGO support is not entirely clear, as it is drawn from a number of different budget lines within the complex structure of the Project, according to information from National AIDS Program staff, something in the vicinity of US\$12 million was spent on the support of more than 200 NGO projects over the three years of the project (BURGOS FILHO, 1995). Projects of diverse types – ranging from hospices for people with AIDS, to prevention intervention for high risk populations, to AIDS in the workplace programs – could be submitted each time the Ministry sent out a call for funding proposals, and would be evaluated by a technical advisory committee appointed by the Coordinator of the National AIDS Program. On average, projects were normally estimated at a budget of approximately US\$50,000, though the budget limit for any given project (as well as for each different organization) was a total of US\$100,000 per year, to be dispersed through a series of payments depending upon

submission and approval of regular narrative and financial project reports (these financial totals would vary over time, particularly after the devaluation of the Brazilian Real, and the ceiling for both projects and total organizational support available from the Ministry of Health would decline during the later years of the World Bank Project and during the 2<sup>nd</sup> World Bank Project that was initiated in 1998).

In spite of delays in the final approval and signing of the World Bank Project, by using matching funds from the Brazilian Treasury, the Ministry of Health moved ahead rapidly in initiating its funding program for NGO projects in 1993, nearly a year before the agreement with the World Bank had been formally finalized, guaranteeing a relatively high degree of NGO approval for the World Bank Project as a whole. In 1993 alone, the National AIDS Program approved 75 projects, with a total value of US\$4 million dollars, submitted by AIDS NGOs, religious organizations, feminist groups, trade unions, and a range of other civil society organizations (BURGOS FILHO, 1995). Not surprisingly, this heavy influx of funding made available through the federal government stimulated a range of activities that otherwise would in all probability have been impossible. Among other things, it succeeded in attracting NGOs from a range of other areas, such as women's health, which had

gradually become increasingly involved in AIDS-related work, but many of whom developed formal projects for the first time in response to the National AIDS Program's call for proposals. At the same time, funds also became available, in many cases for the first time, to smaller, less experienced or sophisticated organizations who would have had difficulty in raising funds from private donors or international cooperation agencies. And it clearly stimulated a veritable population explosion among the AIDS NGOs, as new organizations were formed in some cases with almost no other function than to compete for funding from the World Bank Project: by 1995, according to some estimates, the ranks of the AIDS NGOs had grown to as many as 400 organizations, many of which surely would not have existed if it were not for the funds provided through the World Bank Project (GALVÃO, 1997a; 2000; 2002).

At the same time, this heavy emphasis on the search for funding and the development of projects also transformed the focus of NGO initiatives in a number of important ways. While earlier action, at least through 1992, had focused heavily on advocacy, and had achieved perhaps its greatest successes through political pressure, the almost exclusive emphasis on the development of project activities from 1993 through 1996 tended to limit energy aimed at more political goals. Indeed, in some in-

stances, it would seem that the traditional rules of patron-client politics in Brazil were sometimes incorporated into the administrative structure of the National AIDS Program and the World Bank Project, with the dispersal of project funds potentially linked to political support, or, at the very least, lack of political opposition, on the part of NGOs receiving funds. Whatever the intentions and the mechanisms, the end result would seem to have been a certain depoliticization of NGO activities, with a new focus on technical competence and financial management taking precedence over the earlier emphasis on political action (GALVÃO, 1997a; 2000; 2002).

While the World Bank Project clearly influenced the evolving NGO response to HIV/AIDS in profound ways, it was of course not the only factor. The dynamic of the epidemic itself was clearly crucial, as AIDS had inevitably claimed many of the AIDS NGO movement's most articulate and charismatic leaders. The increasingly long history of the epidemic may be equally important, as the political mobilization that began to take place early on in the period of redemocratization in Brazil continued for more than a decade, and clearly changed along the way just as Brazil itself changed. The stark antagonism between the State and civil society in the 1980s gave way to far more complex relations between these sectors in the

1990s, and there is no reason that the field of AIDS-related work should be any different. Within the broader world of Brazilian politics, the generation of political exiles arrived in positions of official power, and in AIDS-related work in particular, a new generation of activists who were little more than infants during the worst years of the dictatorship increasingly supplanted the generation of political exiles which formed the first non-governmental organizations working on AIDS.

Just as Brazilian politics more generally have changed profoundly over the course of the early 1990s, necessarily transforming the NGO response to AIDS, the broader contours of what has been described as the AIDS industry were also transformed. When the first AIDS NGOs were formed in Brazil in 1985 and 1986, almost nothing in the way of an international AIDS community existed – there was no Global Programme on AIDS, there were no international networks of AIDS-service organizations or of people with HIV/AIDS, and so on. Indeed, Brazilian organizations such as ABIA and the Grupo Pela Vidda-Rio de Janeiro were themselves key players in the evolution of such international responses in the late 1980s and early 1990s, and the evolution of Brazilian responses took place in relation to these broader changes taking place in the international AIDS industry (GALVÃO, 1997a; 2000; 2002).

Even before the influx of funds from the World Bank, the availability of resources for AIDS-related work, and the possibilities and limits that this imposed on the AIDS NGOs, had also changed in important ways. Before 1987, virtually no funding was available for AIDS from any source. Over the course of the next two to four years, thanks to growing interest on the part of a range of international agencies: in particular, private donors such as The Ford Foundation and The John D. and Catherine T. MacArthur Foundation, religious agencies such as Misericórdia, ICCO or CAFOD, and bilateral development cooperation agencies such as USAID. Yet through the early 1990s, these sources of funding remained profoundly limited – even The Ford Foundation, which was one of the most active funders in the late 1980s and early 1990s, was never able to provide more than US\$200,000 per fiscal year for all of its AIDS-related activities. By 1992, a growing number of donors had begun to become active, including programs and agencies (such as The MacArthur Foundation) whose primary focus was on women's health, but who sought to respond to the changing shape of the AIDS epidemic in Brazil, but even if we could compile complete data on all of the sources of funding available through the end of this year, it would clearly pale in comparison to the US\$4 million approved by the Min-

istry of Health on NGO projects in 1993 (BURGOS FILHO, 1995).

While it remains to be seen what the final long-range consequences of the World Bank projects will be, or how the AIDS NGO movement will respond when these projects come to an end and funding possibilities potentially contract drastically, there is room for a good deal of concern. The civil society response to HIV/AIDS in Brazil, centered above all on the action of the AIDS NGOs, has expanded rapidly over the course of the past decade, suffering many of the growing pains of any rapidly expanding field of work, but there can be no doubt about the importance of what has been accomplished. Precisely because the governmental response to the epidemic has been so completely centered within the public health system, AIDS NGOs have been able to play a key role in addressing not only the inadequacies of different governmental programs, but the almost complete omission of government authorities in areas such as justice, education and social welfare.

In short, it is impossible to imagine the Brazilian response to AIDS without the essential services provided by the NGOs, or without their key role in advocating for new ways to conceive of and respond to the epidemic. Yet, at the same time, in spite of their common goals and language, it has always been difficult for AIDS NGOs to work together effectively, and in spite of repeated attempts,

nothing remotely resembling a national network of AIDS NGOs has ever emerged (GALVÃO, 1997a; 2000; 2002). In the past, many of the most important difficulties in terms of collective or collaborative action have had to do with conflicting personalities on the part of a number of key leaders. Increasingly, it would seem that more recent conflicts have centered around access to resources – a tendency which may have been reduced with the abundant resources provided by the World Bank Project, but which may increase if resources available for AIDS-related work become more scarce. The ability of the AIDS NGO movement to overcome these difficulties, and to survive the roller-coaster ride of the World Bank Project with some kind of more deeply-rooted political project, clearly became one of the key challenges for the future. Particularly if the existing focus of virtually all AIDS-related activities within the area of health is to be overcome, and a more widespread mobilization of Brazilian society is to take place, the role of the AIDS NGOs will surely be crucial – yet it will also require a more conscious and concerted effort to re-evaluate their history and trajectory than has thus far been possible, overcoming, at least temporarily, what Jane Galvão has described as “the dictatorship of projects” in order to respond more effectively to the long-term political dilemmas

posed by the epidemic (GALVÃO, 1997a; 2000; 2002).

### RELIGIOUS RESPONSES

Like the responses of AIDS NGOs, religious institutions played a key role in responding to the HIV/AIDS epidemic in Brazil. Yet the ways in which religious institutions, as well as individuals motivated above all else by their religious commitments, responded to AIDS are nonetheless among the most complex and poorly understood aspects of the broader social and policy response to the epidemic. In Brazil, as elsewhere (JONSEN; STRYKER, 1993), the role of diverse religious orders in shaping the broader social response to AIDS has clearly been profound. Both in the problematization of a range of moral issues that are seen to be associated with HIV transmission, and with the population groups most commonly associated with HIV infection, as well as in their traditional role of providing care and support for the sick, and for those groups and individuals most marginalized in Brazilian society, diverse religious institutions and beliefs have clearly been at the heart of the broader social debate about AIDS, and about the ways in which Brazilian society should respond to the epidemic. Yet precisely because of Brazil's religious diversity, together with the relatively informal structure of many religious groups, documenting and assessing the role of

religious responses to the epidemic in Brazil is an especially arduous and complicated task (GALVÃO, 1997b).

The deeply rooted, yet at the same time highly diverse, religious sentiment that characterizes Brazilian society is well known (BASTIDE, 1978; WAGLEY, 1968). While Brazil is nominally the largest Catholic country in the world, any number of other Judeo-Christian denominations, together with a wide range of syncretic cults known collectively as Afro-Brazilian religious cults, are also present in Brazilian life (BASTIDE, 1978). Indeed, it is not uncommon for individuals to participate in more than one religious denomination, and multiple allegiances to Catholicism and Afro-Brazilian sects such as Umbanda or Candomblé are common for large segments of the population. While there can thus be no doubt that religious institutions and doctrines have played a fundamental role, in Brazil as elsewhere, in shaping the social response to AIDS, precisely because many religious groups (and the Afro-Brazilian religions in particular) fail to function in terms of the more organized hierarchy of the Catholic Church, and consequently often lack clearly stated doctrinal positions, a full sense of the religious response to HIV/AIDS is clearly problematic (GALVÃO, 1997b).

In spite of the widespread religious diversity that has historically characterized Brazilian society, however, it is nonetheless possible to fo-

cus, at least for our present purposes, on the three major religious denominations or tendencies that currently seem to dominate the religious landscape, and that have been perhaps most important in shaping religious responses to the epidemic: the organized Catholic Church, the diverse range of religious sects and trends known collectively in Brazil as the Evangelical movement, and the equally diverse world of the Afro-Brazilian religious cults (GALVÃO, 1997b). Each of these traditions has struggled with the issues raised by AIDS in Brazilian society for more than a decade now, and each has been characterized by a range of sometimes quite contradictory responses to the epidemic. While the initial reactions of all three of these broad-based religious traditions was originally highly negative, dominated by a deeply-felt preoccupation with the kinds of moral issues that the epidemic seemed to raise, in each case a range of more positive responses has also emerged over time, offering at least some hope that religious institutions may increasingly play a more constructive role in responding to the epidemic in the future (GALVÃO, 1997b).

Ironically, given its more organized, hierarchical structure, the responses of the Catholic Church have perhaps been the most contradictory over time. Precisely because of its relative power not only in daily life, but in political affairs and issues of official policy in Brazil, the

role of the Catholic Church has nonetheless been crucial in shaping broader public opinion and, consequently, policy making. Particularly in the earliest years of the epidemic, through the mid-1980s, the role of a number of leading Catholic officials, such as the Bishop of Rio de Janeiro, Dom Eugênio Sales, in emphasizing the immoral character of behaviors associated with HIV infection, such as homosexual relations and heterosexual promiscuity, and in fervently opposing prevention strategies such as the promotion of condom use, clearly played a central, highly problematic role in shaping public discourse with regard to AIDS (GALVÃO, 1997b; DANIEL; PARKER, 1991; MOTT, 1985). By linking AIDS to immorality and, in extreme moments, to divine judgement and the punishment of sin, a number of key figures in the Catholic hierarchy helped to create a climate of prejudice and discrimination that has continued to impede more positive social responses to the epidemic up to the present (GALVÃO, 1997b). And while it is impossible to fully establish a relation of cause and effect, there can be little doubt that one of the most important results of this climate was to retard early efforts aimed at re-conceptualizing AIDS as a question of public health rather than of moral values – initial calls for the development of programs and policies aimed at responding to the epidemic clearly suffered from the wide-

spread stigma associated with AIDS and its perceived victims, who were in large part conceptualized as being at risk precisely because of their own uncontrolled and immoral actions.

While the Brazilian Catholic Church, like the Catholicism in other countries, is characterized by its hierarchical organization and relatively formal, morally conservative doctrines, however, it is nonetheless anything but monolithic. Perhaps even more in Brazil than in many other societies, the Church has traditionally encompassed a wide range of theological, social and political perspectives, as is perhaps most evident in the role played by Brazilian Catholics in the emergence of the Liberation Theology movement within the Church more broadly. While moral conservatism has long been associated with important segments of the Church, a range of more progressive tendencies have also been present, and have tended to organize themselves, even within the National Conference of Brazilian Bishops (CNBB), around the overriding responsibility to minister to the most marginalized segments of Brazilian society. If the Church has thus sought to defend notions of moral good and virtue, it has also sought to defend goals related to social solidarity and fraternity, and progressive segments of the Church have long assumed a central role in serving and defending the poor, the sick and the helpless in what is widely understood

as a profoundly unjust social order (GALVÃO, 1997b).

In light of these more progressive tendencies, it is perhaps no surprise that a second, more generally positive position soon began to emerge, at least in some sectors of the Catholic Church, and to counter the moral conservatism that was so vehemently expressed in the early declarations of more conservative figures (GALVÃO, 1997b). By the late 1980s, particularly in the Archdiocese of São Paulo, led by Dom Paulo Evaristo Arns, this traditional concern with care and support in the face of human suffering had also begun to incorporate questions related to AIDS and people with AIDS into a range of concrete actions, such as the development of hospices and home care programs aimed at providing support for individuals suffering the effects of HIV/AIDS (GALVÃO, 1997b). Even in Rio de Janeiro, where Dom Eugênio Sales had played such a key role in articulating a vision of AIDS as the result of moral inadequacy, the Church moved gradually to establish a range of services aimed above all else at responding to the epidemic, providing key financial support for a medical clinic serving marginalized populations such as female and transgender prostitutes, as well as for the development of a hospice specifically serving indigent people with HIV/AIDS (GALVÃO, 1997b).

By World AIDS Day in 1992, the CNBB had issued a formal statement

outlining the role of the Catholic Church in responding to AIDS, and emphasizing the importance of solidarity and of pastoral work with people infected with HIV as fundamental within the broader samaritan spirit of Christianity (CNBB, 1992). While this emphasis on solidarity, care and support for the sick clearly took precedence over the complex moral issues associated with education and prevention, and the document largely avoided any direct concession to condom promotion or other preventive measures running counter to broader Catholic moral teachings, it nonetheless provided firm support for the development of legislative and educational programs aimed at providing AIDS information to the Brazilian public – and clearly failed to condemn the promotion of condom use with anything even remotely resembling the moral fervor of some of Dom Eugênio Sales' declarations in the mid-1980s. While the general tone of this official document could hardly be read as a call-to-arms for accepted public health strategies (such as condom promotion) aimed at blocking HIV transmission, it nonetheless helped to create a more general climate of conciliation with regard to such approaches, and it is notable that although Church officials consistently expressed discrete concern over official educational programs focusing on condom use, they nonetheless for the most part restrained

themselves from entering into open conflict with public health officials over this issue – a stance that differed markedly from the policies of the Church hierarchy in a number of other Latin American countries. Indeed, less than two years later, in 1994, Dom Evaristo Arns, who had traditionally been one of the most articulate spokespersons for more progressive positions on social issues more generally and whose Archdiocese had been especially active with regard to AIDS, would go so far as to publicly suggest that condom use, in the case of AIDS prevention and hence ultimately in the service of the preservation of life, might better be understood as a “lesser evil” when compared with the potential loss of life that the failure to use condoms might pose to those at risk of HIV infection (GALVÃO, 1997b).

What is perhaps most important to emphasize about the role of the Catholic Church, then, is that, like the Church itself, it has been far from monolithic – marked, on the contrary, by a number of diverse positions, as well as by gradual change over time, as the Church and its hierarchy have sought to more adequately confront the challenges posed by the epidemic. While the earliest responses of Church officials were characterized by an extreme moral conservatism that surely contributed to an initial climate of stigma and discrimination, this initial reaction has gradually given way

to a broadening emphasis on solidarity and support for those most affected by the epidemic. Although the most conservative sectors of the Catholic leadership in Brazil have never been able to fully accept many of the most important public health strategies aimed at AIDS prevention, they have generally adopted a tone that is more conciliatory than confrontational, and have increasingly committed themselves to providing an important range of services for those affected by the epidemic. And more progressive sectors of the Catholic Church increasingly moved beyond this emphasis on solidarity and support to implicitly or explicitly support a range of education and prevention measures which, outside of the context of HIV/AIDS, would surely seem to contradict the most basic tenets of Church doctrine. In general, a tacit truce between Church officials and policy makers responsible for governmental AIDS control programs seemed to emerge over time.

While the Catholic Church has long experienced a complex tension between moral conservatism, on the one hand, and more progressive social and political positions, on the other, that has in many ways shaped the terms of debate with regard to HIV/AIDS, the rapidly growing Evangelical movement in Brazil has perhaps been more consistently conservative, and sometimes even reactionary, in its basic approach to social and political life in Brazil.



Indeed, much of the recent growth of the Evangelical movement, and of groups such as the Pentecostal Church and the Universal Church in particular, can be linked to the widespread perception of social and moral decadence on the part of many poorer Brazilians, who have been especially affected by growing rates of poverty and violence in urban communities. Evangelical conversion has thus built heavily upon a discourse of return to moral virtue in the face of the surrounding moral decay that is seen to characterize contemporary Brazilian life. In light of this broader set of circumstances that help to explain the rise of the Evangelical movement (together with some of the ways in which the Catholic Church, for example, has sought to respond to the loss of important parts of its “flock” (GALVÃO, 1997b), it is hardly surprising that many Evangelical leaders, like some of their Catholic counterparts, have focused on HIV/AIDS as yet another example of the more general moral decay racking Brazilian society, and have thus contributed to a climate of stigma and discrimination in response to the epidemic (GALVÃO, 1997b).

At the same time, precisely because the Evangelical movement is more fragmentary, and lacks the centralized, hierarchical structure of the Catholic Church, the possibilities for channeling this moral conservatism into political action or pressure are clearly quite different than in the case

of Catholicism. The organized response, evidenced for example in the Catholic position paper issued by the CNBB, would be almost impossible to imagine within the Evangelical context. So too, however, are the mechanisms for internal debate between contesting tendencies within the Church, and the possibilities for articulating a more progressive Evangelical position with regard to the epidemic seem to have been more remote. While some Evangelical leaders, such as Caio Fábio in Rio de Janeiro, seemed to largely reject moralizing discourse as an adequate response to AIDS, their possibilities for influencing the movement more broadly appear to have been relatively restricted. Like the more progressive initiatives of the Catholics, sectors of the Evangelical movement thus developed important initiatives aimed at support for people with AIDS, such as hospice care, as well as often groundbreaking services aimed at reaching drug users which were increasingly expanded to address the relation between injecting practices and HIV transmission (GALVÃO, 1997b). Yet such programs have generally been isolated in nature, and have largely failed to integrate a broader policy with regard to AIDS within the Evangelical movement.

On the contrary, to the extent that any broader position seems to have taken shape within the Evangelical movement, it harked back to the climate of moral panic and discrimi-

nation that marked the emergence of AIDS in the mid-1980s. This overriding conservatism, and the consequent insistence on responding to HIV/AIDS above all else as a moral issue, is all the more worrisome precisely because the Evangelical movement has increasingly taken an important role in Brazilian political life. In the absence of a centralized, hierarchical structure, the Evangelical Churches have canalized energy in occupying space in the mass media (at least one important radio station and a major television network have been linked to the Evangelical movement), and to electing politicians linked to the movement (in many cases Evangelical pastors) to government office at the federal, state and local levels. The “*bancada Evangélica*” (or “Evangelical bench”) in the national Congress increasingly became a force to reckon with, joining forces on key voting issues with other conservative groups such as the “*bancada rural*” (the “rural bench”) in order to advance a conservative agenda on social as well as economic issues. The possibilities for enlisting the support of the Evangelical media, together with Evangelical politicians, for short-sighted and ultimately counterproductive measures should not be under-estimated, and was to a certain extent foreshadowed in the early to mid 1990s by debates over drug policy – as well as over the appropriateness and legality of needle ex-

change programs proposed by government health authorities. Particularly given the immediate concerns of the Evangelical leaders, and of their faithful, with the impact of drug use on poor communities, it was perhaps no surprise that politicians linked to the Evangelical movement were among the most outspoken critics of the liberalization of drug laws and the treatment of drug use in public health as opposed to criminal terms.

Like both the Catholic Church and the Evangelical movement, questions related to sickness and health, curing, and community or collective support for the afflicted have traditionally played a key role in the life of the Afro-Brazilian religions (BASTIDE, 1978; WIIK, 1994). Particularly given the importance of Afro-Brazilian cults for the poorer segments of the Brazilian population, which have also increasingly suffered the impact of the epidemic, it should thus come as no surprise that the Afro-Brazilian religious groups, like the Catholic Church and the Evangelical movement, came to play an important role in responding to the epidemic on a variety of fronts (GALVÃO, 1997b; WIIK, 1994). At the same time, it is also important to emphasize that the nature of this Afro-Brazilian religious response contrasted with that of the Catholics and the Evangelicals in a number of important ways, and that these contrasts are themselves a reflection of the important differences

that characterize the Afro-Brazilian religions when compared to Catholicism or Evangelism in Brazil – in particular, the almost complete lack of a formal, centralized, hierarchical structure comparable to that found in the Catholic Church, together with the almost complete absence of any kind of political articulation comparable to that found in the Evangelical movement.

Given these important differences in comparison with Catholicism and Evangelism, it is hardly surprising that the response of the Afro-Brazilian religions has been relatively less orchestrated or organized than as systematic and pragmatic. Like both the Catholic Church and the Evangelical movement, the initial response of many Afro-Brazilian religious leaders was to distance themselves from the stigma associated with HIV/AIDS. The reasons for this are surely multiple, but such an initial response is hardly surprising, particularly given the fact that the Afro-Brazilian religions have themselves often been the object of stigma and discrimination on the part of more organized Judeo-Christian religions. This concern was no doubt accentuated by the fact that a strong association has traditionally been noted between Afro-Brazilian religion and a number of population groups, such as behaviorally homosexual men (FRY, 1982), first identified as being at high risk of HIV infection, and the possible connections between AIDS, homosexuali-

ty and promiscuity might easily be used to further stigmatize Afro-Brazilian religious practitioners (WIIK, 1994). Beyond this, a number of Afro-Brazilian religious practices, such as ritual scarification using sacred knives, were quickly pointed to by worried health authorities as potential causes of HIV infection within the context of Afro-Brazilian religious worship (WIIK, 1994).

In spite of these concerns, many Afro-Brazilian religious cults, and their cult leaders, rather quickly became involved with questions related to HIV/AIDS on an *ad hoc* basis. Given the role of the cults in responding to various afflictions perceived to escape the possibilities of cure on the part of modern Western medicine, it is not at all surprising that they were quickly sought out by individuals suffering from health problems brought on by HIV infection, particularly in the mid-1980s when medical science offered relatively few effective therapeutic options for AIDS treatment. In keeping with relatively widespread practice in Brazil, in which folk medicine is often employed at the same time as scientific medical treatment (as a kind of hedging of bets on the part of patients seeking treatment and cure), the Afro-Brazilian cults have continued to serve, on up to the present day, as an important alternative source of spiritual treatment for individuals suffering from AIDS-related conditions (WIIK, 1994).

In addition to such *ad hoc* responses, increasingly, over time, a range of Afro-Brazilian religious groups have become involved in AIDS prevention and support activities. Afro-Brazilian religious leaders were sought out by AIDS NGOs such as ARCA/ISER and ABIA in developing education and prevention programs aimed at reaching the black community in Brazil through its unique cultural expressions. Even governmental agencies such as the State AIDS Program in São Paulo worked together with Afro-Brazilian groups in seeking to develop innovative AIDS education strategies. And at least some individuals linked to Afro-Brazilian religions have built upon this religious base in developing care and support services such as the Centro de Convivência Infantil Filhos de Oxum, a hospice in the State of São Paulo linked to the Candomblé religion (GALVÃO, 1997b; ZANIQUELLI, 1994). In short, while the response of Afro-Brazilian religions in the face of HIV/AIDS has never assumed the more organized, outspoken and public character found, for better or worse, in the case of the Catholic Church and the Evangelical movement, it has nonetheless grown and diversified over time, offering yet another example of the ways in which the deeply felt religiousness of Brazilian life has provided opportunities for responding to the epidemic in meaningful ways (GALVÃO, 1997b).

Taken together, then, the responses of the Catholic Church, the Evangelical movement, and the Afro-

Brazilian religious tradition provided a number of important initiatives in response to HIV/AIDS that simultaneously shaped and influenced public policy while at the same time developing services that might otherwise be impossible within the context of the Brazilian public health system. Hospices for the ill, home care programs, drug rehabilitation and outreach work, and a growing number of education and prevention programs developed within the framework of the different religious traditions are among the key areas of action that have increasingly emerged throughout the country. Unfortunately, however, with relatively few exceptions (such as the initiatives of the State AIDS Program in São Paulo), there has generally emerged little in the way of an active partnership between public health programs and religious initiatives. Religious leaders have rarely been sought out to participate on AIDS commissions at the federal, state or local levels, and both public health officials and AIDS activists alike have often looked to religious leaders and religious doctrine as more of an impediment than a potential source of support for more effective policies and programs in response to the epidemic.

#### PRIVATE AND STATE-OWNED BUSINESSES

In Brazil, as in other countries, the rapid spread of the HIV/AIDS epi-

demio posed a series of challenges for business and industry. Given the fact that the epidemic affects both men and women most frequently during the most productive period of life, the workplace was almost inevitably one of the first social contexts in which the impact of the epidemic is felt. Equally important, the workplace was also one of the primary sites that was explored as offering an opportunity for HIV/AIDS prevention efforts. And while leaders in business and industry certainly did not possess the moral authority and power of persuasion that characterized many religious leaders, they nonetheless played an important role, alongside politicians, community activists, and other social or religious leaders, in shaping broader policy response to AIDS through the specific attitudes and actions that they adopted in the face of the epidemic (TERTO JÚNIOR, 1997).

The potential importance of AIDS in the workplace, and of the workplace itself as potentially a strategic point for intervention, was apparent early on, even during the very first phase in the development of programmatic activities on the part of the State AIDS Program in the State Secretariat of Health in São Paulo. During the period when this Program was initially being organized, for example, numerous contacts and meetings were organized with representatives of labor unions, employee associations, and business

federations in the State of São Paulo with the goal of developing activities aimed at raising AIDS awareness. Unfortunately, the general climate of stigma and discrimination related to AIDS, and in particular the widespread association of AIDS with male homosexuality, led to a serious resistance on the part of both labor unions and business leaders, who tended to dismiss the epidemic as a serious threat to the Brazilian workforce (TERTO JÚNIOR, 1997).

Given such resistance, particularly through 1985 or 1986, very little really concrete was ever accomplished during this early period of the epidemic, in spite of attempts to initiate a dialogue. Indeed, perhaps predictably, it was really only after 1986, when the impact of the epidemic began to be felt within the workplace, and within the judicial system charged with regulating the relation between employers and employees, that a series of test cases began to emerge and to place the question of AIDS more squarely on the agenda of debate both for businesses and for trade unions. Indeed, virtually all of the earliest examples of businesses or industries in Brazil developing internal programs and policies related to HIV/AIDS seem to have emerged only when the first cases of AIDS began to be reported within the work force. And it was only when conflicts between employers and employees with HIV/AIDS began to emerge within the ju-

dicial system that judicial and consequently legal action began to be taken to respond more adequately to the range of problems posed by HIV infection and AIDS on the part of workers (see TERTO JÚNIOR, 1997).

During this early period, motivated by the appearance of cases of AIDS on the part of workers, the vast majority of attention focused less on prevention strategies than on the rights of workers who became infected or ill, as well as the internal policies that might be developed to provide care and treatment and to respond to stigma and discrimination on the part of co-workers. The earliest recommendations made by the Ministry of Health's National AIDS Program, for example, reproduced internationally accepted guidelines for the treatment of workers with HIV/AIDS, advising against the use of HIV testing as a criterion for employment, and pointing to the importance of confidentiality with regard to diagnosis and notification of AIDS cases within the work force. Yet the relative fragility of such recommendations is clearly attested by numerous, widely publicized cases of HIV testing for prospective employees on the part of well-known companies, as well as by the fact that the federal government continued to test candidates for the Instituto Rio Branco, the school which prepares members of the diplomatic corps. Similarly well-intentioned yet nonetheless problematic actions were taken not

only by the Ministry of Health but also, in conjunction, by the Ministry of Labor, which in August of 1988 issued an interministerial *Portaria*, #3,195, obliging the Internal Commissions for the Prevention of Accidents (CIPAS) of state-owned businesses to include AIDS in their educational campaigns aimed at prevention illness and work-related accidents, yet without elaborating any mechanism to monitor or evaluate the extent to which this policy had been adopted and implemented (TERTO JÚNIOR, 1997).

While governmental recommendations have thus proven problematic in guaranteeing full rights and benefits on the part of employees with HIV/AIDS, legislation dealing with physical disability has been successfully used as the basis for legal suits on the part of employees who have been denied their rights. The 1988 Brazilian Constitution, in Article 7, Clause XXXI "prohibits any discrimination referring to salary and employment criteria for the worker with disability" (TERTO JÚNIOR, 1997), and has been used effectively in cases aimed at setting legal precedent. On the basis of a series of cases brought to court in the late 1980s and early 1990s, in particular by the legal aid services established by a number of AIDS NGOs, it is now widely agreed that HIV positive workers must be receive equality of treatment with regard to other workers,

that their health situation must be treated confidentially and honorably, that they must be maintained on the job and protected from arbitrary dismissal, and that they must have access to health care services and health plans provided by the employer (TERTO JÚNIOR, 1997). Clearly, these basic rights in all probability continue to be violated all too frequently, but a growing body of jurisprudence has made it increasingly likely that workers who are denied these rights will be able to legally challenge the practices of their employers.

While legal protections for workers with HIV/AIDS have increasingly been guaranteed as part of the basic rights of all workers suffering from physical disability of any kind, the effective use of business and industry for the development of prevention programs and AIDS awareness campaigns has unfortunately remained relatively limited. Important initiatives certainly exist, but remain highly preliminary and often inconsistent. At least three types of initiatives have been especially important: initiatives developed by businesses or business associations themselves; initiatives developed by businesses in partnership with AIDS NGOs; and initiatives stimulated by governmental AIDS Programs. Organizations such as SESI (Social Service of Industry), which is part of the National Confederation of Industries, has developed a pioneering program of

training courses, meetings and workshops aimed at passing information on AIDS to its membership. Other leading businesses, ranging from state-owned companies such as the Vale do Rio Doce mining company with mines and industrial plants spread throughout the country, to small, private-owned businesses working on the local level, called upon NGOs such as GAPSA-São Paulo or ABIA to provide technical assistance for the development of AIDS awareness and prevention activities within the context of the workplace. And governmental AIDS Programs at various levels, such as the State AIDS Program in São Paulo and the Ministry of Health's National AIDS Program, developed educational materials for use in the workplace and have sought to develop partnerships with leading businesses.

Yet the vast majority of these attempts have nonetheless been precarious at best, with an inconsistent record of success. While NGOs such as ABIA made AIDS prevention for businesses a priority over a number of years, for example, exchanging AIDS-related technical support and information for financial contributions on the part of companies such as Vale do Rio Doce, the State Bank of Rio de Janeiro, and the Xerox Company of Brazil, this program was eventually forced to close when it became impossible to cover staff salaries necessary for the implementation of the project with the finan-

cial contributions being made by the businesses. Repeatedly, initiatives proposed by the federal government's National AIDS Program failed to materialize either because of lack of industry interest or lack of follow-through on the part of the Ministry, and although fully US\$3.9 million of the funds provided by the first World Bank Project were destined for AIDS in the workplace activities, with a special emphasis and US\$2.25 million for initiatives developed by NGOs, a review of the NGO projects approved by the National AIDS Program under the terms of the World Bank Project listed only a handful of projects with a focus on AIDS in the workplace, each with a limit of US\$100,000 maximum, suggesting that only a small percentage of available funds were actually spent in this area.

In spite of such limited initiatives, however, by the mid 1990s a number of important signs nonetheless existed suggesting that more effective action might be possible in the future. Particularly important, trade unions seemed to be overcoming at least some of their original reticence, and taking a clearer stand on AIDS. In 1992, for example, with important input from a number of AIDS NGOs, CUT, the largest association of labor unions in the country, formed a National Commission on AIDS, and important statements clearly including AIDS as a key union concern were issued by

both the highest leadership. Indeed, a number of the most important NGO projects dealing with AIDS in the workplace and funded by the National AIDS Program were developed by organizations linked to CUT, implying a growing commitment on the part of the labor movement. With input from the USAID-funded AIDSCAP Project in Brazil, the Federation of Industries in the State of São Paulo (FIESP), together with SESI, developed studies and training programs in order to provide support for prevention programs in the workplace. Indeed, according to information in a special August 1995 issue of *Exame* magazine, the 20 largest business in Brazil all had developed programs dealing with AIDS in the workplace, though the situation in medium- and smaller-sized businesses was much harder to assess, which was surely a cause for concern in a country with approximately 3 million businesses in all (TERTO JÚNIOR, 1997).

#### THE HEIGHTENED VULNERABILITY OF BRAZILIAN WOMEN

The increasing impact of the HIV/AIDS epidemic on women has already been mentioned above in the discussion of epidemiological trends as well as in relation to the policy responses of a number of different sectors. Given the rapid increase of HIV infection among women in Brazil, however, by the early 1990s the question of women's vulnerability in

the face of HIV/AIDS, and of how to respond to this heightened vulnerability through prevention programs and health care services, had emerged as one of the key AIDS-related policy issues confronting Brazilian society. While it was clear that there would be no easy answers to this question, and that a response to women's vulnerability (like the vulnerability of many other segments or population groups) would ultimately depend upon the long-term transformation of Brazilian society – and, in particular, of the basic inequality that structures gender power relations – the need to respond to the factors shaping women's heightened vulnerability in the face of HIV infection had emerged as one of the key policy challenges facing the response to AIDS in Brazil.

As has already been suggested above, the rapid spread of HIV infection among women has been one of the most striking features of the epidemiology of HIV/AIDS in Brazil. Perhaps the starkest evidence of the changing shape of the epidemic, and of its increasing impact upon women, can be found in observing the rapid transformation of the male/female ratio in reported cases, from 30:1 in 1985 to 3:1 in 1995 (BARBOSA, 1997; CASTILHO; CHEQUER 1997; PARKER and GALVÃO, 1996). A broad range of factors have been important in shaping this change: as Barbosa has noted for example, by mid-1994, of cases of AIDS reported among wom-

en above the age of fifteen, 36.1% were linked to heterosexual transmission, 28.3% to injecting drug use, and 9.2% to blood transfusion, while 26.4% were listed as unknown or unidentified (BARBOSA, 1997). As Barbosa has emphasized, however, over time heterosexual transmission has rapidly assumed increasing importance, while the relative weight of drug injecting has gradually declined: when isolating cases among women reported in 1993, for example, heterosexual transmission accounted for more than 53% of the notifications (BARBOSA, 1997).

The consequences of this rapid increase in cases of AIDS among women have been striking. By the mid-1990s, AIDS had become the leading cause of death among women between the ages of 20 and 34 in the city of São Paulo (CUT/INST 1994; BARBOSA, 1997), for example, and the leading cause of death among women between the ages of 15 and 49 in the state of São Paulo (BARBOSA, 1997). A number of studies suggested that AIDS diagnoses among women may be made later than among men, both because women may delay longer before seeking treatment for symptoms, and because physicians may be less likely to look for AIDS as the cause of a range of symptoms that are traditionally considered to be linked to other causes among women (BARBOSA, 1997). As a result, the interval between diagnosis and death may be shorter

among women than among men, and the possibility for early intervention in order to take advantage of advances in available treatments and therapies may be less likely. In addition, the increase HIV infection among asymptomatic women had been linked to a steady increase in cases perinatal AIDS, in spite of recent advances in available treatments and technologies (such as administration of AZT, use of cesarean-sections, and so on) that might reduce the likelihood of vertical transmission if the mother's HIV status had been identified (BARBOSA, 1997).

While the reasons for the increase in heterosexual transmission and cases of AIDS among women in Brazil were clearly complex and multiple, the popular assumption that vulnerability to HIV infection among women must somehow be linked to female sexual promiscuity was clearly shown to be incorrect. In a detailed analysis of cases of sexual transmission among women between 1983 and 1992 in the state of São Paulo, for example, Santos found that 35% of the female cases reported male partners who were IV drug users, 9.4% reported male partners with multiple female partners, 7% male partners who were bisexual, 15.4% male partners who were HIV positive, and 17.9% without any specification. Only 14.4% of the cases reported were among women with multiple male partners, while fully 45% of the cases were among women

who reported a stable relationship with a single partner (SANTOS, 1994; BARBOSA, 1997). Another study focused on the city of São Paulo found that between 1991 and 1993 fully 75% of the women who had died of AIDS were housewives (CUT/INST 1994; BARBOSA, 1997), and this same trend has also been confirmed for Rio de Janeiro (MATIDA, 1992; BARBOSA, 1997). In short, all available evidence suggested that the epidemic was spreading most rapidly among women who were most likely to be housewives or domestic servants, who were generally monogamous, and who were most often infected by their regular sexual partner (BARBOSA, 1997; PARKER; GALVÃO, 1996).

This profile of the women most likely to be infected by HIV raised a series of problems that were left largely unaddressed in attempts to develop prevention programs and policies. Perhaps most obviously, it called attention to the profound difficulties that surround the question of sexual negotiation and the use of condoms as key elements in existing strategies for HIV/AIDS prevention. As virtually all recent studies of women and AIDS confirmed, given the structure of existing gender power relations, and the deeply rooted ideology of machismo, the negotiation of sexual practices, of contraceptive use, and perhaps above all of safer sexual practices in the face of AIDS, continues to be especially problematic in heterosexual relations due to

the profound power imbalances that exist between men and women (BARBOSA, 1997; PARKER; GALVÃO, 1996). And the difficulties that characterize such negotiation in all heterosexual interactions are perhaps especially evident in relations between husbands and wives, as the highly relative expectations of both male sexual freedom and female sexual fidelity place a series of constraints on the possibilities for negotiating the use of condoms or other forms of risk reduction (BARBOSA, 1997; PARKER; GALVÃO, 1996).

As Regina Barbosa has emphasized, these difficulties were accentuated further still by the culture of contraceptive use that had taken shape in Brazil over the course of recent decades, in large part through the promotion of family planning programs directed toward women (BARBOSA, 1997). Initially designed to stimulate population control, these programs traditionally sought to avoid contraceptive methods (such as the condom, or other barrier methods) which would be perceived to interfere with the sexual relation or to require negotiation between men and women, in favor of methods (such as oral contraceptives and sterilization) which could be controlled by women without any necessary male participation, and which largely avoided the necessity of any kind of negotiation between sexual partners (BARBOSA, 1997; PARKER; GALVÃO, 1996). The relative success

of these programs led to situation in which contraceptive use became widely accepted throughout the country, but limited to a relatively small range of contraceptive options, with an absolute preference for oral contraceptives and sterilization (BARBOSA, 1995). Indeed, on a national level, among women between the ages of 15 and 54, only 1.8% reported condom use in order to avoid pregnancy (BERQUÓ, 1991).

As Barbosa has highlighted, this existing contraceptive culture, when joined together with the structure of gender power relations in Brazil, has posed a serious barrier to condom promotion as an effective means of HIV/AIDS prevention (BARBOSA, 1997). Women lack both the power and the skills to negotiate effectively with their male partners. And precisely because the use of other contraceptive methods is so widespread, even the subterfuge of proposing the condom as a means of birth control (when the real intention is the prevention of disease transmission) is effectively impossible – in short, when a husband knows that his partner has been using oral contraceptives, or, even more powerfully, has been sterilized and thus cannot become pregnant, her possibilities for proposing condom use are clearly restricted. Given the prevailing structure of both sexual and contraceptive culture in Brazil, the most widely promoted strategies for risk reduction in the face of HIV infec-

tion have thus proven to be profoundly problematic (BARBOSA, 1997).

Given the complex range of social and cultural factors that are responsible for the increased vulnerability to HIV infection on the part of women in Brazil, it should be clear that programs targeted to women must be an urgent priority, and that the development the development of innovative strategies for HIV/AIDS prevention will be essential in order to reduce rapidly rising rates of infection. Yet in spite of the epidemiological trends over the course of the late 1980s and early 1990s, relatively little concrete action was taken on any level to respond to the question of women and AIDS. Early perceptions of AIDS as closely linked to male homosexuality have proven especially difficult to overcome, and continued to exert powerful influence on the thinking not only of the lay public, but on policy-makers and planners, and even some feminist and AIDS activists. With the exception of a number of limited prevention programs directed to female sex workers, virtually no targeted prevention programs directed to women had been developed anywhere in the country until the mid-1990s, and even then, it was only through the action of a number of non-governmental women's health and AIDS service organizations that the first pilot projects began to be developed (BARBOSA, 1997).

By the early 1990s, increasing concern with issues related to wom-

en and AIDS had begun to be expressed by a number of leading AIDS NGOs, such as ABIA and GAPA-São Paulo, as well as by feminist organizations, such as SOS Corpo, CEPIA, and the Coletivo Feminista de Sexualidade e Saúde. In addition, a number of private donors such as The Ford Foundation and The John D. and Catherine T. MacArthur Foundation, principally through their reproductive health and population programs, had begun to make limited funding available for advocacy work and prevention activities targeted to women. It was not until mid-1994, however, that the National AIDS Program held an initial consultation of experts on women's health to discuss the issue of women and AIDS, and it was only in late-1994 that a campaign of public service announcements was developed encouraging sexually active women to negotiate condom use – though without taking account of the power issues involved in sexual negotiation, and, apparently, without having sought out the advice of the women's health community in the development of the campaign (BARBOSA, 1997; REDE NACIONAL FEMINISTA DE SAÚDE E DIREITOS REPRODUTIVOS, 1995). While the federal government made some funding available through the World Bank Project grants to non-governmental organizations for projects targeting prevention efforts to women, this funding remained relatively insignificant within the overall scope



of activities, and no systematic program initiatives had been designed to reach out to women or to meet women's needs have thus far been developed (BARBOSA, 1997).

Perhaps even more worrisome, when considered on a longer-term basis, is the fact that HIV/AIDS programs generally have been developed in a highly vertical fashion, with strong relations between local, state, and the federal AIDS program, but relatively weak horizontal relations to other health programs on any of these governmental levels (BARBOSA, 1997; PARKER; GALVÃO, 1996). While the Integrated Women's Health Program (PAISM) first designed in the 1980s has never been fully implemented anywhere in the country, women's health programs nonetheless did exist throughout Brazil, taking primary responsibility for family planning and other health care needs associated primarily with reproductive health. Yet few efforts seem to have been made to integrate STD and AIDS programs and services, directed primarily to men, with programs and services focusing on women's health (BARBOSA, 1997). On a long-term basis, the complete lack of articulation between women's health and AIDS programs and services, and the failure to even begin to develop an integrated (let alone innovative) strategy for responding to AIDS as a key part of women's reproductive health care, seemed almost guaranteed to assure that lev-

els of both heterosexual and vertical transmission would continue to rise dramatically in Brazil, and that the complex issues associated with women and AIDS would necessarily emerge as one of the key areas of policy debate in the late 1990s.

#### MAIN POLICY ISSUES IN BRAZIL

While they hardly exhaust all of the important policy issues that must surely be confronted in seeking to respond to the HIV/AIDS epidemic, on the basis of this overview of the response to AIDS in a number of key contexts such as public policy, community-based organizations, religious institutions and private and public businesses, it is possible to point to a number of key policy issues that confronted AIDS-related efforts in Brazil by the middle of the 1990s. While the list could clearly be extended almost indefinitely given the wide range of questions raised by the epidemic, for the purposes of the present discussion, it is perhaps useful to focus selectively on what appear to be the most fundamental challenges facing the country in the mid 1990s. With this in mind, at least three interrelated sets of issues are worth further consideration: (1) the future of funding for both prevention and care; (2) ways to effectively increase access to information, condoms, and related prevention services; and (3) the continuing difficulty in guar-

anteeing access to adequate diagnosis, treatment and care.

Perhaps somewhat ironically, particularly given the size of the World Bank Project, the question of how to guarantee adequate funding for both prevention and care was one of the most pressing concerns facing AIDS policy in Brazil. In spite of the funds guaranteed through the World Bank Project, it is important to remember that this project was initially designed for only a three year period of time, and that its scheduled conclusion was fast approaching. There were no guarantees concerning the future, particularly when a range of important problems, such as the failing infrastructure of the public health system as a whole, would necessarily compete for access to resources. Even within the Ministry of Health, many officials believe that infrastructural reinforcement (for example, repair of the physical plants of Brazil's decaying public hospitals) should be a higher priority than single disease programs, whether with funds come through loans from the World Bank or directly from the National Treasury. And as one moved outside of the Ministry of Health into the wider world of funding for social issues in Brazil, competition with regard to allocation of resources would obviously increase.

In short, there were no guarantees that funding from the World Bank would be extended following the end of the 1<sup>st</sup> AIDS Control and

Prevention Project, and no guarantees that even the Ministry of Health would continue to give HIV/AIDS the same level of priority. As was clearly demonstrated from 1990 to 1992, the degree of attention given to AIDS within the federal government depended heavily on the composition of the Ministry of Health at any given moment, and one of the most serious structural difficulties related to AIDS programming in Brazil was the fact that the National AIDS Commission had been conceived as a technical advisory body rather than a political body capable of providing support for the continuity of AIDS programming from one administration to the next.

Even if the World Bank Project were to be extended, as it ultimately was, it was clearly limited in a number of ways that required adequate evaluation. As has already been pointed out above, the vast majority of the funds provided through the World Bank Project were destined for prevention activities, which was clearly the focus of interest from the Bank's point of view at the time. As important as prevention activities are, one could clearly question the wisdom of placing the needs and concerns of people living with HIV/AIDS at the bottom of the list of priorities. And even if it could be convincingly proven that these needs were being met through other program activities and with other resources, the unpleasant fact of the matter is that given

the number of Brazilians already infected with HIV, the costs associated with prevention and care for people with HIV/AIDS in Brazil would almost inevitably skyrocket in the near future. There was, at this point, little sign of any adequate planning to address these needs, nor any sense of how to cover the costs that would be involved. Innovative programs had been developed, both by public hospitals as well as by non-governmental organizations, but nothing on the scale that would clearly be needed in years to come.

Ultimately, then, a whole range of services that had thus far received relatively little attention would clearly need to be addressed. Under the terms of the World Bank Project, important steps have been taken to broaden access to free and anonymous HIV testing services, which was clearly a very important step. What to do for those who tested positive, how to ensure adequate diagnosis of opportunistic infections and guarantee early medical intervention for the vast majority of those who rely on the precarious public health system, how to provide access to clinical services, how to organize both hospital care and home care more effectively and economically... These were all questions that, in the mid 1990s, at least, seemed to have few answers, and, perhaps more worrisome, to have received relatively little attention within the existing priorities of AIDS programming and policy mak-

ing at the federal level. They were the questions that would ultimately have to be addressed in order to confront the long term impact of the epidemic on the public health system.

If education and prevention activities seemed to have received primary attention, particularly in the most recent phase of AIDS programming, marked as it has been by the imprint of the World Bank Project, serious problems nonetheless continued to exist with regard to access to prevention services. Perhaps most notably, in spite of frequent complaints from virtually every sector concerned with AIDS prevention, the Brazilian government continued to charge a high importation tax on condoms as part of protectionist policies aimed at helping the Brazilian rubber industry, and it had not been possible to mobilize political pressure sufficient to guarantee the reduction or extinction of this tax. Even with such a reduction, however, serious logistical problems existed that made regular condom distribution to even the highest risk populations irregular and inconsistent at best (FNUAP, 1995). While the National AIDS Program planned to purchase and distribute 200 million condoms between 1994 and 1997, community-based organizations continued to complain of problems in receiving condom supplies, and often received shipments on the verge of passing the product deadline for distribution (FNUAP, 1995).

Although problems with access to condoms were especially easy to detect, precisely because they were so concrete, access to prevention information more broadly continued to be a concern in spite of all that has been done to encourage access to AIDS prevention information in recent years. While existing studies of knowledge, attitudes and practices were limited in their scope and representativeness, they nonetheless demonstrated high levels of concern about AIDS, but low levels of behavior change. At least in part, the disparity between concern or anxiety and effective preventive behavior was probably the result of sometimes confusing or ambiguous information concerning the possible strategies (including, but not limited to, condom use) that might be adopted in order to reduce the risk of infection. As the epidemic increasingly moved into the poorest, least well educated sectors of Brazilian society, access to information about HIV/AIDS continued to be an important concern that had still not been resolved in spite of the advances that have been made in recent years.

Responding to these diverse questions would by no means be an easy task, particularly because it would ultimately require not only technical expertise but also political will. Brazil had had the great good fortune over the course of the past 15 years to count on the dedication and perseverance of a remarkable number

of highly talented and committed individuals working at every level in the fight against AIDS. At the same time, while much had been accomplished, few legal and/or institutional structures had been put into place to guarantee the long term continuity and the growing efficacy of this cumulative effort. In seeking to respond to the most pressing policy issues currently confronting the AIDS community, ranging from the availability of resources to the guarantee of access to both treatment and prevention services, renewed political commitment and the mobilization of Brazilian society more broadly would clearly be essential.

#### CONCLUSION

In Brazil, as in so many other countries, the HIV/AIDS epidemic is complex and dynamic. It has been characterized by extensive change over time, and by an evolving range of social and policy responses. Any attempt to accurately characterize and assess HIV/AIDS policy in Brazil will necessarily be incomplete – and in all probability even outdated by the time it is completed and published. This is all the more true precisely because no other aspect of the HIV/AIDS epidemic in Brazil has been so little studied and analyzed. Due to the pressing urgency of the epidemic itself, the actions taken to respond to it have rarely been evaluated, either internally, through pro-

gram or project evaluations, or externally, through independent policy analyses. And this is true in spite of a long-standing tradition of critical social and political analysis in Brazil of public policy generally, and of health care policy in particular.

While the current study can hardly be considered definitive, it nonetheless offers at least a number of insights that may be of some use in seeking to advance further studies, and better policy decisions, in the future. Looking back over the history of responses to HIV/AIDS in Brazil, at what has been accomplished as well as what has not, it is clearly impossible to separate the specific issues associated with HIV/AIDS from the broader context of social and political history in Brazil. Reviewing the policy initiatives in almost every area discussed above, for example, the history of AIDS in Brazil would seem to be characterized by a rough, yet nonetheless fairly clear, set of historical periods.

An initial phase of the policy response to HIV/AIDS in Brazil would seem to run from approximately 1982/83, when the first cases of AIDS were reported and initial program mobilization took place in the State of São Paulo, through 1985/86, when the first non-governmental AIDS-service organizations were founded and a National AIDS Program was created. In spite of important early initiatives on the part of the State Secretariat of Health in São Paulo, this phase,

in Brazil as in so many other countries, was characterized by widespread denial on the part of most government officials, particularly at the federal level, together with a wave of moral panic, fear, stigma and discrimination captured most vividly in the declarations of religious leaders such as Dom Eugênio Sales. In the absence of leadership at the national or international levels, responses to the epidemic tended to grow up from the ground, from the representatives of affected communities such as the emerging gay rights movement, and from the commitment of progressive sectors within state and local public health services who could quickly be enlisted as the allies of these communities. Growing community mobilization, culminating most obviously in the formation of GAPA-São Paulo in 1995 and ABIA in 1986, provided important incentives, together with the pressure of a growing number of State and Municipal AIDS Programs, for the development of some kind of response at the national level, culminating in the delayed, but nonetheless fundamentally important, creation gradual implementation of a National AIDS Program in 1985 and 1986.

With the creation of the National AIDS Program, a second major phase of the policy response to AIDS would seem to run from roughly 1986 through 1990, when the leadership of the National AIDS Program would change for the first time. At the gov-

ernmental level, this period would be marked, above all else, by a relatively pragmatic and increasingly technical approach to the epidemic. Building, first, on previous state and local initiatives, in the development of a national plan for AIDS prevention and control, as the implementation of the National AIDS Program proceeded, increasing international cooperation and a growing tendency toward centralization in Brasília would also lead to a gradual increase in tensions between AIDS programs at various levels of government. At the same time, as increasing complex and diverse initiatives began to emerge in different governmental responses to the epidemic, a range of initiatives on the part of civil society began to overcome at least some of the widespread denial that had characterized the previous period. An increasing number of non-governmental organizations were formed throughout the country, such as basically independent chapters of GAPA in virtually all major Brazilian cities, and these organizations played a major role in calling increasing media attention to the epidemic as well as in placing growing pressure on governmental agencies for a more rapid and aggressive response. Gradually, diverse religious orders as well as private and public businesses began to address the growing impact of AIDS at the local level by developing a range of specific initiatives and services aimed

filling the previous vacuum of voluntary and solidary action. Indeed, as organizations of people living with HIV/AIDS began to form in 1989 and 1990, solidarity became the order of the day, and leaders such as Herbert Daniel emerged as key actors not only on the national scene, but internationally as well, in calling for a response to the epidemic based more fundamentally on political commitment than on technocratic expertise.

A third, clearly distinct phase, can be seen to run from 1990 to 1992. If 1990 would open with a certain sense of optimism that changes of leadership in the federal government might lead to more effective policy decisions with regard to AIDS, the experience of the next two year period would in fact demonstrate the fragility of the accomplishments that had been made over the course of the 1980s. Virtually all of the key elements of the National AIDS Program were discontinued for significant periods during the Collor administration, and a growing antagonism between the National AIDS Program and virtually every other sector involved in responding to the epidemic almost completely precluded the possibility of collaboration or cooperation across sectors in seeking to develop more effective AIDS-related policies. While both non-governmental and religious responses to the epidemic continued to grow and prosper, the complete lack of effective dialogue between civil soci-

ety and the federal government, together with the relative lack of cooperation between the National AIDS Program and State and Municipal AIDS Programs, made the difficulties of sustaining a long-term response to the epidemic strikingly clear, calling attention to the urgent need to rethink the bases of effective action against the epidemic not only in technical but also in political terms.

A fourth phase in the history of the policy response to the AIDS epidemic in Brazil would seem to run from 1992, with the re-organization of the National AIDS Program in the Ministry of Health, to roughly 1996. Initially, perhaps in part because of the disastrous performance of the previous administration in the Ministry of Health, and the resulting extreme polarization between the federal government and virtually every other sector concerned with the epidemic, there was a concerted effort on all sides (governmental programs at every level, NGOs, universities, and so on) to work together in seeking to rebuild a national response to the epidemic. This collaborative spirit was clearly reinforced and solidified during the process of elaboration of a proposal for the 1<sup>st</sup> World Bank Project, in which traditional rivalries and territorial disputes were in large part set aside in favor of what was widely believed to be a common good – a spirit of collaboration which was surely re-

inforced by the National AIDS Program's skillful use of national resources, even before the availability of World Bank funds, to support a wide range of NGO activities understood as part of the World Bank Project in spite of the timing. With the formalization of the agreement with the World Bank, however, and the gradual appearance of a growing range of administrative problems related to the implementation of the World Bank Project, the sense of unity and common purpose that seemed to reign during 1993 and 1994 has increasingly been called into question, and growing tensions between State and Municipal AIDS Programs and the centralized coordination of the National AIDS Program have tended to increase. In spite of various declarations of imminent victory in the war on AIDS, it had been impossible to resolve a range of very basic policy issues, such as the importation tax on condoms. And even many of the less politicized NGOs had become increasingly restless as the Ministry of Health failed to open new calls for projects or to renew funding for already approved initiatives. The relative transparency that seemed to characterize the elaboration of the World Bank Project had given way to a general lack of transparency concerning the use of funds and the implementation of initiatives, and as the 1<sup>st</sup> World Bank Project be-

gan to near its conclusion, little clarity seemed to exist concerning the future once the 1<sup>st</sup> Project had come to an end.

Clearly, these four major periods in the history of the policy response to AIDS in Brazil can only be understood within the wider context of Brazilian political life, on the one hand, together with the broader evolution of global responses to the HIV/AIDS epidemic on the other. It is not merely a coincidence that these phases conform, almost exactly, to a set of evolving developments in Brazilian political history more broadly. The initial response to AIDS from 1982/83 to 1985/86 can only be understood fully within the context of the *Abertura* period, with the election of progressive opposition forces, open to dialogue and consciously responsive to the concerns of civil society, at the state level, and the continuity of the military regime, with its fundamentally authoritarian mentality, at the federal level. In much the same way, the shift in federal policy, as well as the growing non-governmental response to the epidemic, from 1985/86 to 1989/90, was very much in keeping with the spirit of the Sarney government and the gradual redemocratization of Brazilian life, characterized by intensive organizing of civil society (and the birth of NGOs in a whole range of areas) together with the frustratingly slow transformation of the federal government's administrative

machinery, which in large part sought to overcome the heritage of the authoritarian period, without losing its power and hegemony, by maintaining an almost absolute control over data and information (even epidemiological statistics) while at the same time developing increasingly sophisticated, and almost always highly centralized, technical initiatives (very much in the spirit of the National AIDS Program). Like the Collor government itself, the period from 1990 to 1992 stands as a kind of time out of time in which the national as a whole, and the AIDS community quite specifically, seemed to be living a collective nightmare that would hopefully soon come to an end. The reestablishment of a new government following the resignation of Collor, and with the complete maintenance of democratic institutions, clearly signaled new phase in the redemocratization of Brazilian society, a growing sense of maturity and a new willingness on the part of both civil society and the state to work together in solving the social and economic problems facing the nation – and once again, the recent history of AIDS programs and policies in Brazil clearly reflected these broader trends and tendencies.

At the same time that the response to AIDS was thus been shaped by the particularities of Brazilian politics and history, however, it was surely also influenced by a wider range of forces that are often more

international than national in their nature and origin. Although it may be an historical accident, it is nonetheless not insignificant, for example, that the first decade of the HIV/AIDS epidemic in Brazil took place not only during the period of redemocratization of Brazilian society, but during a period of intense change in the relations between developed and developing countries due to the international debt crisis of the 1980s. It was during this time that the International Monetary Fund (IMF) together with the World Bank, imposed a series of conditions on debtor nations such as Brazil (whose debt of \$112.5 billion in 1990 was the highest of any country in the world), aimed at structural readjustment of the Brazilian economy through policies which would stimulate exports while at the same time curbing government spending on a range of social issues, including health care and preventive education. From 1980 through 1991, for example, Brazil received seven major structural adjustment loans from the IMF and the World Bank (LURIE; HINTZEN; LOWE, 1995), and the Brazilian economy underwent a period of spiraling inflation and instability that not only limited the possibilities of investments in social areas such as health, but simultaneously created what might be described as a psychology of instability that seriously affected debate and action on all social issues. While there may

be no direct or immediate cause and effect relationship between this broader economic context and the specific policy decisions related to HIV/AIDS, it is nonetheless impossible to understand the social context of the epidemic in Brazil (as in other developing countries (LURIE; HINTZEN; LOWE, 1995) during this period without taking this backdrop into account, as it clearly conditioned AIDS-related policy, ranging from the availability of funding for AIDS programs on to the more general decay of the public health system which would seriously limit the possibilities for adequate care and treatment for patients. In much the same way, it is perhaps impossible to understand the recent commitment of World Bank resources to HIV/AIDS programs, in Brazil and elsewhere, without taking into account the Bank's own internal criticism of the social impact of structural adjustment, and its conscious decision to act in a range of social areas, such as health, that have suffered from the negative consequences of many structural adjustment programs.

Finally, in addition to these broader social and economic trends in the late-20<sup>th</sup> century, which, like the particularities of Brazilian politics, surely shaped the ways in which AIDS-related policy has evolved in Brazil, it is also important to situate the Brazilian response to AIDS within the broader context of the evolution of global responses to the

epidemic. In Brazil, as elsewhere, the earliest response to AIDS emerged in large part at the local level, and pressure from the bottom up was of fundamental importance in seeking to mobilize change at higher levels of society and government. When such change began to take place, not only nationally with the formation of the National AIDS Program, but also internationally with the establishment of AIDS units in agencies such as the WHO and PAHO, the ways in which different sectors responded to such development was simultaneously shaped and influenced by a series of international developments. It would be impossible to imagine the evolving response of the Brazilian Catholic Church, for example, without taking into account declarations on AIDS from the Vatican, or the increasingly radical opposition of some AIDS activists without thinking about the impact of Act Up in the United States. The fact that organizations of people with HIV/AIDS began to form in 1989 and 1990 is hardly isolated from similar international events. Particularly with regard to an epidemic that has been described as fundamentally post-modern, possible only in the era of globalization, of international media networks, fax machines and electronic mail, the ways in which Brazilian society has responded to HIV/AIDS must clearly be interpreted within this broader context of political forces and cultural influences.

As the Brazilian response to AIDS entered its second decade in 1996 (roughly ten years after the formation of the first non-governmental organizations and the founding of a National AIDS Program), both its important successes and the great obstacles that it would need to overcome seemed strikingly clear. Yet it would have been hard to predict the remarkable changes that were about to take place as 1996 would play itself out as a fundamental transition period inaugurating a new phase in the Brazilian response to AIDS thereafter. By mid-1996, the echoes of the 10<sup>th</sup> International Conference on AIDS in Vancouver, Canada, would begin to be felt, and the possibility of providing, for the first time, effective treatment capable of transforming HIV infection into a manageable, potentially chronic, disease would begin to be seriously considered. The struggle to make HIV/AIDS treatment and care an integrated part of a broader strategy to control the epidemic was by no means initiated in the wake of the Vancouver AIDS Conference – on the contrary, the most fundamental argument of this text is precisely the fact that the foundations for such an integrated approach were laid long before 1996, in the struggles of activists, researchers and policy-makers seeking to confront the epidemic over the course of the 1980s and the 1990s. But with the technological developments first clearly signaled in

Vancouver, together with the perhaps even more important foundation laid by the responses described here, the possibility of transforming the response to AIDS in Brazil into a model that other countries might emulate would become a reality. To be continued...

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# Universal access to AIDS medicines: the Brazilian experience<sup>1</sup>

Paulo Roberto Teixeira<sup>2</sup>

<sup>1</sup> Article based on an interview by the author with Cristina Câmara, special advisor in charge of the Civil Society Liaison and Human Rights Unit, and Flávio Guilherme de Souza Pontes, advisor to the Communications Division, both of the Brazilian National Commission on STD/AIDS

<sup>2</sup> Coordinator of the Brazilian National STD/AIDS Program  
E-mail: pteixeira@aids.gov.br

## INTRODUCTION

This article focuses on the Brazilian policy for distribution of medicines to persons living with HIV/AIDS. It attempts to present readers with the social scenario in which this policy has been developed and implemented, and describes the history of how the epidemic has been dealt with in Brazil.

Some historical references are mentioned in order to provide a better understanding of the principles underlying the Brazilian policy, which primarily result from the inevitable association between public health and human rights in the AIDS pandemic. Among such references are the Brazilian public health movement, the creation of the Unified National Health System (SUS) under the country's 1988 Constitution, and links between the government and civil society organizations (CSO) in Brazil.

An analysis of the international scenario provides an idea of the role

and repercussions of the Brazilian STD/AIDS Program. The article describes the sequence of events beginning with the 13th International AIDS Conference in 2000 in Durban, South Africa, through the approval by the World Trade Organization (WTO) of a separate Ministerial Declaration on the TRIPS Agreement (Trade-Related Aspects of Intellectual Property Rights) and Public Health in order to help readers grasp the importance of social and political mobilization in this process, culminating with the victory by developing countries at the 4<sup>th</sup> WTO Ministerial Conference in Doha, Qatar, in relation to increased flexibility in the TRIPS agreement.

## UNIVERSAL ACCESS TO AIDS MEDICINES: THE BRAZILIAN EXPERIENCE

Before focusing on the core issue, I believe that some references will help situate readers. I began my public service career in the Public

Dermatology Division of the São Paulo State Health Department. At the time there were two lines of work in the institution: the first priority was Hansen's disease, and the second was sexually transmissible diseases (STD). Having worked in the field of STD in the State of São Paulo since 1978, I was designated to organize the first program to respond to AIDS in Brazil. At the time there was already a strong public health movement in both São Paulo and Brazil as a whole from the political and philosophical point of view, as a class organization issue for health professionals. The movement, consisting of public health professionals, developed a critique of the health policy practiced by the military government and conducted discussions that led to the creation of the Unified National Health System (SUS) and the approval of Constitutional provisions to guarantee universal social protection, unification of pub-

lic health services, and participation by civil society.

The public health movement was present in 1983 when the AIDS program was organized in São Paulo, and under the first democratic Administration elected in the State, Governor Franco Montoro and the State Health Secretary responded quickly and effectively to demands by the community. This is an important reference for understanding why there was such an early and (for the time) such a broad response to AIDS. From the beginning, the São Paulo AIDS Program was organized with all the components still existent today, including prevention, epidemiological surveillance, treatment, and human rights, in addition to a strong component of linkage with CSO, which at the time focused primarily on the rights of homosexuals.

The São Paulo Program soon spilled over to other States of Brazil. The largest States began setting up their own programs to fight HIV as soon as they detected their first cases. Meanwhile, the National Program in the Ministry of Health took four years to effectively get off the ground. The first initiatives at the national level began in the second half of 1985, when there were already programs organized in 13 States. For all practical purposes the National STD/AIDS Program was not organized in the Ministry of Health until 1986. Thus, even at the governmental level, the Brazilian re-

sponse to the AIDS epidemic emerged from the bottom up and in a decentralized way, although social-political dynamics generated fluctuations in this trend over time.

Another important reference for the creation and success of the Brazilian STD/AIDS Program was the fact that the Dermatology Division of the São Paulo State Health Department already included a strong community mobilization component and the struggle for the rights of people with Hansen's disease and against the stigma and discrimination associated with it. In terms of discrimination and stigma, one can easily draw parallels between Hansen's disease and AIDS. Therefore it was significant that the State Dermatology Division already had a multidisciplinary team emphasizing community involvement and the struggle for the rights of affected individuals. The longstanding experience with Hansen's disease both supported and provided the initial structure needed to set up the AIDS Program. At the time there was a strong link between AIDS and homosexuality, which also proved problematic. If there had not been a team in place to deal with issues pertaining to rights, stigma, and minorities as a government commitment and responsibility, it might have been much more difficult to create an AIDS Program with the above-mentioned characteristics. Taking on work with AIDS required a team-level discussion and resulted

in an absolutely conscientious decision to tackle the problem. At that stage the staff professionals were not required to work specifically with AIDS, because there were alternatives. Several public universities proposed to become reference centers on behalf of the State Health Department.

In relation to medicines for AIDS, in 1989 the State of São Paulo began purchasing and distributing AZT, the first anti-retroviral drug distributed by the public health care system in Brazil. The first purchase covered only a small portion of the demand in the State: no more than 7% of the patients that needed the drug. However, although this initial supply was limited, it was a deliberate initiative as part of a strategy to create a need, to generate demands, and to spark involvement by society on the issue of anti-retroviral treatment in Brazil. The first free distribution was in the city of São Paulo, followed shortly by Santos (in the same State), which also began purchasing AZT. The Mayor of Santos at the time was from the Workers' Party (PT).

These initiatives helped mobilize public opinion and the community, and in 1990 the Ministry of Health decided to begin purchasing all the AIDS drugs available on the market, including anti-retroviral drugs and medicines for opportunistic diseases. In São Paulo, where AZT was already partially available, the decision by the Ministry of Health allowed for universal distribution. What does

universal distribution mean? Any citizen, even individuals in treatment covered by private health plans or health care outsourced by the government, had the right to receive publicly distributed AIDS medicines. This policy contradicted the Ministry of Health guidelines, according to which the medicines were only supposed to be distributed to individuals enrolled in public treatment centers. In other areas of the country, adoption of the Ministry of Health guidelines resulted in undesirable practices like resale of medicines by patients themselves. As mentioned, there were institutions that required patients to be enrolled in specified public health care services, which in turn lacked the capacity to meet the entire demand. Patients needed the medication but could only get appointments six to eight months later. As a result, those 'at the head of the line' and who happened to be poorer began to sell their places in line to others who could pay. It was not until 1993 that a full-scale nation-wide distribution policy was adopted, as already existed in the State of São Paulo.

Before triple therapy was proposed in 1996, AZT, ddC, and ddI were the only drugs available from the anti-retroviral group. Faced with the limited action of these drugs, in reality the greatest concern was over the purchase and regular distribution of medicines for opportunistic diseases,

including acyclovir, pentamidine, amphotericin, and ganciclovir among numerous other drugs.

The adoption of triple therapy led to major changes in the debate on access to AIDS drugs. The efficacy of triple therapy was quickly proven, and the demand increased, sparking greater pressure by the community for access to the publicized benefits. Meanwhile, others were questioning the high cost of treatment for people living with HIV/AIDS. Budget spending on medicines, an issue that was already problematic, took on a larger dimension and the Ministry of Health was somewhat hesitant to maintain the distribution policy, adding new drugs. Thus, the Ministry of Health did not begin distributing 'combo' therapy until 1996-97, whereas São Paulo had already begun in 1995. As a result, the drop in AIDS mortality was first observed in the State of São Paulo, where the first CD4-count network in Brazil had also been set up. Although triple therapy was announced at the 11th International AIDS Conference in 1996 in Vancouver, Canada, since 1995 there was already an absolute consensus that monotherapy should no longer be prescribed, but should be replaced by combination therapy, which required purchasing protease inhibitors.

The Brazilian response to the AIDS epidemic has the following determinants: the demand, broad media cov-

erage, commitment by health professionals, and mobilization by CSO. In general one can say that this struggle has been the result of integrated actions by health professionals and the community within a favorable public opinion scenario. The country is now entering a new era. When the work began in São Paulo, the first social movement was headed by gay rights organizations, but other partners soon emerged, including associations of people with hemophilia and thalassemias. These groups participated because of difficulties in controlling the quality of blood transfusions in the country (70% of hemophiliacs in Brazil were HIV-infected). It was the struggle against the AIDS epidemic that actually led to quality control in the blood supply. After decades of a fruitless struggle against lack of control in Brazil's blood banks, based on AIDS the government gained the legitimacy and a popular mandate for radical intervention. In 1987, in the States of São Paulo and Rio de Janeiro, blood banks frequently had to be inspected with police backup, such was the lack of control and absence of government authority in the blood bank industry.

Everything happened at break-neck speed. The Group to Support AIDS Prevention (GAPA) was set up in São Paulo in 1984 and officially founded in 1985.<sup>1</sup> The basis for this

<sup>1</sup> GAPA was the first CSO created in Brazil in response to the AIDS epidemic.

organization was the community group circulating around the events held by the São Paulo State AIDS Program. In a sense there was a convergence of various existing opportunities, which included issues such as social justice, democracy, human rights, the right to health, community participation, transparency, etc.

Before the advent of triple therapy the reality of people treated in the health services was truly dramatic. There was a terrible lack of beds, outpatient services, professional health care staff, etc. Patients put enormous pressure on health care services, and the scenario was frequently tragic, with clinics and corridors of emergency wards full of patients on gurneys. From 1996 to 1997 there was an increase of some 30% in the number of people with AIDS who turned to health services because of the announcement of free anti-retroviral therapy. However, at the same time it was much less problematic than expected because at the same time these same individuals were no longer occupying the hospital beds and day hospitals, due to the better overall health conditions obtained through the new treatment regimen. If it had not been for combination anti-retroviral therapy, the 30% increase in caseload would have caused a total breakdown in the health care system, beyond any hope of management.

## ACTIVISM AND SOCIAL CONTROL

There have been undeniable advances in dealing with the AIDS epidemic, with activism as one of the key determinants. Furthermore, activism will continue to be a determinant in the future response, because the HIV/AIDS epidemic will continue to exist for many decades. Any slip-up may be fatal, from the point of view of both epidemiology and treatment, and to avoid this hazard the role of activists is absolutely crucial, including the maintenance of rigorous epidemiological surveillance, adequate preventive measures, guaranteed access to quality treatment, and human rights, all of which should be part of a continuous process of improvement on the gains already made.

The Brazilian community movement has matured, specialized, and improved. It is now capable of following and participating in all the initiatives and strategies ranging from research work on vaccines to behavioral interventions, a phenomenon that is infrequent in other countries. It obviously has both the political and technical capacity to accompany and invest in the various areas and analyze all the possibilities.

This competence expanded, consolidated, and grew within the overall response to the epidemic. The community movement in Brazil now has huge strategic potential. The movement is focused on anticipat-

ing and analyzing the next 10 to 15 years, while community movements in most developing countries are still struggling for AZT for HIV-positive pregnant women in order to reduce vertical transmission. These characteristics of the Brazilian community movement help lead to increasingly strategic, long-term, sustainable, and well-structured activities.

## THE INTERNATIONAL SCENARIO

The milestone that consolidated the Brazilian position in relation to the AIDS epidemic was without a doubt the 13th International AIDS Conference in Durban, South Africa, in July 2000. Since the Brazilian policy of universal access to AIDS drugs was adopted, it has resisted recommendations to the contrary by UN agencies, the World Bank, bilateral cooperative agencies, and other more backward political forces, both domestic and international. Even before triple therapy, Brazil had already achieved extremely important results in the control of tuberculosis and other opportunistic diseases, with a resulting improvement in the quality of life of people living with HIV/AIDS in the country. Such advances have not been experienced by other countries and have gradually become more and more visible in Brazil. This process was consolidated in Durban, where the Brazilian policy received recognition in the international scenario. At the confer-

ence, Brazil presented its policy as an issue of rights for all, all over the world, and demonstrated that other developing countries can also adopt such a policy. Brazil offered its technical support for this purpose, even for local production of AIDS drugs, in a deliberate attitude of entering this international scenario.

Although the results obtained from the policy of universal access to anti-retroviral drugs had already been outlined since the emergence of triple therapy, it was at this time – at the Durban conference – that there was a consolidation and better understanding of the Brazilian policy. This recognition, even on the part of some UN agencies, and the undeniable support of international public opinion were essential for strengthening Brazilian policy and determining the extent of Brazil's participation during the subsequent months in the international scenario.

The 2<sup>nd</sup> Forum on Horizontal Technical Cooperation in Latin America and the Caribbean, held in Rio de Janeiro in November 2000 and known as Forum 2000, where countries from Latin America and the Caribbean met to outline and discuss common strategies in the struggle against the AIDS epidemic, expanded the international focus on the Brazilian experience and attracted attention from the international media, further bolstering the positive results of the Brazilian experience and the efficacy of the tech-

nology developed by Brazil to deal with the epidemic.

Local production of generics, the possibility of breaking patents, and the offer of technology transfer became instruments for price negotiations with other countries and the pharmaceutical industry, leading to a real reduction in prices on the Brazilian and international markets. Since then the world has identified alternatives to the historical passivity of developing countries in negotiations with the pharmaceutical industry, proving that such negotiations can be conducted favorably, based on political mobilization. There was a turnaround in the discourse on lack of access. Brazil demonstrated low-cost local production, competence in the utilization of complex therapies, and alternative routes to lower-cost access.

Other countries soon discovered that the notion of insurmountable incompetence associated with underdevelopment was outdated. They began to trust in their own capabilities, in their own strength. This was a most important change.

There is no basis to the warning by some laboratories that the Brazilian position could lead to a reduction in investments for research and development of new drugs. The pharmaceutical industry will continue to be highly lucrative. What should happen is the necessary adjustment of profit margins, especially in the case of poor and developing countries. Profits may even increase,

because the market will expand. Considering that the industries' substantial profit occurs in the primary market, that is, where this discussion is not taking place, it makes no sense that profits would be reduced or that there would be no new investments. At any rate, this debate should serve as a warning for governments and society to begin to think of alternative forms of public investment in drug research and development, currently in the hands of private enterprise.

The Brazilian experience has shown tremendous influence in the recent international scenario marked by the United Nations General Assembly Special Session on HIV/AIDS (UNGASS), the WTO Ministerial Declaration on the TRIPS Agreement and Public Health, and the debate on drug patents. The results obtained in Brazil, particularly with anti-retroviral therapy, had a direct impact on the global discussion and behavior.

In late 2001, WTO member countries meeting in Qatar passed a declaration proposed by Brazil and India stating that the TRIPS agreement could not override issues of public health. The declaration considered the right to health as a fundamental reference for interpreting TRIPS, thus avoiding possible retaliations against measures taken by individual countries to protect their public health. According to the declaration approved by the 142 participating countries, it was up to each

country to set rules for granting compulsory licensing and, whenever necessary, criteria for characterizing a national public health emergency.

Yet this was not the only victory. Over the course of 2001, countries led by Brazil which had essentially been defending public health issues had succeeded in including and approving, by the UN Human Rights Commission, the definition of access to medicines as a human rights issue. The resolution was passed in April 2001 with 52 votes in favor and only one abstention, the United States. Less than a month after the victory in the Commission, the World Health Organization (WHO) unanimously passed another similar resolution, submitted by the Brazilian government, guaranteeing access to AIDS medicines as a fundamental human right.

Although the United States had taken a stance against increasing the flexibility of the TRIPS agreement at the time, the U.S. government announced during the UNGASS that it was withdrawing the complaint it had filed in the WTO against the Brazilian intellectual property law. The request to convene a "panel" in which the Brazilian law was supposed to be challenged had been filed in February 2001.

However, negotiations were just beginning to include a separate declaration on TRIPS and public health on the agenda of the 4<sup>th</sup> WTO Ministerial Conference, held in November

2001 in Qatar. In September of that same year, under Brazilian pressure, a preparatory meeting for the Ministerial Conference agreed to include the theme. However, the following month, during another preparatory meeting, negotiations over a consensus text for a separate declaration reached an impasse and were suspended; the final decision on whether to include a declaration was postponed for Qatar and thus depended on direct negotiations between Ministers of State at that meeting.

The national and international media played a key role in this process, not only providing space to increase the transparency of negotiations over the inclusion or exclusion of the separate declaration, but also issuing important opinions about increased flexibility of the TRIPS agreement. For example, two weeks before the 4<sup>th</sup> WTO Ministerial Conference a *New York Times* editorial expressed support for the proposal by Brazil and other developing countries in favor of signing a separate ministerial declaration on TRIPS and public health.

However, the proposed declaration still underwent intense negotiations during the WTO Ministerial Conference in Qatar, and although it was not passed with the precise wording proposed by Brazil and other developing countries, the final text guaranteed that the TRIPS agreement could not prevent member countries from taking measures to

protect their public health and that it should be interpreted and implemented in keeping with the right of WTO members to protect public health and their population, in particular, in ensuring medicines for all their citizens. This declaration significantly changed the international scenario. Numerous countries and the international community as a whole have mobilized as a result, and Brazil has assumed responsibility in relation to other developing countries, in the name of international solidarity and cooperation, playing a leadership role in the process including policy issues, declarations, international resolutions, and effective work with the Global Fund to Fight AIDS, Tuberculosis, and Malaria.

International relations interfere in the dynamics of domestic policies, and Brazil inevitably depends on (and will experience) the results of this global mobilization. It would be unfeasible to deal with the international economic order without alliances, establishing partnerships and international mobilization. This historical process will thus reflect and contribute to the sustainability of the Brazilian Program. The AIDS pandemic will have a major impact in the coming decades, new drugs will continuously reach the market, and if there is no change in the world order in relation to intellectual property and marketing of medicines, Brazil's program may become unfeasible, or at least tremendously

costly for the country, on a level that will be absolutely unfair for our social and economic reality.

There is no doubt that Brazil's international leadership will bring positive consequences for its domestic policy. It is already evident that various sectors of Brazilian society have joined the Brazilian response to the AIDS epidemic. The struggle against AIDS in Brazil today is both presented and viewed as belonging to political leaders, government, the community, and the press. This shared ownership and responsibility is absolutely proper and desirable. It greatly increases the possibilities for maintaining and enhancing action against the epidemic, because AIDS has become a national cause.

#### THE GLOBAL FUND TO FIGHT AIDS, TUBERCULOSIS, AND MALARIA

The Global Fund to Fight AIDS, Tuberculosis, and Malaria was one of the concrete actions arising from the discussions launched at UNGASS. Again, Brazil's participation was key for comprehending the importance of large investments to fight the epidemic – not only financial investments, but also political ones, for building a new reality, consistent with the needs created by the AIDS pandemic, which means including the health issue on every human rights agenda. Brazil was one of the most active countries in setting up the Fund, especially in having the

UNGASS principles guaranteed and adopted. The country played a vital role in guaranteeing equitable participation by the various players involved in conducting the Fund and defining its mission, including treatment, multi-sector mobilization, and participation by CSO and people living with HIV/AIDS, tuberculosis, and malaria. The Fund is an international solidarity effort. If it succeeds in providing the means for expanding access to anti-retroviral therapy, with a resulting increase in international consumption of medicines, greater purchases of medicines, and broader agreements on differentiated prices, there will be an important impact on prices that will also be reflected in Brazil. Brazil has initially decided not to apply for resources from the Global Fund, given the situation in dozens of countries where public funds to fight these diseases are virtually non-existent.

This is the first time that an international fund has provided CSO and developing countries with voice and vote under the same conditions as donor countries. Traditionally, international funds such as the International Monetary Fund, the World Bank, the Vaccine Fund, and the Global Environmental Facility have been structured so as to guarantee that votes are proportional to the amount of the contribution by each respective country, thereby impeding beneficiary countries and civil society organizations from ex-

ercising greater activity in the management and disbursement of available resources.

The Global Fund to Fight AIDS, Tuberculosis, and Malaria – consisting of seven wealthy countries, seven developing countries, two CSO, and one representative each from the private sector and foundations – has emerged under a new paradigm, whereby the developing countries have the competence and the right to set their own policies to fight these diseases based on local demands and needs. There will thus be no priorities defined ahead of time by donors, as was usual until now. Again, Brazil's participation was crucial for developed countries to understand that the regional characteristics of AIDS and the political and social demands to confront the epidemic require that definitions be made in the sphere of the countries affected by it and not from the top down.

In the Global Fund's structure, Brazil represents Latin America and the Caribbean during the first two years. This decision was made by the countries of the region themselves, given that Brazil currently has both the other countries' trust and the greatest experience in fighting the epidemic.

The dynamics outlined for the Fund aim initially at prioritizing the countries that will apply for funds, taking a number of factors into account, including level of poverty, severity of the epidemic, and the



country's own level of mobilization. A prerequisite is that the project-formulating process should occur within the country itself. A local committee necessarily including government, civil society, and other stakeholders will analyze and establish local priorities, and the Fund will seek to meet what has been identified as essential by the countries.

#### IN SHORT...

We can identify important turning points in the fight against AIDS in Brazil. In 1983, installation of the first programs; in 1988, control of the blood bank system, the right to medicines for opportunistic infections and the initial work involving injection drug users. Another milestone was the year of 1992, with the political choice to sign a loan agreement between the Brazilian government and the World Bank, coinciding with the reformulation of the National STD/AIDS Program and including community participation. The year of 1996 witnessed the advent of triple therapy and the adoption of a domestic policy for universal access to all available treatment. And beginning in 2000, more organized, planned international action – such as the UNGASS in June 2001 – and the approval, in November of that same year, of a consensus paper in the WTO for the Separate Ministerial Declaration on TRIPS and Public Health.

Domestic and international recognition of Brazil's effort in the struggle against the AIDS epidemic can be seen as the greatest Brazilian victory in this struggle. Such recognition lends legitimacy to the Brazilian Program in the struggle against HIV/AIDS, and especially to the country's policy of free universal access to anti-retroviral drugs.

## Beyond magic solutions: prevention of HIV and AIDS as a process of Psychosocial Emancipation

Vera Paiva<sup>1</sup>

<sup>1</sup> Professor, Institute of Psychology – University of São Paulo (Nucleus for the Study of AIDS Prevention)  
E-mail: veroca@usp.br

### INTRODUCTION

At the outset of the epidemic during its first decade (the 1980s), most policy makers and health professionals just didn't care about the emerging epidemic, blinded by the symbolism associated to AIDS and the stigmatization of so-called "risk groups". The ones who cared, activists full of energy, believed we could eventually achieve some spectacular breakthroughs and control the further spread of the epidemic... Soon enough we have in fact learned that prevention of sexually-transmitted infections (STI) and of AIDS diseases depended more on a lengthy process of individual and collective apprenticeship focused on surpassing complex cultural, socioeconomic, political, material and subjective difficulties.

In Brazil, the process of responding to AIDS has benefited substantially from an intense interaction

between health professionals who cared, and who became activists in different State programs, and people affected by HIV who were networking and organizing Non-Governmental Organizations. This has taken the form of sustained cooperation – and frequently "co-optation" – characterized across the board by big controversies as well as by manifestations of mutual support of Governmental and Non-Governmental Organizations, national and international networking, confrontation and cooperation.

It is no easy task to present a rigorous assessment of the process, mainly because there is no foolproof method to describe adequately the interaction of the various factors involved, or to understand the complex synergy which has been required to make it actually work or not. Successes on what has been done cannot obviously be disre-

garded, but we need to address those matters that have tended to lag behind in the shadow. Some of the challenges we face will be pointed out through the text.

In the light of the progress made over the past few years in the areas of prevention of new HIV infections and organization of care for people living with AIDS in Brazil, the present text sets out to discuss the concept of "psycho-social emancipation", as it follows the frameworks of social and individual vulnerability, social and individual human rights and the fostering of subjects and full citizenship. Within this framework, the answer for the question "Are our experiences transferable?" should be NO! We may just inspire, make visible the context of its dynamic and permanent building up, some of its ethical principles, with no will to disseminate it as a guide line for "best practices".

The following observations are based upon a decade of research experiences and lessons learned from experiences and projects in collaboration with AIDS programs, health professionals and activists working in prevention and care in São Paulo.<sup>1</sup> It is a product of the network of academics, activists and public services professionals gathering round NEPAIDS Nucleus for the Study of AIDS Prevention, of the University of São Paulo, Brazil)

#### Human rights and politicized quality of life definitions.

If there is a so-called “Brazilian Model”, a recognized national purposeful commitment to fighting the disease on a truly international scale, I think it came out more clearly in the middle of the 1990s. This was a time when a timing consensus had been developed regarding the complexity of aspects involved, the need for a coalition as we emerged from some years of “no response” from the Federal Government. Facing the challenge of putting on paper a plan to be funded by the World Bank and Brazilian Federal Budget, we could emerge then from a position of “ambiguous and cynical executors” of so-called “references of best practices”—mod-

els propounded by a variety of international funding agencies who supported our scattered work.

This new leadership and commitment essentially reflected Brazil’s recent history of democratic resistance. It had been constructed and adhered to by people sharing similar attitudes and views with regard to individual and social human rights, to the free access and universal right to public health, to a firm pledge to emancipation and to the building of full citizenship.

This network of people agreed that most determinants of health, and of “quality of life” as its indicator, are out of the control of the health sector; but accepted that the health sector is responsible for designing the answers. I would dare to say that there was a consensual assumption that enhancing care and prevention should go way beyond the limits of the current approaches based on “best proven technologies” to limit morbid conditions and overcome disabilities. We would ‘define quality of life’ understanding that

*“the more democratic a society, broader will be its notion of quality of life, more complex and sophisticated will be its definitions of well being, more inclusive will be the parameters to judge and evaluate equal access to material and cultural goods.”<sup>2</sup>*

This means that quality of life definitions will differ across different times (and social history), across cultures (and subcultures), across social and economical status (classes). It should be stratified at least by: classes, genders, ethnic and cultural backgrounds, religious groups.

The question would be: who defines it? Health professionals and researchers? Patients and affected people? The public, the voters and politicians as the state regulates health care systems, or pay for it?

Certainly these are three different ways of reasoning, not only technically based on some definitions of “best practices”, but politically articulated. Understanding this has been part of the leadership attitude that made the Brazilian Aids response an exception and a model to other public health programs also in Brazil, as we create a permanent process of communication among different forms of reasoning, and paths and choices are clarified as the public debate is part of the process.

#### The continuum between prevention and care.

“Integral care with emphasis on prevention without depreciation of treatment”, is a constitutional prin-

<sup>1</sup> This is a product of the network of academics, activists and public services professionals gathering round NEPAIDS (Nucleus for the Study of AIDS Prevention, of the University of São Paulo, Brazil). I thank José Ricardo Ayres and Ivan França Junior for many contributions in framing these reflections, and especially for their comments on this text.

<sup>2</sup> MINAYO, M. C. S.; HARTZ, Z. M. A.; BUSS, P. M. Qualidade de vida e saúde: um debate necessário. In: *Ciência e Saúde Coletiva*, v. 5, n. 1, 2000.

ciple that puts prevention and care as two facets of the same challenge, built into the 1988 Constitution, promulgated at the onset of the democratic government after years of dictatorship. An important step forward to cement this approach to responding to AIDS was the growing acceptability in the 90s of the idea of vulnerability (both individual and collective) as an alternative to the concept of “risk” (“groups”, “risky practices”)<sup>3,4</sup>.

Viewed from the more structural and programmatic angle, the policy initiatives which have led to AIDS patients benefiting from access to quality treatment have certainly had a significant impact on preventing further infections in the future. Only when it was finally publicly acknowledged that people with AIDS had a right to best proven treatment and to respect for their dignity, that there was no reason for them to surrender any of their rights as citizens, and when organized activists started to reject the idea of “civil death”<sup>5</sup> did prevention in itself begin to be understood as a right for all Brazilians, for all our citizens.

In 1992, the Federal Government decided to fund the universal distribution of AZT using resources from the national budget - against all “best

practices” recommended for developing countries. People living with HIV and the most vulnerable groups were positively encouraged to forego their isolation and actively seek out STD and AIDS services. Furthermore, anonymous testing centers were set up and counseling facilities came on stream. Over time, AIDS patients and others were able to benefit from these initiatives and, at the same time, great steps were made in the enhancement and improvement of epidemiological surveillance, the public laboratory network throughout Brazil was strengthened and, finally, the distribution facilities network for supplying medical drugs were put into place.

The further challenge was that of sustaining such a program over the long term, a program regarded until then as an “impossible dream” by international agencies. Brazil’s independence facing pressures from the World Bank, which permitted its cash from the financing agreement to be channeled only into educational and prevention activities (since we were a “developing country”), eventually led to producing generic drugs and, from there, to proceed to the international policy of confronting global pharmaceutical production and accessibility

policies, enactment of human rights and patent laws.

Viewed from the individual and subjective angle, since 1992 the obvious positive caution involved in a person submitting himself to the anti-HIV test became abundantly clear – because, as far as the patient was concerned, there was the palpable prospect of access to treatment, and hence to survival. We could bring thousands of conscious vulnerable people and professionals in contact, and under the care of the health system, provide education and training, testing and counseling.

Many challenges in this area remain quite urgent.

- better multi sector integration, “transprogramming”<sup>6</sup>;
- expanding the underlying concept of prevention that AIDS affects all people, “all people”, actually meaning “HIV negative people”.

– Prevention has mostly been thought only for “HIV negative” citizens: disregarding thousands of Brazilian living with HIV and discordant couples (of the same sex and of different sexes).

– Reproductive rights and health care for people living

<sup>3</sup> MANN, J.; TARANTOLA, D. J.; NETTER, T. W. (Edts.). *Aids in the world*, 1992.

<sup>4</sup> AYRES, J. R.; FRANÇA JR.; CALAZANS, G.; SALETTI, F. H. Vulnerabilidade e prevenção em tempos de AIDS. BARBOSA, R. M. e PARKER, R. (Org.). *Sexualidades pelo Avesso*. São Paulo: Editora 34, 2000.

<sup>5</sup> DANIEL, H.; PARKER, R. A terceira epidemia: o exercício da solidariedade. In: \_\_\_\_\_. *Aids: a terceira epidemia – ensaios e tentativas*. Rio de Janeiro: Iglú Editora, 1991.

<sup>6</sup> Notion proposed by J. R. Ayres, in the Meeting “Challenges and conquests in the care for HIV/AIDS”, from 3-5 April 2002. Organized by ABIA, São Paulo.

with HIV have not been protected and promoted.

Governmental and non-governmental programs have been directed, correctly, towards the fostering and encouragement of non-discriminatory policies aimed primarily at defending the rights of people living with HIV, broadening general awareness of the fact that AIDS affects all people “equally” and without distinction.

The simplistic result of this approach has been that programs and research, mass “interventions” or small face-to-face groups have ended up effectively treating its target public as “HIV-negative” (synonymous to “all”). They should protect themselves from possible “HIV-positive” people. We talk about the obstacles preventing “HIV-negative” individuals to accept or even consider others to possibly be “HIV-positive”, but the difficulties faced by people living with HIV to perform the appropriate tests, to reconstruct a new life for themselves, protecting themselves and others from re-infection, is rarely openly discussed<sup>7</sup>. It was as if such people were not part of the country, but belonged elsewhere. Their reproductive rights, particularly, are still marked by silence

or restricted to behind-the-scenes controversies<sup>8</sup>.

Reproductive health care, component of the Women’s Health Programs, rarely encourages “wives and mothers” to undergo anti-HIV testing in the gynecological and pre-natal services (spaces for “all”, where HIV is not even thought about). Moreover, people living with HIV have no space where they can reflect upon or discuss their reproductive intentions (as they are treated in spaces which is not used by “all”, but which is specialized in HIV/AIDS). Such topics constantly emerge as one of the key demands made in the support groups for female and men who have sex with HIV+ women. One of the few occasions on which the sexuality of people living with HIV is actually discussed is during the compulsory counseling session following an HIV test, and access to counseling sessions of this type has not increased<sup>9</sup>. The focus of such sessions is usually on the need for using a condom or at the very least, modeling and conducting ‘behavior prescription’. There is no consideration given to the contextual dimensions of sexuality, and certainly no discussion of what his or her reproductive intentions might be.

### Brazilian sexes and genders

Diversity is a problem for those who seek to generalize, attempting to fit programmatic suggestions into a range of different contexts. To eschew the temptation to try and find a universal panacea – the “most effective technique available” – in exchange for something that we acknowledge as being dependent on a unique social and inter-subjective setting has been an innovation indeed. Recent efforts brought to care and prevention workers a deeper understanding of the concept that sexual practices do not exist outside a particular context, or sexual practices have different meanings in different sexual scenarios and bonds, as well as within each of the concrete scenes experienced by each individual or in a particular moment in life.

This framework was maybe easier to deliver in Brazil and our response to Aids certainly is due to the uniqueness of what we have in common as Brazilians, described by many authors and R. Parker in his book “Bodies, pleasures and passions”<sup>10</sup>. Many Brazilian projects responding to Aids have been in the last decade an “experimental test”, a live laboratory, of his and other Brazilian authors’ as-

<sup>7</sup> The most comprehensive review of literature on the sexuality of people living with HIV: M.A Schiltz, Th. G.M. Sandfort. HIV-positive people, risk and sexual behavior. In: *Social Science & Medicine* 50 (2000). p. 1571-1588.

<sup>8</sup> SANTOS, N. J.; VENTURA-FELIPE, E.; PAIVA, V. HIV positive women, reproduction and sexuality in São Paulo, Brazil. *Reproductive Health Matters*, London. n. 6, v. 12, 1998. p. 31-41.

<sup>9</sup> Enhancing care initiative website. *Women and AIDS: challenges to health services*. www.eci.harvard.edu. AIDS care teams/Brazilian team. Access on April 2002.

<sup>10</sup> PARKER, R. *Bodies, Pleasures and Passions* – Sexual Culture In Contemporary Brazil. Boston: Beacon Press, 1991.

sumptions. Parker points out that 5 subsystems coexist and are articulated in the singularities of Brazilian 'sexualities':

- the religious discourse, mainly catholic and Iberian, that values monogamy, marriage and reproductive sex;

- the social hygienic discourse, that defines the "healthy and unhealthy sexuality", the normal and the abnormal (most often seen as anti-natural like homosexuality, rather than as a sin);

- the modern sex science – all types of "sexologies", that value explanations of body functioning and sex artifacts, which is a hit in all written and electronic mass media, including open TV, and allows us to enter elementary schools and conduct safer sex workshops, for example;

- the patriarchal gender ideology that defines the polarities masculine-active and feminine-passive;

- the "erotic Brazilian" ideology, that celebrates the national character and identity as being sensual and eroticized, which assumes that everybody has a right to desire and make abstinence focused campaigns an impossible dream.

These subsystems mingle in very singular ways.

One among many good examples is a project conducted in Manacapurú, a 70.000 inhabitants town by the Solimões river, 100 Km of unpaved road plus 45 minutes by boat from Manaus, capital of Amazon state. In 1996 this project began with a group of STD health professionals based in Manaus as they set up a network of STD services in the Manacapurú region, training public health sites and making medications and testing for STD and AIDS widely available. In the end of 96, the very conservative city mayor was convinced to accept an STD/AIDS prevention project as an asset to his intentions of making Manacapurú a site for ecological tourism. The next step was to get the project approved by the city council and unions (of fishermen and transportation workers). This broad coalition approved that female sex workers should be the first group trained as peer educators. From 1998, peer educators worked throughout the year, finally setting up a place in the district which also quickly became a space for socialization for men who have sex with men and transvestites. This group of men expanded the project producing and conducting popular and street theater interventions. During the National Women's Day (a day with events traditionally coordinated by feminists), all peer educators of the project paraded and performed

throughout the city turning the 8<sup>th</sup> of March into a festival with educational material and prevention activities. Recognized as experts since then, sex workers and transvestites have been invited to talk about STD/AIDS prevention everywhere, as well as to educate young people in public schools on safer sex. In 1999, many other small cities around Manacapurú asked for the expansion of the project and a Gay/Lesbian NGO was founded in the city. Compared to a baseline conducted in the beginning of 1988, private pharmacies and drugstores increased condom sales 11 times, and selling posts increased 3 times in a survey conducted in 2000, with no direct target work on the part of private sector.

We can collect horrible stories of discrimination and abandonment in other cities in Brazil, where the local leadership explored the same context and sexual culture in a very different way. But the good examples show that in all the communities and particular groups affected by AIDS, even the poorest, less educated and most vulnerable, safer sex education has in fact been possible. This is true, for example, among women living with HIV that benefit from the lessons of the programs. Their report of consistent condom use is three times higher than usage by Brazilian women in general (21%)<sup>11</sup>,

<sup>11</sup> CEBRAP & MINISTÉRIO DA SAÚDE, 1999. *Comportamento sexual da população brasileira e percepções sobre HIV e AIDS*. Versão Preliminar do Relatório de Pesquisa/Julho. Available in [www.aids.gov.br](http://www.aids.gov.br). Access on April 2002.

although over a third of sexually active women living with HIV in this country still do not use condoms consistently<sup>12</sup>.

Programs can certainly make a difference, even when these cannot radically transform the material and structural circumstances or the kind of mentality which tends to encourage increased vulnerability to HIV and AIDS.

Again, many challenges in this area remain quite urgent.

- share with participants of preventive and care initiatives what we know about the diversity of sexual and gender culture, as SCIENTIFIC FACTS not only as an ethical perspective or political “wishful thinking”;

- adapt safer sex guidelines in which “all of us” should in fact mean “each one of us”;

- genders – should be definitely plural, both genders and not a synonym of women’s oppression.

Both prevention and/or counseling activities should share with patients themselves or educators what we know about the sexual conduct in different social-cultural contexts and give due weight to the reality of diversity. We know we need to adapt guidelines for safer

sex and apply them to the lives of “all of us”, but this should really mean the lives of “each one of us”. It has been difficult to abandon the focus on the idea of “universally applicable safer practices”, “risk behavior and practices” out of context or meanings, or on re-modeling probable or previously identifiable “failures”. We translate diversity as the production of “different materials” which only help to market the same ‘use a condom!, abstinence!, monogamy!’ adapted to the tastes and language of the “target public in question” (women or men, “heteros” and “homos”, young people, sex workers etc), not to the complexity of cultural and social context. HIV positive people hardly count.

While concern with gender relations and respect for sexual diversity have indeed been incorporated into many prevention activities since the beginning of 90s<sup>13</sup>, the needs of women living with HIV regarding their responsibilities for their families and children have in effect not been taken properly into account in the course of the organization of their care. Their more frequent demands are: nowhere to leave their children while attending the relevant care service and low attention has been

paid to the issue of access to reproductive care<sup>14</sup>. A further point is that ‘gender’ continues to be thought of in the singular, as being synonymous with female oppression. There has been little attempt to look more deeply into prevention activities or to deal with the impact of gender culture and relations regarding the increased vulnerability of *males*. ‘Men’ receive almost no guidance as to how to deal with their reproductive dilemmas (also virtually non-existent as far as women’s health programs are concerned).

The initiatives carried out with young people were the first to consider this dimension relating to the ‘two genders’ in the history of the Brazilian response to AIDS.

The tradition of popular education  
under inspiration of Paulo Freire:  
from the ‘individual as a consumer’  
to the ‘subject-citizen.’

The Brazilian response to AIDS also benefited from our tradition of popular education, known as the “pedagogy of the oppressed”, known also as part of the constructivist pedagogy field. In this tradition, we seek to promote citizenship while encouraging agency – as sexual subjects or a patient who

<sup>12</sup> Enhancing care initiative website (op.cit).

<sup>13</sup> PAIVA, V. In: *Reproductive Health Matters 2*, 1993. p.98-109.

<sup>14</sup> SANTOS, N. J.; VENTURA-FELIPE, E; PAIVA, V., 1998. op.cit.

<sup>14</sup> Enhancing care initiative website. www.eci.harvard.edu. Access on April 2002. op.cit.

adheres (not complies) to health care guidelines<sup>15</sup>.

The challenge has been to overcome the idea of “consumers” of services and products (drugs/services) and to begin thinking in terms of adherence (to condoms or to medication). It implies understanding that the consumer is only one of the faces of a full ‘citizen’. It is common in many care or prevention initiatives to promote the idea of fostering “empowerment” as many around the world say. The individual participant is mostly regarded as synonymous with “consumer” (of a service, a collective identity, etc). Modeling behavior interventions and individual rights mobilizations are usually the chosen approach when we understand the participant of activities as a “consumer”.

We are talking about how we conceptualize the named individual, “a human person judged to be so by his special physical or psychic characteristics”<sup>16</sup> who participates in prevention and care activities.

The individual as consumer is a subject who has the right to choose and to consume what already exists in the form put together by some manufacturer or service provider. The latter might be a producer of ideas and values disseminated by the mass media, by religious or educational institutions or by health services.

An individual who has “consumer rights” should wish to consume and have every interest in becoming a “consumer”. He thus becomes a target of a kind of “banking style process” in which a mass of information or training process defined as relevant by the educator concerned (the ‘producer’) is in effect “deposited” in the person who will then go on to consume such and such products (which includes new practices) and services deposited in him, as Paulo Freire would say. Or he might be a ‘client’ of workshops or support groups aimed to “model” new forms of behavior and to review practices which have been determined *a priori* as not particularly healthy.

The consumer as such must learn to use the products (condoms, printed material containing advice on safe sex, HAART medication, etc) in an appropriate way and to conform to the particular behavior patterns in which he has been instructed. The assumption, even unwittingly, is that the “producer” knows what is most appropriate and acceptable to “all” and acts accordingly, quickly and exuding good intentions. The producer wishes to avoid running the eminently public risk of the consumer not doing what is expected of him; care givers or educators choose the medium (which functions as “media” or a “marketing

strategy”) which will best sell this idea, product or behavior.

The ‘patient’ as an object of clinical manipulation is a consumer, the person is seen as a ‘carrier of HIV’, and he or she will receive treatment within a care organization aimed to hand over or to evaluate the effect of the prescription of the drug to treat the infection. The care organization ensures that the doses of the product are properly understood by the patient, just like in any manual utilized for that and all kind of other products on the market – from frozen food to video-players. He is seen as an individual suffering from some handicap – an immunological problem, or some lack of information or skills – who must be dealt with, or trained or treated.

How often have we termed as “intervention” the primary and secondary prevention activities we have initiated? The ‘Dictionary’ defines intervention as “the act of intervening, putting oneself between, to place oneself in relation to another, to interfere in or to interpose authority...”

Those who are unable to gain access to these products, fail to get access to services and to carry through the various directions, or simply have no desire to consume the proffered products, stay on the outside, do not interact or intervene in debate, and have no access to

<sup>15</sup> PAIVA, V., 2000. Gendered scripts and the sexual scene. In: PARKER, R.; BARBOSA, R.M.; AGGLETON, P. (Edts.). Framing the sexual subject – the politics of gender, sexuality and power. LA/Berkeley/London:University of California Press.

<sup>16</sup> Definition by “Aurelio”, our best selling dictionary.



counseling, workshops, products. Even being part of the interaction, he or she may indeed feel fatalistically at fault, guilty of not behaving properly because, but unconscious of, structural obstacles.

In this regard, structural inequality becomes a natural state of exclusion and the strongest defenders of this concept of the individual as a consumer thus see exclusion as a natural and innate state of affairs, or not a problem for the service provider. The conclusion is that the 'excluded', in effect, will always be around – like a natural phenomenon.

An alternative concept of the individual participant of care and prevention activities comes across when she or he is conceptualized as the starting point for lively 'interaction' and not a consumer of a finished 'product'. The initial proposition needs to be negotiated about, adapted, communicated with - and not imposed upon or in other ways instructed to carry out this or that order. The 'individual/citizen' in fact relates and he follows a path of reconstruction or deconstruction of individual and collective appropriation of a range of proposals placed before him, by public services, community leaders, academics and the media, involving prevention or care. He is encouraged to feel that he has "the right to have rights and to create rights"<sup>17</sup>. This individual has

rights (and obligations) as someone who regards himself as part of a wider environment, over which he is able to exercise influence, and he is able to regard himself as the 'agent and subject' of his own actions. He is encouraged to progress, to improve his own quality of life, while at the same time considering himself to be part of a much broader community (of the Brazilian nation, the poor, blacks, or the groups of people of the same sexual orientation). From this viewpoint, he is able to 'deal with inequality while constantly thinking of broadening the scope for beneficiaries and, above all, how to be included.' Inequality is thus not a natural state. Rather it is constructed by society and can be dismantled – collectively.

The range of activities consisting of the way in which we relate to actual people will turn out to be radically different in those initiatives at the structural or programmatic level. Yet, face-to-face spaces which genuinely provide support to individuals in respect of their daily life choices depend on how we define the participants.

From the point of view of the 'individual-consumer', social and economic rights of both men and women, including rights concerning faith and culture, all fall into the black hole of individual achievement, of increased self-esteem per-

ceived as a result of individual will, of empowerment considered to be a "balancing/hydraulic" compensating factor over the next person, perceived as the outcome of individual will, willpower that remains unconscious of the collective and contextual constraints (Use a condom! Take your medicine correctly! Convince yourself that you can do it! Be efficient! Improve your self-esteem!). Such individuals are transformed into pure starting place of consumption or of consumer rights, complaining about the faulty merchandise. They cannot be stimulated to invent the "unprecedented but viable", as Paulo Freire would have it.

#### PSYCHOSOCIAL EMANCIPATION

The "best attainable care" is the left over for the poor and excluded, as was discussed in the recent international debate on ethics in research, and what remains for them is the right to health and education of a "feasible" quality. Most people do not participate in the definitions of priorities and hierarchies of what should be feasible. Prevention, 'experts' used to say, should be the only feasible action because we are banned from dreaming about accessible treatment. We need to remember that treatment is available in plenty for the elites of every country who increasingly show more solidar-

<sup>17</sup> AYRES, J. R., 2000. ECI working group meeting. São Paulo.

ity to one another and relate more among themselves than with their fellow countrymen, in a world in which a certain type of globalization is all-pervasive, stretching from Africa as far as the Americas.

From the viewpoint of the 'individual-citizen', we should think in terms of "liberating", "emancipating", "politicized" and "consciousness-raising" education, of "adherence" (and not of simply complying to prescriptions), together with social solidarity. We should think about the kind of care centered upon multidisciplinary teams and not about the infectious diseases expert, of the more politicized face-to-face and community support groups. We should focus on inventing social movements to transform mentalities, against discrimination or sexism, into a situation where positive affirmation is espoused – celebrating diversity, communication, collective action, in order to outlaw injustice, inequality and inequity.

Let us concentrate upon initiatives which give appropriate weight to positive political identities, collective identities which can communicate among themselves and construct broader alliances. The challenge inherent in sustaining and expanding our dream to reach out to and benefit more people with access to medication and other areas of health services is a source of encouragement, and certainly a challenging creative exercise for

citizens themselves, for citizenship mentality, more difficult to imagine emerging in a consumer mentality context. These innovations can only come about in the public health services, where health is as yet not regarded as a 'consumer product', but as a 'right'. In the private schools and other private sector educational and health services, the overriding *leitmotif* continues to be that of catering for the consumer, it is the logic of the market.

Consumption without independence, or without being able to call into question unfair social inequalities, means accepting and perpetuating 'exclusion' as a 'normal' state of affairs. It also means pushing the many difficulties arising in the course of the process into second place, and to perpetuate a lack of understanding of the context which engenders them: the result of inequality between sexes and genders, or between different ethnic or religious groups, the consequence of an adult-centric vision or visibly marked by a badge of class.

So, our 'bigger challenge' would be to waken the "sleeping" public citizen inside every private consumer, by transforming care and prevention activities into spaces which can embrace and foster psycho-social emancipation.

Dissatisfaction with the product consumed certainly results in consumer rejection or eases the so-called consumer back into a state

of old-fashioned fatalism, silence or long-suffering deception. But this degree of dissatisfaction has rarely been creatively transformed into a particular ideology within a context of values which encourages good communication and, furthermore, which holds that a particular interest is a social obligation. This is the core of what we wish to examine in depth when we take into consideration the activities of what we have called "psycho-educational activities"-support groups for adherence, safer sex workshops, etc.

We find that these spaces must be politicized, acknowledging that there exist large numbers of other excluded people, or never forgetting the limits of what we are doing when facing structural inequalities. It means overcoming the guilt instilled in us as the result of failing to follow the guidelines set down for us, unaware of the historical conditions which brought about our heightened exclusion and vulnerability, means reducing the individual frustration arising from the limitations imposed by social-cultural contexts. To politicize means having to approach defined and readymade solutions with a certain flexibility. It means, in essence, communicating and negotiating proposals.

To politicize means to look beyond one's own narcissistic reflection – and to rediscover that which is common to us as agents of exclu-

sion and that which makes us different from "all" – and to abandon a defensive politics of identity to become part of "people as a whole". To emancipate we need to make history, to strengthen political alliances – which has little to do with seeking support for "my struggle", "my" consumer rights, for "me".

When this kind of psycho-social emancipation approach is available within HIV and AIDS prevention and care programs, high value is naturally placed on knowledge and wisdom absorbed in real life experiences. A wisdom to be shared with those professionals in charge of different activities. This is an approach which encourages joint efforts to innovate services, to discover other solidarity spaces and other solutions outside the scope of the specific projects or health sector initiatives. It avoids people accepting with grateful humility a quality service which we know to be superior to the other available health services in Brazil but which is far from being perfect. It also has guaranteed social control over the quality and the ethical aspects of care.

From the subjective and individual point of view, activities which also promote citizenship and encourage people to be the agents of their whole life – subjects who are capable of choosing and deciding, who

adapt proposals and guidelines 'to their own reality' and are supported in this endeavor – enable people to reflect upon and to modify their behavior, while being aware of the context that generates their vulnerability (and creates obstacles to change). Awareness of the context, which can facilitate safer sex practices or which teaches people to deal with obstacles in the most vulnerable circumstances, depends on the alert subject formulating for himself practices which are acceptable in his real life, participating in the mobilization of groups and communities who seek to reduce common difficulties collectively and within the social environment in which they live.

A politicized, psycho-social emancipating process is always going to be more difficult. The art of politics is the art of negotiation. It is far less glamorous and takes patience and time. It is to consider our various different facets and sometimes conflicting individual needs, to have sufficient flexibility to achieve our potential as persons, and to overcome challenges in each inter-subjective situation.

It is not possible to "consume" ready-made changes. We are only likely to change as the result of the living reality in which we inhabit and not of that which is sold as a background for the sale of readymade

products for consumption, however well packaged and targeted. "Interventions" which magically transforms and affords the ultimate, definitive care, protection and help do not exist.

We are only capable of change on the basis of what we are – an unequal country, burdened with symbolic and structural violence, a country of less than democratic institutions, and with a wide diversity of complex communities and creative people, with their thousand different characteristics, and all in search of some kind of fulfillment and happiness.

#### IS OUR BRAZILIAN RESPONSE TRANSFERABLE?

If we have gotten our point across we understand that every place needs an exercise of politicizing its process, negotiating and finding its "best processes and practices". Not from any universal and all transferable guideline or "best practice". We may 'inspire' other context-based initiatives, we may share common values and an idea of human rights – necessarily individual and socio-economic human rights. Taking into account what Boaventura Santos<sup>18</sup> has stated: within the constant tensions that justify the search for a progressive policy and politics of global human rights

<sup>18</sup> SANTOS, B. S. Por uma concepção multicultural de Direitos Humanos. In: CAPINHA, G; FELDMAN-BIANCO, B. (Org.). *Identidades: estudos de cultura e poder*. São Paulo: Hucitec, 2000.

at the same time we search of a local validity and legitimacy.

#### END NOTE: ABOUT PEDAGOGY OF OPPRESSED

The “pedagogy of the oppressed” was originally formulated in the 1960s. To this day, it acts as a pillar of support *vis-à-vis* social movements fighting poverty and other forms of social exclusion. Within this tradition, to gain access to education is in itself a key step, but only when popular language (from both a vocabulary and syntax point of view) and the topics which are relevant to the lives of those socially oppressed, are given their due weight. It only makes sense and has a genuine impact if the various educational activities manage to break the silence and social invisibility of those who nowadays we call the “excluded”.

From the mid-1980s, when in Latin America the democratization process got under way, other definitions of oppression in addition to that of poverty began to be included in various social policy agendas. The sexes, gender issues (*gender* mostly still in the singular, referring to women) and race (mostly referring to blacks) entered the political arena mainly through the practice of identity-seeking and positive affirmation: we are “women”, or “feminists”, “homosexuals” or “GLBT”, “blacks” or “HIV positive” (and not “Aids victims”). A new aspect of liberating pedagogy

emerged with “workshops”, “support groups”, “experience-sharing groups”, and so on. These are spaces in which the aim is to share intimate experiences of the difficulty of truly living that part of one’s being that one feels stigmatized or excluded. These are the spaces which set out to address the burden of exclusion rooted in the body/person who is “different” or less powerful (the female body or that of a young person, none-white bodies, those who express different needs, sick bodies, handicapped bodies, etc). They set about organizing group sessions in order to refuse old stigmas and to rebuild, collectively, positive identities. Many such collective processes have also been able to formulate initiatives focused on fighting discrimination.

This experience was eventually incorporated into proposals for education and care. In other texts, we have termed this kind of experience “face-to-face” or “group” experience, “psycho-educational groups”, because apart from the pedagogical methods developed for freedom-enhancing education in the popular movements, they embrace group psychology techniques. In our Brazilian experience, these precepts were inspired principally by the Latin American concept of “psychotherapy of the oppressed”, but they were also the result of a number of American experiences – which emerged *inter alia* from anti-psychiatry, psy-

chodrama and bioenergetics. These proposals of “experience-sharing groups” led to the emergence of a more inter-subjective approach which, on the one hand, basically put more value on the concept of personal diversity and creativity, reinforcing affirmation of shared identities while, on the other hand, providing opportunities for emancipation and citizenship.

These initiatives were put together as the result of disillusionment with the public space built by democracy, founded upon lifestyle norms which make people regard themselves as excluded minorities and entire groups of citizens who are deprived of the prospect of exercising their rights. This happens because they have to decide on their own their more singular choices and values in life. These spaces have underpinned the consumption of “readymade identities” while many groups continue to glamorize as consumer products positive identities and lifestyles, or behaviors predicated by its “vanguard”. But they can also perpetuate isolationism when they act in an overly dogmatic manner. They in effect turn away their “consumers”, who feel unable to face material real life and symbolic hegemonies. They remain the “outsiders” who fail to feel comfortable out of the shared spaces of protected consumption or when, indeed, they are unable to enact in real life a rigidly incorporated identity or

where they are denied the right of simply being different.

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## HIV/AIDS prevention: multiple challenges

Kenneth Rochel de Camargo Júnior<sup>1</sup>

<sup>1</sup> Professor of the Institute of Social Medicine in State University of Rio de Janeiro (IMS/UERJ), Head of the Department of Planning, Management and Policies in Health at IMS/UERJ  
E-mail: kenneth@uerj.br

### WHY “PREVENTIONS”?

The multiple nature of HIV/AIDS has been known for a long time. Besides the “three epidemics” that Jonathan Mann<sup>1</sup> spoke about, we can see more and more clearly that cultural and social-demographic characteristics shape the manifestations of the epidemic, which takes on different features in different communities. That is why it is no longer possible to talk about HIV/AIDS prevention as if it were some monolithic block with linear determinations. Indeed, it is increasingly obvious that prevention activities, as activists and academics have been predicting for a long time, focus on and delimit publics and incorporate – if not in practice, at least in discourse

– the concept of vulnerability. Perhaps this is the first challenge to recognize: the complexity of the task. Prevention involves not only avoiding the appearance of new cases of HIV infection but also re-infection of HIV+ persons, impeding the occurrence of opportunistic infections, delaying the immunodeficiency development and combating discrimination and restriction of rights.

This complexity is also due to certain paradoxes that are caused by the often-conflicting demands of vulnerable groups, which at times generate important ethical dilemmas. For example, the need to test pregnant women as part of the prevention of vertical transmission of HIV cannot put in jeopardy their civil rights by obliging them to have a

compulsory examinations as part of pre-natal accompaniment. This is certainly less of a problem than it was several years ago, but it has not yet been completely solved.

Analyzing the almost 20 years of the history of the epidemic in Brazil, it has to be admitted that the panorama has changed, and in many cases for the better. Specifically with regard to the subject analyzed by this text, we must recognize undeniable progress made, starting with the actual reduction in the growing trend of incidence of cases of AIDS in the last two years, even taking into account the necessary corrections for delay in notifications (CN DST/AIDS, 2001). While this is cause for relief, on the other hand our responsibilities are all the

<sup>1</sup> “According to Dr. Jonathan Mann, of the World Health Organization, we can indicate at least three phases of the AIDS epidemic in a community: [...] The first is the epidemic of the HIV infection that silently penetrates the community and often goes unnoticed. The second epidemic, which occurs some years after the first, is that of AIDS itself: the syndrome of infectious diseases that install themselves as a result of the immunodeficiency provoked by the HIV infection. Finally, the third (and perhaps potentially the most explosive) epidemic of socio-cultural, economic and political reactions to AIDS, [...] which Dr. Mann claims are ‘as fundamental to the global challenge of AIDS as the disease itself’ (DANIEL; PARKER, 1991. p.13).

greater, and the rest of this paper is an attempt to identify where the main obstacles are to be found.

#### THE THEORETICAL-CONCEPTUAL CHALLENGE

The ways that HIV is transmitted with most epidemiological relevance – such as unprotected sexual relations or sharing of syringes – depend on the actions of individuals to make them concrete. Therefore, reducing or eliminating these actions should be enough to bring about a drop in the occurrence of these ways of transmission. Of course, there is nothing so simple or easy in this matter.

First of all, when we speak of human beings and their actions we are no longer in the terrain of well-behaved objects of research by “hard” sciences, where theoretical consensual models dominate research and dictate rules of action. The sciences of man, anthropology, sociology, psychology are marked by the existence of different theoretical currents, with presuppositions, methodologies and canonical texts that are different and at times conflict with one another. This being the case, it is impossible to produce linear and unequivocal discourses on which to base theoretical proposals to support prevention actions.

The HIV/AIDS pandemic clearly posed the need to introduce these complex objects on the horizon of biomedical research. Quite commonly, however, this has happened

in a subordinate manner, the result being that theoretical schools that adjust best to the *démarches* of the biomedical sciences research methods, and epidemiology in particular, have been adopted to the detriment of others. Another factor behind the predominance of these models is the support granted to them by certain international organizations that are or have been important in financing prevention programs or professional training and which later on were prominent in tackling the epidemic, so that certain theoretical-conceptual models have become “official”, regardless of their academic acceptance – see, for example, the texts issued as “Best Practices” by UNAIDS (1996; 1997; 1999a; 1999b; 1999c; 1999d; 1999e; 2000).

Some authors have recently dwelt on this topic, especially Merchán-Hamann (1999, p. 86), who examined the proposals of health education for HIV/AIDS prevention and observed that “[...] the theoretical models and the conceptual reflection that should guide practices are still subject to some of the determinist and reductionist premises of behavioral or comporment psychology.” Special mention should also be made to Pimenta, whose doctoral dissertation project (2001. p.17-24) identifies six different theories on which different prevention projects in Brazil are based, all of them setting out from the principle that individuals are rational agents and that

changing action depends fundamentally on providing adequate information. The discussion as to the adequacy or not of this model goes far beyond the objectives of this paper. I would just like to register here this option, once again not clearly explained in most of the texts mentioned in the bibliography consulted. It should also be noted that I eschew using the word “behavior” in this context. It is worth noting that the mere selection of terms like this implies adopting (even if the author himself fails to perceive it) certain theoretical commitments, as claimed by Giami (1994) with regard to research on sexuality, and Bourdieu (1989) in the more general context of research in sociology.

These processes, as mentioned earlier in a paper on prevention (CAMARGO JÚNIOR, 1999), lead to the adoption of certain theoretical models, occasionally without this being always clear even to those who propose and implement prevention programs. This does not mean that adopting specific models is undesirable or even avoidable; the real problem is the lack of a critical perspective with regard to them.

The urgent perspective of the responses and the militant profile of most of the people who engaged in the struggle against HIV/AIDS have resulted in these problems not receiving the attention they deserve all this time. When we look at the material produced by various non-

governmental organizations (NGO), with (more frequently) or without the support of the federal government, we notice an emphasis on producing material geared towards action, without any deeper theoretical elaboration to explain the model adopted or the reason for this option. Although there is clearly a certain consensus as regards forms of action – such as emphasis on education, use of peer educators, channeling the material to specific audiences, and respecting the peculiar discourse of the target segments of the population (CN DST/AIDS, 1996 and 1997a), this consensus was already present even before these programs were implemented, when the fund-raising projects were drawn up. So the claim cannot be made that this “major model” was adopted because of its efficacy.

This brings us to the second problem, likewise linked to the theoretical-conceptual dimension: evaluation. Since the models of theoretical reference for the interventions are not explicit, it becomes all the more difficult to set up evaluating processes. In a concrete sense, even accepting that the past trend of the HIV/AIDS epidemic incidence in Brazil has diminished, as stated at the beginning of this paper, at the moment we cannot determine which experiences among the many projects implemented have been the most – or even actually – effective (UNAIDS, 1999c).

As a matter of fact, one of the problems pointed out by Araújo (2000, p.5) in her review of the recent literature on HIV/AIDS prevention, is precisely the lack of in-depth evaluation discussion.

#### THE CHALLENGE OF SUSTAINABILITY

One question that has been posed ever since the first national project (AIDS I) financed by the World Bank is the program's financial sustainability after the original project is concluded. Although, according to the National Bureau of Sexually Transmitted Diseases and AIDS (CN DST/AIDS, 1998b), this situation has made some progress and that dependence on external resources has diminished, there still remain problems to be solved.

On the one hand, the government-NGO relation is not easy to resolve<sup>2</sup>. If NGO are basically sustained by means of resources derived from the governmental sphere, this compromises the very characteristic of the NGO. On the other hand, resources provided by international financing agencies, which could guarantee more independence for these organizations (at least in the economic-financial sense), tend to grow increasingly scarce in light of the adverse economic circumstances in the international scenario.

In addition, simply transferring attributions of the State to the so-called “third sector” – though part of the neo-conservative doctrine that has been the tonic of governmental action in our country over the last few decades – is not necessarily subscribed to by many of these same agents, some of whom have quite a sharp perception of their own problems of representativeness (GALVÃO, 1997, p.103).

Even considering the consensus as to the need to focus on preventive actions, and that this necessarily presupposes the commitment of society, the concrete ways in which this participation takes place fail to be absolutely clear. As I see it, the current model of action, whereby NGO perform the role of para-State agents contracted by the health sector in a manner not unlike that prevalent in the Integrated Health System (SUS) with regard to assistance services, represents at best a situation of imbalance.

In short, although the clearest expression of the problem under discussion lies in the economic sphere, the solution is necessarily political and involves debating the role of the State, which tends to exacerbate in the future as the artificiality of “consensus” imposed from the outside becomes clearer, especially because of the damaging results of their application.

<sup>2</sup> For a more detailed discussion of the historical trajectory of these institutions, see Galvão, 1997, 2000.



## THE CHALLENGE OF INTEGRATION

The actions implemented to face the HIV/AIDS epidemic in Brazil were obviously not carried out “in the dark.” As already observed in an earlier paper (CAMARGO JÚNIOR, 1999, p.229), these actions have been institutionalized within the context of a determined bureaucratic organization of the Brazilian State – the Ministry of Health – which historically has operated based on certain intervention models, among them the so-called vertical programs, a label that *mutatis mutandis* could also be applied to the National AIDS Program. Programs of this type are organized on the federal level, structured on segments of the population or specific health disorders, and poorly integrated with the ensemble of other health activities.

Nevertheless, one of the objectives of the current model of organization of health care in our country, despite all the obstacles against its being set up, has traditionally been to overcome this model of health actions by constituting the SUS integrated health system. One of the keywords present since the first proposals of its project has been integrality, an indefinite term (PINHEIRO; MATTOS, 2001) where we can nonetheless distinguish at least three ideals:

- integration between prevention and curative intervention;
- integration of care for individuals so that they are not taken as frag-

mented objects, generating care with quality and efficacy;

- integration of health actions also on the managerial level, avoiding overlaps, duplication and waste.

Ideally, then, HIV/AIDS-related actions should be integrated with the operation of the health system proper. This, however, has not been the case. The reproduction of the vertical structure of the Ministry of Health in the other spheres of public administration, with the creation of bureaus for AIDS programs in state and municipal health secretariats has ambiguous effects, especially in the long run. If on the one hand this guarantees the visibility and priority necessary to confront HIV/AIDS, any problem that escapes these programs’ specific sphere of action will have additional difficulties in implementing solutions. For example, an HIV+ person being treated with anti-retrovirals may require a simple chest X-ray, but since this type of service is not specific to the program, the individual will fall into the “common grave” of attendance to the general public.

To put it differently, the quality of care offered to people with HIV/AIDS is limited in regard to the general quality of health care in the public area. From the point of view of prevention, this means that preventive activities should also be integrated to the daily routine of health activi-

ties. When a woman goes to collect material for the preventive examination for cervical cancer, this opportunity should also be taken to make her aware of the use of condoms, for example. In particular, the family-health programs should include routine HIV/AIDS-prevention activities. Although training of this type is already in fact being offered both for higher-level professionals and health agents, the actual implantation of these measures in daily routines is still dubious.

There is also a sense of integrality with special interest for HIV/AIDS prevention, namely, the impossibility of dissociating prevention from care and treatment. A prevention program that is not accompanied by measures to care for people with HIV/AIDS runs the risk of ineffectiveness; fortunately, the Brazilian program is exemplary in this sense. Notwithstanding the success of the therapeutic component, there are still problems to face. In the first place, seropositive people should be integrated to the prevention programs to prevent them not only from spreading the virus but also from becoming re-infected (it is still unclear, for instance, what additional risks are represented by re-infection with different strains of HIV). It is necessary, for example, to pay special attention to serodiscordant couples. Still concerning the integration between prevention and care, one fundamental area of action is during the pre-natal period. The efficacy of the protocols

against vertical transmission has already been shown, however the fact that even in big cities with established health-service networks like Rio de Janeiro or São Paulo, women give birth without knowing their serological status shows that there is still a long way to go in this area. Special attention should also be paid to adherence to therapy, seeing that the risk of selecting resistant strains due to inadequate or interrupted treatment poses yet another problem for prevention.

Furthermore, one should not ignore the need to diagnose and cure – whenever possible – other infectious diseases that can represent additional risks of HIV infection, such as sexually transmitted diseases and the additional health disorders in people with HIV/AIDS, including tuberculosis. These are situations that demonstrate the need for broad HIV/AIDS prevention to look beyond the frontiers of “behavioral intervention” in order to be really effective, in fact, a recent publicity campaign of the Ministry of Health deals precisely with the importance of prevention and/or early treatment of STD.

Up to now, the perspective of integration is being approached from the intra-sectoral point of view, with relation to action in the health area; however, it is essential that this inter-sectoral integration should coincide with other public policies, in particular in the education field. Although some progress has been recorded in

this area, notably with regard to preparing support material for educational actions (FIGUEIREDO, 1998; PINTO; TELLES, 2000; UNAIDS, 1997), there is still little visibility of such actions within the educational network.

#### THE CHALLENGE OF EPIDEMIC DYNAMICS

Even though there has been some reduction in the past HIV/AIDS incidence trend, this has not been true for all groups, and for some groups in particular – such as women of fertile age – the trend remains high. The change in the profile of cases in Brazil over the years has been characterized by changes labeled as heterosexualization, feminization, pauperization and interiorization. Perhaps there is even a process of “ethnicization” of the epidemic taking place, but it not yet possible to confirm this speculation, as data on the ethnicity of people affected are not available in the aggregate data announced by the Ministry of Health, and very likely they are not even collected. In fact, the drawbacks of the federal information system on HIV/AIDS represent another problem for prevention.

The processes for producing these differentiated trajectories have been discussed for years, one important mark in this process being the concept of vulnerability posited by Mann and colleagues (1992; PARKER; CAMARGO JÚNIOR, 2000). In short, social-economic processes that produce

inequality and discrimination tend to make certain groups more exposed to various health disorders, and HIV/AIDS does not deny this logic. This being the case, one can expect that the flaws of a society are mirrored in the progressive distribution of cases. From the prevention point of view, this translates as the need to grant priority precisely to the most fragile, the most needy, the most marginalized by society. And in this sense, certain groups such as prison inmates and injecting drug users have become notable challenges for prevention. As far as the latter are concerned, mention should be made of the recent (this paper is being written in December 2001) decision by the governor of the State of Rio de Janeiro, Anthony Garotinho, to veto a law proposed by the State Assembly that proposed to implement a harm reduction program by supplying syringes, the argument being that this “would stimulate the consumption of drugs.” Far from being an isolated case, the episode illustrates the difficulty in implementing prevention programs for some of the most vulnerable segments of the population.

Nevertheless, one should not lose sight of the more general context in which the epidemic unfolds. While it pleases some sectors of the Brazilian conservative *intelligentsia* to use the expression “the Brazil cost” to refer to presumed obstacles to the economic expansion of the produc-

tion of the private sector in our country, a “Brazil cost” has to be admitted for the general public. The cost of unemployment, violence, lack of assistance, scarce and poor-quality education, and low wages translates not only into increased vulnerability to many health problems, but also into concrete limits for assistance and prevention programs. A miserable population receiving an excellent prevention program is still miserable, and this limits the efficacy of the program. This should not serve as justification for the omission or lack of programs that fail to take into account, for example, the prevalence of illiteracy in a given community, which immediately limits the efficacy of actions based on the distribution of leaflets and primers. This obvious affirmation, however, only strengthens the need to think of the problems of the Brazilian population, including the HIV/AIDS epidemic, in a systematic fashion.

#### THE HUMAN-RIGHTS CHALLENGE

As noted at the beginning of this paper, preventive measures can end up becoming risks for group and individual rights. A classic example of this setback can be seen in the analysis by the Ministry of Health itself concerning the early campaigns in the mass communications media: “The Ministry of Health, in the political administration of the AIDS question, promoted intimidat-

ing publicity campaigns to reinforce attitudes and practices formerly combated, and suspension of almost all its activities. This led to its virtual isolation and to a considerable mobilization of civil society seeking to guarantee rights already won and demanding concrete answers from the public sector, in light of the aggravation of the epidemic” (MS, 1998a. p.32). The first publicity material, in particular the material that reinforced the stigma of AIDS as an incurable disease, lent its weight to the already existing discrimination against people with AIDS.

Although there has been no more notification of problems such as those that occurred in the early years – children being prohibited from attending classes or people being expelled from small towns because they were seropositive or presented immunodeficiency – this does not mean that those problems have been completely solved. On the other hand, even today there are top-level health professionals who claim that AIDS is a “homosexual disease,” the corollary being that it is therefore less important – or even unimportant – in the universe of public health problems. The need to recognize and approach more vulnerable groups of the population in a different manner poses the permanent dilemma of reinforcing existing prejudices or not lending importance to specific demands that

are still relevant. This is particularly significant for groups that are still stigmatized, such as homosexuals or users of injectable drugs. As regards the former, although important advances have been made, there have been no substantive changes in many aspects that still bear relevance, albeit indirectly, to prevention, such as the legalization of civil unions, which would allow, for example, greater flexibility in granting legal and welfare benefits to partners. The current governor of the State of Rio de Janeiro, Mr. Garotinho, also vetoed in 2001 a bill presented on the matter in the State Assembly. In respect to drug users, specific progress has been made in damage-reducing programs, but the non-existence of federal legislation on the matter leaves state and municipal programs still at the mercy of the whims of the incumbent governors and mayors.

#### THE CHALLENGE OF CONTINUOUS STRUGGLE

Paradoxically, one major problem for the continuity of prevention efforts is precisely the success (albeit relative) of programs to combat the HIV/AIDS epidemic. For example, in a pamphlet aimed specifically at men who have sex with men, the Centers for Disease Control and Prevention (CDC) states that “abundant evidence shows the need to maintain prevention efforts for each generation of young homosexual and bi-

sexual men" (CDC, 2000. p.1). The relative success of the prevention campaigns produces a false sense of security that can lead to an increase in unsafe practices.

The very success of anti-retroviral therapeutics can also lead to underestimating AIDS as a health problem. Although using the disease as a "scarecrow" does seem in itself to be ineffective as a prevention strategy, the opposite must not be assumed true, that is, that the weakening of the impact of HIV/AIDS in the social imagination does not have repercussions in adopting prevention measures.

To put it more broadly, one might say that this is yet another aspect (paradoxically a result of positive facts) of the trivialization of the epidemic, something already feared for some years (MANN *et al.*, 1992). As the HIV/AIDS epidemic affects poorer (and consequently less visible) segments of the population, combating the epidemic can unfortunately lose its political relevance, given the structural inequality that characterizes our society.

Also in this regard, we can predict more problems in the future if the vaccines being tested today eventually come into use. Since these vaccines do not offer total protection, and are expected to slow down the spread of the virus among the population, an intense educational campaign will be called for so that the prevention actions are not abandoned.

### A BRAZILIAN MODEL?

Is it possible to state that there is a "Brazilian model" of HIV/AIDS prevention? If "model" refers to a relatively fixed and invariable standard, then I believe that the answer is no. But if we are thinking of an outline with traits taken from various current experiences, then it is possible to present a set of characteristics that have taken root over the years.

First of all, the proper use of mass communications media. Despite a sorry start, campaigns improved as time passed and there seems to be an adequate understanding of what the desired objective of this type of medium is: to spread objective knowledge about the disease and make the population aware of the problem associated with HIV/AIDS, without worsening – indeed, preferably combating – the discrimination suffered by those infected by HIV.

Another activity that has been carried out with relative effectiveness is the distribution of condoms, which until a short while ago were exclusively for men, and only lately have become available to women too. At certain times the distribution activity was threatened with discontinuity because of financial-budgetary problems (CN DST/AIDS, 1997b). These activities of spreading information and distributing condoms are necessary, albeit insufficient, conditions for prevention programs. While

their existence is no guarantee of prevention, their absence would compromise it irremediably.

The use of the so-called "peer educators", despite the lack of precise information about what exactly is being done, as mentioned earlier in this paper, at least represents a step in the right direction. This activity, when spread through micro-social levels and adapted to specific target-publics – adolescents from low-income urban areas, sex workers, injecting drugs users, and men who have sex with men, to mention just a few examples (CN DST/AIDS, 1997a) – has more chance of being successful than attempting to "change behavior" based on generic publicity campaigns.

Two established forms of activity should be mentioned with certain reservations, in the absence of any real evaluations of their implementation, namely the use of instruments of the "Dial-AIDS" or "Dial-Health" type, and counseling in the Testing and Counseling Centers (CTA).

Finally, another important generic characteristic has been the relatively ample political commitment to the issues arising from the epidemic, even to the point of advanced legislation on distribution of medicine being introduced by a conservative politician. This sort of mobilization was not characteristic of Brazilian social policies in the second half of the 20<sup>th</sup> century, but rather the result of a series of contingent

factors that ended up creating favorable conditions for the development of a more participative model (CAMARGO JÚNIOR, 1999; PARKER, 1994): the political situation in Brazil, the demise of the military regime, and redemocratization; the effervescence of this process, especially in the health area; the important participation of militants for democratization, such as the two Herberts (Daniel and de Souza, also known as “Betinho”), as the galvanizing agents of the mobilization to combat HIV/AIDS; and the World Bank’s inducing of NGO participation in the program. Even with all the problems pointed out by many authors concerning the development of policies in this area, it must be admitted that the present situation is a considerable advance, especially if we consider the general panorama of public policy in our country. This is also an important aspect in the sense of the political sustainability of prevention measures, bearing in mind that some of these – such as practically everything to do with sex education and distribution of condoms – face the systematic opposition of influential sectors of Brazilian society, including the Catholic Church.

## CONCLUSIONS

In spite of all the problems, re-examining these almost twenty years of HIV/AIDS in Brazil is encour-

aging. I say encouraging not only on account of the reduction in the past trend for epidemic growth, but also because of the undeniable advance made in certain areas, chiefly in the political sphere, as understood in a broad sense. Despite the innumerable problems that still remain, the maturing of AIDS/NGOs in Brazil is evident, and also the governmental agencies dedicated to confronting the epidemic and which have progressively incorporated important cadres formed in the various fronts of the struggle developed since 1985, the year when the first Brazilian AIDS/NGO was founded: the São Paulo AIDS Prevention Support Group (GAPA-SP). Nonetheless, there remains much to be done, and this paper could not come to a close without pointing to some possible future lines of action.

First, I feel I have shown the need to draw up long-term strategies, bearing in mind that we still have a long time to live with the HIV/AIDS epidemic. These strategies should emphasize training human resources to work in this area, in both the governmental and the non-governmental sector. Such training, which has been going on more or less spontaneously within NGOs, is vital for guaranteeing the turnover of personnel in these areas. The way this has been happening has not guaranteed a quick enough staff turnover, which underscores the importance of specific programs aimed not only at

prevention work but also managerial and political activity. Academic institutions and political organizations such as trade unions can provide the necessary expertise to draw up this type of training program. As for the training of human resources in the public sector, this should be integrated with other programs in this area, such as training family doctors. Specifically for healthcare workers, it is important to stress the approaches of the human sciences and the political and civil-rights questions associated with HIV/AIDS, since biomedical training tends to eclipse these dimensions, which in itself can create problems for the development of prevention activities. One particular chapter of skill-building should be given maximum priority, namely health education, preferably disassociated from traditional models, where healthcare workers play the role of “supposed knowledge” and spurns the experience and point of view of the population with which they work.

Furthermore, a closer tie is needed between academia and activism, in terms of stimulating critical reflections on adopted practices, as well as spreading the knowledge generated by endless research projects presently underway. Appropriate mechanisms to socialize information must be developed, and in particular there is a virtually unexplored potential in the new information technologies, notably the

Internet. Although access to computers is still far from available to most of the Brazilian population, the majority of NGOs are likely to have some recourse of this sort which could also easily be used to spread information at little or no extra cost. Evaluating interventions deserves special attention, given the almost total lack of progress in this area.

On the more general political front, constant visibility to the epidemic has to be ensured, as well as strengthening and expanding alliances already in place. The last few years have been notably hostile towards the development of solidarity-based policies. Although the probable restriction of future financing from abroad could strangle resources and jeopardize ambitions with regard to carrying out public policies, we can always hope to achieve some advances in the political sphere after the neo-liberal tide has gone out.

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## World Bank strategies and the response to AIDS in Brazil

Ruben Araújo de Mattos<sup>1</sup>; Veriano Terto Júnior<sup>2</sup> & Richard Parker<sup>3</sup>

<sup>1</sup> Professor, Institute of Social Medicine, State University of Rio de Janeiro (IMS/UERJ)

E-mail: rubenm@uol.com.br

<sup>2</sup> General Co-ordinator, Brazilian Interdisciplinary AIDS Association (ABIA)

E-mail: vterto@portoweb.com.br

<sup>3</sup> Professor and Chair, Department of Sociomedical Sciences, Mailman School of Public Health, Columbia

University, and Director and President, Brazilian Interdisciplinary AIDS Association (ABIA)

E-mail: rpg11@columbia.edu

### INTRODUCTION

The main purpose of this paper is to examine the World Bank strategy for AIDS in Brazil. This is not, however, a text focusing merely on those who are somehow involved with the theme of AIDS. We consider that the examination of this specific strategy may cast some light on the way in which the World Bank has related to Brazil (and other countries) in the nineties.

A first aspect deserving immediate comment is the discovery that not all strategies of the Bank for a country are set out in the documents outlining aid strategy for the countries. The case of AIDS is a good example of this: the Bank's latest document on its strategy for Brazil mentions practically nothing about AIDS, even though the Bank considers AIDS an important question.

AIDS is a major issue on the World Bank directors' agenda. Many might

think that this statement sounds strange. In 1994, Sven Sandström, the World Bank managing director, recalled that

*People are sometimes unaware that the Bank is one of the major providers of external assistance to the developing countries in areas such as education, nutrition and health. The Bank is also the single largest source of external funding for AIDS prevention and control in the developing world.* (SANDSTRÖM, 1994).

On that same occasion, Sandström said that combating AIDS should become an integral part of the Bank's strategies for countries. The importance of health for the Bank was evident at the time: in 1993, the Bank dedicated one of its Reports on World Development to the subject of health (WORLD BANK, 1993). And as Feachen (at the time a professor at the London School of Hygiene and Tropical Medicine who has held several positions in the World Bank) said, when it dedicates one of

these reports to one sector, the Bank is saying that this sector is important to it (FEACHEN, 1999. p.1207).

In its 1993 Report, however, known by its subheading "Investing in Health", the Bank recognised the importance of AIDS, characterising it as one of the major challenges for the future (WORLD BANK, 1993. p.35-36). The Bank has been seeking to meet this challenge by intensifying loans to AIDS control projects.

Besides providing loans for the control of AIDS, however, the World Bank has been suggesting ideas on which would be the most appropriate public policies to control the epidemic. The document "Confronting AIDS: Public Priorities in a Global Epidemic" (WORLD BANK, 1997a) clearly illustrates the Bank's participation in putting forward ideas. In fact, this document was published in a series whose aim was to "present, to a vast audience, the conclusions of studies dedicated to

a fundamental aspect of development” (WORLD BANK, 1997a. p. vii).

The Bank’s directors clearly consider AIDS to be not only a problem of health but also a fundamental issue for development. The president of the Bank, James Wolfensohn, when speaking before the United Nations Security Council in January 2000, reiterated this position:

*Many of us usually think of AIDS as a health issue. We are wrong. AIDS can no longer be confined to the health or social sector portfolios.* (WOLFENSOHN, 2000)

Yet it is still curious that it was due to AIDS that, for the very first time, a World Bank president was invited to speak at a meeting of the United Nations Security Council. On that occasion, and on many other occasions, president Wolfensohn committed to a campaign to raise funds for international AIDS support.

In short, AIDS seems, at least in the minds of the Bank directors, to be a major development problem. This justifies that it be recommended for inclusion in country strategy documents, appear in the portfolio, and its relevance to governments and other donors be rigorously defended.

The World Bank has been investing funds in Brazil since 1994 when the contract for the first loan, of US\$160.000, was signed for STD<sup>1</sup>/

AIDS control. A second loan of US\$165.000 was approved in 1998, to last until 2002. Both are amongst in the biggest loans ever made by the Bank to AIDS control projects in the world.

Although the Bank points out that AIDS is not a health but rather a development problem, in the case of Brazil, the Bank has been treating AIDS as part of the lending to the health sector. In fact, the Bank’s strategy for the health sector in Brazil has been based on three main points: to offer loans to extend access to the basic services in the poorest areas; offer political advice and carry out studies to increase the efficiency and effectiveness of the health system; and offer funding to projects that control certain transmissible diseases (WORLD BANK, 1998. p.1). The AIDS I and AIDS II projects are included in the third point.

The Brazilian experience in combating AIDS has not been based on the ideas offered by the Bank. On the contrary, the Brazilian government has gained experience in guaranteeing AIDS patients universal access to anti-retroviral medication<sup>2</sup>, an experience that, because of its innovative characteristics, has been discussed and adopted as a model in a number of other countries. The key issue is that the free distribu-

tion of medications is not one of the policies recommended by the Bank, nor is the adoption of the principle that health is a universal right, nor the theory that it is a duty of the State to secure it. Apparently the existence of significant divergences between the positions of the Bank and government on the health policy and policy against AIDS has not hindered the realization of loans in these two sectors.

Precisely because of these peculiarities which reveal the complex nature of the relations between the World Bank and the countries, particularly Brazil, it may be convenient to examine the AIDS theme a little more carefully in the context of the World Bank strategy for Brazil, for health and AIDS on the international scene.

This is the main purpose of this paper. We do not intend to evaluate the Bank’s role concerning AIDS in Brazil, as the complexity of the theme goes beyond the scope and specific purposes of this paper. We consider the Bank’s strategy for AIDS a case which may be analyzed to help us understand the working methods and strategies of the Bank. In particular, we intend to show how there has been a move away from loan-centered strategies to strategies based on proposing ideas.

<sup>1</sup> STD is the acronym currently used in the health sector for sexually transmitted diseases.

<sup>2</sup> These are drugs that delay virus replication (and development of the disease) in patients already infected by HIV. Their use has reduced the AIDS mortality rate in Brazil by up to 50% in the past five years.

We believe that for this purpose it is essential to first discuss the recent changes undergone by the World Bank, which shape the general context in which AIDS plays a more important role in the institution. Next, we will examine, albeit briefly, the main divergences between the recommendations or suggestions offered by the Bank and the health policy guidelines in Brazil, in order to finally discuss the Bank's strategies for AIDS in Brazil.

#### THE WORLD BANK ON THE THRESHOLD OF THE NEW CENTURY

The Bretton Woods institutions, the World Bank and the International Monetary Fund (IMF) have been the target of innumerable criticisms by non-government organizations throughout the world. Not without reason, the criticisms have intensified since the eighties, when the two institutions were involved in disseminating proposals for economic adjustments, whose damaging effects have been laid bare.

It is quite true that the criticisms do not come from NGOs alone. One example, as early as the late eighties, was when the United Nations Children's Fund (UNICEF) exposed shortfalls in the economic adjustments, which in some cases worsened the living conditions of children

in the poorest strata of the population. UNICEF then proposed a more humane adjustment. But the NGOs have been essential in the movement that has exposed the shortfalls in the so-called globalization (in the way it is being implemented).

The demonstrations are not restricted to attacks on the Bretton Woods institutions. If we are to look, for example, at the Prague Demonstration<sup>5</sup> in mid-2000, we will see that most demonstrators in the streets were

*"... against the predatory globalization adopted by global capitalism, but in favor of an alternative globalization, more just and equal, that permits the whole world population to live a decent dignified life, and not just one third of the population, as is the case"* (SANTOS, 2000).

The Bretton Woods institutions are attacked because they are considered to be institutional bastions of the old predatory globalization that is reluctant to change.

This image is not without reason. Throughout the eighties, the proposals for economic policy defended by the World Bank and IMF have caused perverse effects. Contrary to the promise to include the most peripheral countries in the new world economy, the economies of developed countries have remained closed to them; but globalized capital took over the

privatization promoted by the governments of developing countries. Nevertheless, the resources obtained by the governments of such countries through liquidating their assets were quickly dissipated in the vain endeavor to reduce their debts. Economic policy recommendations tended to cause unemployment, increasing the numbers of people living in poverty; meanwhile, widespread reductions in public spending, considered essential for keeping public accounts eroded resources as well as the already fragile social welfare institutions of those countries. Added to this is a criticism of a nationalist nature: the World Bank and IMF were imposing these economic policies on the governments of the countries, which, in addition to an attack on sovereignty, caused alarm in those who still insisted that the State should play a fundamental role in promoting development and social policy. All that, without even mentioning the damage caused to the environment by so-called development projects which had been supported by the World Bank since the sixties.

But the nineties brought change. Undoubtedly, this change is still incipient, since it has not been clearly expressed in alterations to the institutions that sustain the current world configuration, nor produced ef-

<sup>5</sup> The extensively reported demonstrations occurred at the time of another annual IMF and World Bank meeting, which was held in Prague in 2000.

fective changes in their operation. But the political agendas and discourse of some directors are showing some change. As Boaventura Santos says:

*If the questions of poverty, hunger, growing inequality between rich and poor and canceling the debt of the poorer countries are on today's political agenda, this is largely due to the transnational democratic movement. The same impact is visible in the rhetoric of directors and institutions.* (SANTOS, 2000).

These changes are quite visible in the case of the World Bank, whose recent course shows a differentiation and a certain moving away from the recommendations of its twin, the IMF. Evidence of this is the recent article by Joseph Stiglitz, former World Bank chief economist and vice-president, dedicated wholly to a fierce onslaught against the IMF. In his article, Stiglitz recounts the efforts he made, while still chief economist of the Bank, to persuade the IMF against the mistakes in the economic policy it proposed in response to the Asia crisis (STIGLITZ, 2000).

After so much criticism, the World Bank has attempted to build, or rather rebuild, its institutional image. Nevertheless, the Bank's leanings should not be wholly attributed to achievements of the transnational social movement, as this would risk overlooking the complexity of the

Bank's own survival strategies. In fact, a quick glance at the history of the Bank might suggest that, if any doubts remain regarding the capacity of this institution to contribute towards the development of countries, there seems to be no doubt regarding its capacity to rebuild and develop itself, adapting creatively to a wide variety of international situations<sup>4</sup>. Perhaps the changes in the Bank in the nineties are also the results of institutional continuity strategies in an international scene marked by deepening inequalities between countries, by the entry of globalized capital into various top sectors in the Bank's operations, and by the crisis in what may commonly be called international aid community.

However, perhaps it is now time to review our image of the World Bank as the eternal ally of the IMF in maintaining the interests of the powerful and sustaining predatory globalization, without leading us to adopt, through this review, a naive attitude of considering the Bank to be a loyal ally in the building of an alternative for that kind of globalization. Our critical surveillance now recognizes the changes and identifies their contradictions, especially those that relate to the gap between the discourse of the Bank's directors and specific action regarding a country, a sector or even a specific theme.

But it now also understands the changes in the Bank's strategies.

It would be convenient, therefore, to start analyzing the Bank by characterizing the main points of change in the nineties. We would like to highlight three main points: the change in the Bank's objectives, with increasing emphasis on poverty; the change in the view of structural adjustments, both with regard to policy content and, principally, with regard to adopting the so-called conditionalities<sup>5</sup>; the growing importance of the supply of ideas and political dialogue. These changes are easily characterized in the agendas and discourse of the directors and it is worth mentioning their repercussions on Bank strategies for Brazil and AIDS. Let us now look at each of these moves towards change.

First, however, mention should be made that, in the nineties, the Bank actively attempted to draw closer to non-government organizations, its most fervent critics. On one hand, it endeavored to expand the channels for dialogue between the Bank and NGOs. On the other, whenever it could, it sought to finance and encourage governments to finance NGO actions. A strategy of partnership could easily be perceived in such moves. But without a doubt, they did allow, at least at the rhetorical level, for the dis-

<sup>4</sup> For a brief report on some of this rebuilding, see Mattos, 2000, especially the chapter four.

<sup>5</sup> The term conditionalities refers to the conditions required by the Bank to consolidate a loan.

course of the Bank to incorporate several demands from the organized social movements.

#### FROM DEVELOPMENT TO COMBATING POVERTY

“Our dream is a world without poverty.” This is the World Bank slogan. Coined in the nineties, it sums up the institution’s attempt to rebuild its image: the Bank’s intention is to show that its main purpose is to reduce poverty.

It is not the first time that the discourse of the World Bank’s directors mentions combating poverty. In the seventies, the then World Bank president, McNamara, first included the subject in the portfolio of the Bank, which until then had focused on more traditional areas, such as economic infrastructure and some sectors of production considered strategic for economic growth. Yet, at that time, the fight against poverty was just another area of the Bank’s activity, a diversification of its portfolio.

The current slogan of the Bank has another connotation: its intention is to state the main purpose of the Bank, which is no longer development but rather combating poverty. This has an affect on the Bank’s strategies for the countries: all projects must be

presented as having some impact on reducing poverty.

In the document presenting the Bank’s strategy for Brazil (WORLD BANK, 2000) we have a good example of the consequences of this new attitude, although still at the rhetorical level. With the explicit intention of giving a more concrete meaning the reduction of poverty, as imagined by the Bank, there is a section that groups together initiatives that may deserve Bank support. They are conveniently split into three categories: the prerequisites for effectively reducing poverty, including therein the measures required for economic stability, such as the social security reform; initiatives aimed at reducing poverty, including providing health services for the poor; and initiatives which indirectly affect poverty (WORLD BANK, 2000, p. 32)<sup>6</sup>. It is clear that all interventions are presented as, to a greater or lesser degree, they had a positive effect on reducing poverty, which is obviously questionable.

This readiness to justify all projects supported by the Bank based on its allegedly positive impact on poverty does not mean that the concern about poverty is, in fact, a major item on the public policy agenda. The key issue for specialists and the Brazilian government is not thinking

how to reduce poverty, subordinating the aims of the economic policy to this social policy. The key question lies in presenting the actual subordination of the social policy to the economic policy, as if the latter were essential for reducing poverty, even though its immediate effects are to increase it.

Why did the Bank adopt this anti-poverty objective? Partly, perhaps, because it admits to some of the criticism made against the Bank’s performance in structural adjustments, which revealed the effect they had on exacerbating poverty, at least in some cases. But perhaps the most important is the Bank’s response to an international situation that, otherwise, could call into question the very need for the World Bank.

The World Bank is funded by lending to member countries. And, under its own by-laws, it may only lend when (at its own discretion) the government is unable to raise the resources directly on the financial market under reasonable conditions. Now, with the change in capital flows towards some developing countries, especially those that have, as an exemplary manner, put in practice privatization programs, private investments have increased in areas where the World Bank formerly op-

<sup>6</sup> The division is not, however, presented in this form. The Bank considered it more appropriate to combine the first two, presenting them as more directly linked to poverty. Thus, it may be said that the Bank will allocate around two thirds to the group of initiatives that would supposedly combat poverty more directly. In reality, the measures which are supposedly necessary to reduce poverty may worsen poverty, at least at a circumstantial level. It would, therefore, be interesting to know how the two thirds of the Bank’s resources are to be distributed between the first two groups of action. (Would it be the Bank’s intention to allocate one third of the resources to each of the three areas?)

erated. But the Bank needs to continue lending, since this is the best way to ensure collection of its loans. So, there is a search for new areas for lending, areas still uninteresting for capital. Over the years, the Bank has successfully created new lending opportunities, sometimes creatively transforming the negative consequences of previous investments into justification for supporting new projects. Combating poverty is now a great opportunity.

Moreover, it is worth recalling that the theme of development, which was to be the Bank's primary mission, is outmoded, at least among world elites. The dissemination of neo-liberal ideas and the blind belief in globalized markets have banished the developmentalist outlook, at least in the minds of the world's elites, precisely those that give financial and political backing to the Bank<sup>7</sup>. Consequently, the governments of developed countries have been reducing the financial resources allocated to international co-operation for development.

In response to this crisis, we may note a joint effort, of the organizations involved in this aid for development, to preserve their budgets, rebuilding new prospects for their

role. It is not a coincidence that combating poverty started in the mid-nineties as the widespread consensus among international organizations and donor agencies: the consensual goal of the international community is now to eradicate poverty by 2015. It is around this goal that appeals are made to resume spending of the governments of developing countries on international development. It is interesting to note the tone of such appeals. The World Bank is fully engaged in this effort. In fact, AIDS has been a particularly useful theme in this effort to raise funds.

The Bank has, in fact, demonstrated a large capacity for rebuilding and developing itself, overcoming sometimes very hostile situations. It seems that the emphasis on reducing poverty integrates all the Bank's adaptive answers into the new world context, for better or worse. But it has direct repercussions on the sector strategies and the Bank's strategies for the countries. It is not that the Bank is now seriously in favor of reducing poverty but rather that the Bank's specialists now have to justify their performance in terms of their potential impact on reducing poverty<sup>8</sup>.

## BEYOND THE WASHINGTON CONSENSUS

A second point in the Bank's transformation during the nineties concerns structural adjustments. In the eighties, with the worsening of the foreign debt crisis of developing countries, the World Bank created a new kind of lending: structural adjustment lending. Most loans were allocated to financing specific projects. Nevertheless, in the case of structural adjustments, the purpose of lending is to lighten the balance of payments, not being attached to any specific project. But in exchange for the loan, the government agrees to a set of commitments by adopting certain economic policy measures.

Structural adjustments were created in a particular institutional climate: a school of thought that became known as 'public choice' enjoyed great prestige among the Bank's top specialists. The followers of this school of thought considered that the governors of developing countries tended to pay too much attention to their own interests. Consequently, they tended not to adopt the adjustment measures of the economic policy that were supposedly becoming imperative given the changes in the world economy, since such adjustments would jeopardize some of their

<sup>7</sup> Latouche, in a recent article, says that "Development is no longer successful in the 'serious' international forums: IMF, World Bank, World Trade Organisation, etc." (LATOUCHE, 2001).

<sup>8</sup> In this sense, monitoring the consequences of specific projects supported by the Bank on poverty is perhaps an interesting strategy of pressure on the World Bank.

own private interests. Therefore, they would need to be given incentives, as it were, to adopt the necessary measures. This attempt to induce governors to adopt economic policies with which they did not necessarily agree was tacitly inserted in the first structural adjustment proposals. Taking advantage of the vulnerability of the governments' balances of payments, the Bank would offer to lend, in exchange for commitments from the governments to implement the adjustments proposed by the Bank's specialists, even against their will<sup>9</sup>.

It is clear that in this process, it was also tacitly admitted that the Bank's specialists were more capable of identifying the required adjustment measures than the national governments. Although there is a wide variation in the recommendations made by the Bank for different countries in the context of negotiating loans for structural adjustment, there was widespread consensus regarding the main points, a consensus that one analyst called the Washington Consensus: the recommendations involved strict fiscal austerity, reduced public spending, privatization programs, measures to open up the national economy and other points.

The structural adjustments were severely criticized. From the point of view that they insisted on defending nationalist and developmentalist positions, the proposed

adjustments seem to be imposed from outside the country. In fact, it was common sense to complain about this imposing character, attributed to the World Bank and International Monetary Fund. In turn, the adoption of the recommended package of proposals eliminated the possibility that the State would adopt a developmentalist policy. On the other hand, evidence was found that such adjustment measures did not lead to the results announced by their supporters, and did not guarantee the inclusion of the national economy in a supposedly globalized economy; on the contrary, the measures seemed to worsen the living conditions of the poorest segments of the population even further.

During the nineties, however, the Bank changed its stance regarding structural adjustments. On one hand, it took on board the criticism that the early adjustments did not take into account the worsened status of the poorest classes, although it continued to insist that they were necessary. By acknowledging this, the Bank learned a lesson: it may be possible that a government will have to adopt tough adjustment measures in the future, but if it does, it must include protection measures for the poorest segments of the population, in order to mitigate their perverse effects.

On the other hand, the top executives of the Bank proceed to review the economic grounds underlying the first proposed adjustments. Since the end of the eighties, public choice has been losing ground in the Bank, with the institutionalist approach prevailing. Instead of national leaders who are overly interested in their own affairs (as the disciples of public choice thought), the institutionalists attributed the hardships of development to the fragility of the economic and political institutions in the developing countries. Therefore, the institutionalists believed that the key issue of development was now to be found in the development of institutions, including the increase in the capacity of governments to ensure an adequate economic environment.

As the institutionalist view gained ground in the Bank, it began changing its tune with regard to the role of the Bank itself and the whole international aid community. It would not be right for this community to impose policies on the governments of developing countries, but rather to assist these countries in developing their institutions, in order to ensure that the people themselves steer their own development.

This new stance appears, for instance, in an address by the World

<sup>9</sup> Cf. Mosley *et al.*, 1995.

Bank president regarding AIDS in Africa. Speaking to the United Nations Security Council, Wolfensohn argued that it was fundamental for the Africans to organize their process of integrating into the “modern open global economy” and putting an end to poverty. The role of the international community would be to help them build the institutions required to help them take hold of their own future (WOLFENSOHN, 2000).

At the same time as this change in tune, the World Bank directors formulated what, in their eyes, was to be a new development paradigm: comprehensive development. If this outlook does not contradict the discipline of the macro-economic policies which the market demands so much, it at least opens up the development agenda, going far beyond what the Washington Consensus suggested, especially with regard to the importance of social policies, compensatory or otherwise<sup>10</sup>.

But perhaps the most important change occurred in the tacit provisions by which conditionality was imposed on the structural adjustments. Here the Bank was also learning a lesson as it became involved in adjustment lending: the Bank did not have the capacity to oblige or persuade governments to adopt the

recommended policies; at least not to the degree that had been envisaged earlier. Governments would often not honor the political commitments agreed with the Bank, or would only honor them in part, managing to renegotiate them in their favor after having received the adjustment loan.

It can easily be seen that the ideas set out in the Washington Consensus spread rapidly among the governors and that, during the eighties and nineties, there was a convergence of macro-economic policies adopted by the various national governments. The lesson learned by the Bank was that this convergence could not be attributed to the persuasive (or imposing) effect of its structural adjustment lending. The Bank was gradually realizing that the success (from its viewpoint, of course) of the adjustment loans somehow reflected the earlier adoption of the proposed measures by the governors, and the political willingness of these governors to implement them.

So, instead of lending to governors who were not fully convinced of the adequacy of the suggested policies, almost as if in an attempt to buy the adherence of these governors, the Bank now only offered loans

when it was sure that the governors would adopt the most important points of its recommendations. Avoiding specific commitments agreed at the time of lending, the Bank starts to value to the plans of the government itself. The Bank's analysis evaluates the consistency of its plan, and detects the areas where government intentions and the Bank's agenda overlap. In the case of major divergences, the Bank prefers to intensify political dialogue, which may include in the formulation and putting forward of ideas regarding which policies would be most suitable.

The current strategy for Brazil, for example, gives value to the Multi-Year Plan for development drafted by the Brazilian government. If, in the document on the strategy published in 1997, the Bank was somehow evasive when it indicated the guidelines of selectivity that it was to adopt<sup>11</sup>, in the most recent document, it leaves no room for doubt when it includes the following in the list:

*Full consistency with government objectives, as expressed particularly in the MYP [Multi-Year Plan], and strong commitment by the government to reforms in the area supported.*  
(WORLD BANK, 2000. p.31)

<sup>10</sup> This supposedly new view is mentioned in many speeches by the Bank's directors.

<sup>11</sup> The document said: “it is hard to develop a guideline for selectivity for the Bank's aid in such a large and complex country as Brazil, where the size and diversity of aid requirements are so wide-ranging and where the Bank, consequently, plays a fundamentally catalysing role.” (WORLD BANK, 1997 b)



In other words, it is the Brazilian government that is at the helm<sup>12</sup>, but it is the Bank that evaluates, for each sector, whether there is close commitment to the reforms required, from the Bank's viewpoint, of course. This leads us to the increasing importance of the offer of ideas.

### OFFERING IDEAS

The World Bank president, in one of his speeches, referring both to the prospect of the World Bank's role and of the so-called donor community, stated;

*what we as a development community can do, is to help other countries – by providing funding, of course; yet it is much more important to provide the know-how and the lessons learned from challenges and how to tackle them. (WOLFENSOHN, 1999)*

In fact, offering ideas seems to be one of the fundamental activities of the Bank. In the new context of conditionality, which is supposed to respect the sovereignty of nations, the production of supposedly universal know-how, to which all bow down, is now a major tool of persuasion. The Bank has been striving to produce and disseminate this know-how, generally presented as if taken from the experiences catalyzed by the Bank.

The intellectual work of preparing these lessons and drafting documents to be distributed to widely differing audiences is guided by sector and country strategies, in the same way as the lending. These strategies focussed on intellectual production, however, are not necessarily part of the documents on aid strategies, and are not as explicit. The Bank seems to increasingly rely on more strategies to deal with future divergences between it and governments. Therefore, these strategies are recorded in the political dialogue of the Bank with the governments. Nevertheless, these strategies, which focus on the supply of ideas have not been closely examined either by researchers or the social movement.

Let us take the case of the health sector as an example and analyze the Bank's strategy for AIDS in Brazil. This case contains both general documents and specific documents for Brazil.

### THE STRATEGY OF SUPPLY OF IDEAS AND DIVERGENCES BETWEEN THE WORLD BANK AND HEALTH POLICIES IN BRAZIL

As already mentioned, in 1993 the World Bank dedicated one of its reports on human development to the health sector. In it, the Bank

acknowledges that the possibilities of obtaining improvements in the health conditions of the populations were enormous:

*But in order to obtain good health conditions it is essential that there are good policies. Some countries have made full use of the potential of medicine; others have done almost nothing, despite the vast sums being spent. This report takes lessons from this multiple experience that will help the authorities to realize the enormous returns in potential of the investments that their countries make in the health area. (WORLD BANK, 1993. p. 19)*

And what were these lessons? In general, the recommended measures may be divided into three groups: those focusing on creating a more favorable environment so that families may improve their health; those which aim to promote diversification and competition in the sector; and those which seek to achieve more discerning public health spending. This last group includes proposals for reducing the public financing of complex aid services. Governments should prioritize their spending with a package of highly cost-effective welfare and public health services.

The report proceeded to analyze the cost of various welfare and public health projects, selecting those that had more impact for the money spent. In the opinion of the Bank re-

<sup>12</sup> This attitude protects the Bank. Everything now occurs as if the Bank were in defence of closer attention to poverty, in relation to the Brazilian government. Should, however, the Brazilian political leaders be more convinced of the need to limit public spending (and social policy spending), then the Bank is left only to "intensify" its political dialogue in order to persuade the government to, at least, secure the compensatory measures for the adjustments. The Bank seems to be becoming "progressive".

port, since the other projects were not as efficient, they should not be financed by the government.

For example, concerning AIDS, prevention by disseminating condom use would be, in the Bank's opinion, one of the actions deserving government support. The same would not occur with the welfare to AIDS patients, known to be costly.

This standpoint would contradict the actions taken by Brazil in its health policy. With the 1988 Constitution, Brazil now recognized health as a universal right, the State being responsible for ensuring it. The ideal pursued since then is a configuration of the health system that can guarantee everyone free access to any health services that may be required.

Let us look at this divergence in more detail: as early as 1987 a World Bank document stated:

*the most common approach to health care in the developing countries has been to treat it as a citizen's right and strive to provide everyone with free services. This approach does not generally work.* (WORLD BANK, 1987. p.3)

Two years later, with Brazil already under the new Constitution, Bank specialists stated in a document specifically relating to Brazil that:

*The outlook for the Brazilian health system is not good. In the forthcoming decades there will be a boom in the demand for services as the age of the population increases and the constitutional right to free public health care for everyone is claimed.* (WORLD BANK, 1989. p. xviii)

The diagnosis made by the Bank regarding the Brazilian health system at that time highlighted its supposedly iniquitous nature, especially concerning the application of resources. It would be iniquitous "because too many funds were spent on hospital-based care and very little on prevention and basic care, in terms of cost" (WORLD BANK, 1989. p. xx).

Another argument in the Bank's criticism of Brazil's policy refers to the poor capacity of the system to reach and provide for the poorest regions and persons. These criticisms justify the Bank's preference to support incentives with greater impact on the poorer regions and people, and define its general purpose in health actions as improving the health of the poor (WORLD BANK, 2000). On the other hand, the other key point is to adopt cost-effective spending, always giving value to prevention. Only this last characteristic is clearly visible in the Bank's strategy for AIDS in Brazil.

#### THE BANK'S STRATEGY FOR AIDS IN BRAZIL

The two projects funded by the Bank for the control of sexually transmitted diseases (STDs) and AIDS in Brazil focus on the prevention of the disease and on NGO participation. Nevertheless, the projects are not solely based on preventive measures. The AIDS I project assigned a little over 40% of the funds to the component most directly linked to

prevention. Around 34% of the funds were allocated to health care and the rest to institutional development, surveillance, research and evaluation (GALVÃO, 2000. p. 146). In the AIDS II project, the percentages are the same (WORLD BANK, 1998).

In Brazil, the issue of AIDS was addressed well before the first project financed by the World Bank. Since its origin, it has been marked by two fundamental points: the participation and demands of social movements related to AIDS; and the contribution from specialists committed to building up a health system that would ensure the universal right to health care. This dual action allowed that the first loan from the Bank be granted without the government moving away from its universalistic goals. On the contrary, the Brazilian government was able to lay the foundations of what was to become an innovative program with free distribution of anti-retroviral medication for AIDS patients. The government had already decided, before starting negotiations with the Bank, to begin free distribution of drugs for AIDS. As recognized in a document published by the Ministry:

*With the return of the former directors, in 1992, once again the agreement with the World Bank would play its strategic role. By guaranteeing funds for preparing the human resources, acquiring equipment, and for prevention programs, it enabled managers to have their own independence in key areas of work and to*

*concentrate their efforts on securing funds for drugs in the governmental sphere.* (BRAZIL, 1999. p.18)

In 1996, given the potential of the combined use of drugs both to increase the survival and quality of life of HIV-infected patients, the National STD and AIDS Co-ordination decided to extend the medication distribution program, setting itself the goal of distributing drugs to all AIDS patients. While the Co-ordination was looking for funding for this expansion, Congress approved a specific law, Act 9313, obliging governments to provide drugs free of charge to AIDS patients, using funds from the Single Health System (SUS).

The Brazilian AIDS medication distribution program is undoubtedly an innovation. It consolidates the view of a universal right that drives the SUS. Furthermore, it extends that view, as free access to medicine is only universally guaranteed for a few diseases. It is an ambitious program, the costs of which were around 630 million Brazilian reais in 1999. The program has had a clear positive impact, as in the drop in AIDS mortality.

The distribution program clashes with World Bank recommendations. The anti-retroviral therapies would not be very cost-effective and would be an excessive subsidy to AIDS pa-

tients. Bank recommendations are for AIDS patients to pay for their treatment in the same way and in the same proportion as patients with other diseases (WORLD BANK, 1997a. p.13).

Even so, with this divergence, in 1998 the Bank approved the second loan for STD and AIDS control. What it shows is that, even where there are differences of opinion regarding a policy implemented by a government, the Bank does lend on some occasions. But this does not mean that it accepts the positions taken by the Brazilian government. On the contrary, the Bank's strategy is, first, to stress that the Bank's funds are not for financing medicine. Second, it wishes to intensify the political dialogue with the government to dissuade it from the free universal distribution of drugs by demonstrating that the resources allocated to it could have a greater impact on health care if used in another way. It is in this sense that the following statement, included in the evaluation of the AIDS II project by the Bank specialists, may be understood:

*Studies to examine survival rates of AIDS patients and costs of treatment of patients will be carried out under the responsibility of the Project and will give the Bank an opportunity to continue discussions with the government on the implications of the costs of care and public funding for AIDS patients in the priorities and overall*

*expenses for health care in Brazil* (WORLD BANK, 1998)

The battlefield then moves from the negotiation of loans to the debate on ideas.

It would be rash to say whether the Bank will cease its lending activities for AIDS control in Brazil. But it is a possibility. The Bank has been increasingly preoccupied with AIDS in Africa, and it would not be surprising if it were to concentrate its efforts in AIDS control on that continent. On the other hand, loans made to Brazil are relatively large in the overall AIDS-related projects supported by the Bank. And the Brazilian management of the AIDS I project has been considered by the Bank as highly satisfactory. These two factors may contribute to the existence of an AIDS III project. Nothing, however, is certain.

In the context of these uncertainties, the concern with the capacity of the preventive actions to continue after the end of the AIDS II project is understandable, especially if there might not be an AIDS III. The strategy adopted in AIDS II to minimize this problem has been to emphasize decentralization. When Bank specialists evaluated the project, under the item on sustainability<sup>15</sup>, they proffered the following argument:

*Sustainability of the activities considered in the Project would be pro-*

<sup>15</sup> Sustainability refers to the fact that the positive effects of the project last longer than the bank's lending. In projects involving service funding, for AIDS, for instance, sustainability refers to the capacity of funded actions to continue even after the project has ended.

*moted by strong government support of preventive services and HIV/AIDS care. Non-government organizations have played a major role in securing the government's attention on this area of health policy. With regard to the funds that the government is spending on health, and more particularly, on drugs for the care of Aids patients (outside the proposed project), the costs for continuing the activities covered by the project are very low.* (WORLD BANK, 1998)

Reading between the lines, for a government that supports actions for Aids on such a large scale and has been ready to spend so much on initiatives that were not so cost-effective, there would be no reason not to pay for the preventive work after 2002, especially that carried out by NGOs. If this strategy is successful, it would block the survival interests of some NGOs against the policy of freely distributing medication. Nonetheless, the Bank also seems somewhat concerned with the rise in public health spending. In this sense, it is still learning the lessons of structural adjustment.

It remains to be seen whether the social movement, which has attempted to create a policy of a universal right to the services and medication required for treatment, will take up the fight to guarantee the universal right to health care on a larger scale. It remains to be seen whether Brazilian society will be moved to preserve the rights secured for Aids patients and extend them to other disease carriers. It remains to

be seen whether the political mobilization in defense of the universal principles of the SUS system will be able to overcome the obstacles against its funding. It remains to be seen whether we will fight for this value of our culture, that is, recognizing that it is not fair that someone should be deprived of the care he or she needs merely because they cannot pay for it. Whether we will confirm the social choice made in the Constitution.

It remains to be seen, on the other hand, whether the Bank, in its political dialogue with the Brazilian government, will fulfil what it claims to be its principles: "respect for different values and social choices" (WORLD BANK, 1997. p. v).

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## Legal responses to the HIV/AIDS epidemic in Brazil

Roger Raupp Rios<sup>1</sup>

<sup>1</sup> Federal Judge

E-mail: algerio@uol.com.br

### INTRODUCTION

The AIDS epidemic has led to numerous reactions and a variety of responses in different settings. Ranging from discriminatory behaviors based on stigmas fed by social exclusion rooted in racial, sexual, and socioeconomic prejudices (PARKER; AGGLETON, 2001) to the institutionalization of its own field of academic studies, the AIDS epidemic is now a reality that virtually no one can overlook.

To a greater or lesser extent, the legal component has permeated practically the entire debate within this huge range of settings for discussion and response.

Analyses of the main social contexts in which stigma and discrimination are manifested involve the following issues: the level of legal protection guaranteed (or denied) by existing legislation (PARKER;

AGGLETON, 2001. p. 28-34); the ways by which drug-related harm reduction policy raises legal controversies concerning the “needle exchange” strategy and the prohibition of alleged incentives for illicit drug traffic (MARQUES; DONEDA, 1998; WODAK, 1998); the impact of public health policies related to STD/AIDS from a gender perspective, requiring a systematic review of the legal instruments that operationalize the Brazilian National Unified Health System, or SUS (ARILHA, 2001); the debate on the position of international funding agencies, with attention towards the legal and Constitutional principles regulating the social order, as written into Brazil’s 1988 Constitution (MATTOS; TERTO JÚNIOR; PARKER, 2001) and public prevention policies with commercial sex workers, requiring a focus on the relationship between female and male prostitu-

tion and the law (RIOS, 2000). This is a brief list of the most relevant issues, the discussion of which entails a number of legal aspects.

There are many ways of (re)acting towards the epidemic. One can immediately glimpse two predominant perspectives, which can be classified as ‘descriptive perspectives’ and ‘operational perspectives’, briefly described below.

However, before defining these two broad perspectives, this study aims to reflect on the practices of legal authorities (judges, public prosecutors, lawyers, law enforcement officers, and professors and students of law) vis-à-vis the epidemic.

My reflection is based on the hypothesis that in light of its effectiveness as a social intervention tool, Brazil’s legal response to the AIDS epidemic is unique and innovative within the country’s legal tradition as a whole. This uniqueness lies in

the fact that for the first time, a satisfactory degree of broad, nationwide effectiveness has been reached with a universalistic, beneficial law that focuses on the struggle against an epidemic shrouded in so many stereotypes and stigmas, capable of fueling large-scale discrimination.

What are the legal concepts and practices that have been developed within this framework, fostering the hope for strengthening the effectiveness of the law? On the other hand, which concepts and practices have tended to undermine this dynamic, the knowledge of which could potentially further strengthen the rights of HIV-positive individuals? What consequences could this phenomenon have for improving the Brazilian legal tradition as a whole?

These are the legal issues involved in promoting a more in-depth debate of the social responses to the AIDS epidemic. The answers to these questions can help improve the quality of the theoretical discussion and intervention in this field. Experience with the epidemic can help unveil these horizons for Brazilian society, even beyond the specific issues raised by the epidemic itself. In other words, such observations

can help improve the entire Brazilian legal system.

#### DESCRIPTIVE AND OPERATIONAL LEGAL PERSPECTIVES IN RELATION TO THE AIDS EPIDEMIC

As mentioned above, two main perspectives emerge when the effects of the epidemic challenge both the law itself and institutional practices by legal authorities.

The first of these is the 'descriptive perspective', involving a compilation and systematic review of the legislation enacted to date in Brazil, encompassing Federal, State, district, and Municipal levels. Despite the difficulty in conducting a project of such breadth, the Brazilian Ministry of Health has produced a comprehensive review of the country's legislation pertaining to STDs/AIDS (BRASIL, 2000)<sup>1</sup>. This compilation, although unquestionably important, is beyond the objectives of the current article, which aims primarily to analyze the law's effectiveness in relation to the epidemic rather than to describe the legislative and administrative sources for Brazilian guidelines on the issue.

Another response provides an 'operational perspective'. Highly rel-

evant, it systematizes and discusses the most effective legal arguments and procedural strategies for the best possible legal protection required by HIV-positive individuals. Based on consecrated hermeneutic canons in legal theory, this perspective requires interpretations of the Constitution and prevailing legislation aimed at extracting the greatest possible efficacy vis-à-vis the reality of the AIDS epidemic, while also pursuing the most adequate procedural strategies.

#### LEGAL RESPONSES TO THE HIV/AIDS EPIDEMIC: INDIVIDUAL AND COLLECTIVE HEALTH ENTITLEMENT AND AN UNDERSTANDING OF THE "LEGAL PERSON" CONCEPT

As mentioned previously, this study is conducted on the level of reflection and analysis. This reflection is based on a hypothesis, namely the novelty of the Brazilian national legal experience in response to the AIDS epidemic. The task at hand is to explain and develop this hypothesis.

In fact, legal treatment of the AIDS epidemic has produced a new moment of tension in Brazilian legal history between the 'law on the books'

<sup>1</sup> This refers to an extensive compilation of domestic and international human rights legislation (volume I), Brazilian Federal provisions pertaining to the Federal administrative organization (volume II – book I – especially in relation to governmental health care management and its agencies, procedures, and programs, regulation of treatment procedures, prevention, distribution of medicines, epidemiological surveillance and health inspection, and hospitalization), Federal provisions on public policies related to medicines, condoms, breastfeeding, blood products, research, immigration, health insurance and health plans, educational measures, social security, social assistance, public and private employment, civilian and military employment, fiscal benefits, penal law, penal prosecution, and ethical norms under the Federal Board of Medicine (volume II – book II); the collection concludes with volume III, grouping various State, Municipal, and Federal District legal provisions.

and 'law in action'<sup>2</sup>. Yet this tension has been resolved in a peculiar way in relation to HIV. Unlike past experiences, in which legal promises have frustrated their low-income and marginalized would-be beneficiaries (confirming the gulf between the 'law on the books' and 'law in action'), in the case of HIV there has been a widespread concrete enforcement of the legal provisions.

To explain better, with the AIDS epidemic, Brazilian law acts by providing for a series of public policies that circulate between (1) their universalistic nature, encompassing the legislation ensuring rights for HIV-positive individuals and (2) the universe of discriminatory representations that have traditionally dominated the Brazilian legal and political mindset. One can argue that none of this is new, at least so far. Brazilian legislation has often promised to establish a new, universalistic reality, acknowledging the rights of all, when in practice these rights are not enforced, blocked by racist and elitist world views and practices, as demonstrated by the phenomena surrounding the abolition of slavery in Brazil (IANNI, 1988; PRUDENTE, 1988; ANDREWS, 1998) and the persistent historical resistance to implementation of land reform and dismantling of the unproductive *latifundio* land tenure structure<sup>3</sup>.

However, when we reflect on the AIDS epidemic we notice something different. Brazil has Federal legislation guaranteeing free distribution of medicines, as well as public policies to implement this health care right. To a major extent this set of initiatives by the public sector is working satisfactorily. Note that in the case of the AIDS epidemic, a health care model is being implemented that simultaneously encompasses preventive and therapeutic measures, as well as actions targeting society at large and specific groups such as homosexuals and commercial sex workers.

Thus, rather than the above-mentioned tension seriously jeopardizing the law's effectiveness, the situation has led to successful implementation of measures in the fight against AIDS. This has occurred precisely in an area where heavy resistance was expected against enforcement of the legislation, given the nature and intensity of the discrimination towards the disease, so frequently associated with stigmatized groups like commercial sex workers, gays, and drug users.

The AIDS epidemic has been associated with numerous stigmas. Suffice it to recall the beginning of the epidemic, when a direct link was drawn between positive blood tests and homosexuality (TERTO JÚNIOR, 1996), to

the point of being identified as 'gay cancer' and having received the 'scientific' classification of GRID, or gay-related immunodeficiency. Since then, gays, prostitutes, call girls, and drug users (HEILBORN; GOUVEIA, 1999) have been perceived as the "natural" repositories and vehicles for the disease (SHARROCK, 1997). Perception of the epidemic developed through a reactive and discriminatory logic, where finger-pointing attempted to distinguish between HIV-positive individuals 'at fault' and the 'innocent victims', establishing and reinforcing standards for normalcy and health, consistently to the detriment of an undesirable 'other', held responsible for what was perceived as a social disease (STYCHIN, 1995; SHARROCK, 1997, p. 364).

This association between HIV-positive status and social estrangement is not a new phenomenon with epidemics. Before AIDS emerged, other epidemics, especially those of sexually transmitted diseases, were linked to undesirable minorities viewed as breaching the social mores (sexual, moral, or economic). Suffice it to recall the association between disease, family breakdown, and prostitution or between syphilis and numerous other infectious diseases linked to African slaves (COSTA, 1999; SCHWARCZ, 1993; SHARROCK, 1997, p. 359).

<sup>2</sup> I am referring here to the discussion by Faria (1993) on the ambiguity between the so-called *law on the books* and *law in action*.

<sup>3</sup> Among the interpretations of Brazilian reality in relation to the selective effectiveness of the law vis-à-vis social and economic demands, see the classical work by Faoro, 2000.



### How was it Possible to Overcome these Challenges and Enforce the Legislation Related to the AIDS Epidemic in Practice?

The issue obviously raises a number of responses and perspectives. Social, economic, political, and anthropological factors can be listed. From the point of view of this analysis, which is specifically legal, I highlight two points: (1) the configuration, in the Brazilian legal order, of health as both an individual and trans-individual right, based on the provision of universalistic public policies in health care, founded on the notion of social solidarity and (2) the expansion of the understanding of the “legal person” concept, allowed by the recognition of different social realities highlighted by the impact of the AIDS epidemic.

#### THE RIGHT TO HEALTH IN THE BRAZILIAN LEGAL ORDER: REPERCUSSIONS OF THE FUNDAMENTAL LEGAL PRINCIPLES AND THEIR CHARACTERISTICS IN LIGHT OF HIV/AIDS

In this section I outline the fundamental traits of the right to health in the 1988 Brazilian Federal Constitution. This characterization is essential for understanding the positive potential of the right to health

in the Brazilian legal order, one of the decisive factors for implementing public policies to respond to the AIDS epidemic. Such provisions are guidelines for legislative and executive activity, besides serving as indispensable orientation when these rights are discussed in court.

#### Characterization of the Right to Health in the 1988 Constitution

The right to health in the Brazilian legal order entails (1) the status of a fundamental right and (2) individual and trans-individual entitlement. It includes individuals, groups, and the community as a whole. It encompasses (3) duties by default and positive duties on the part of the State and the community as a whole<sup>4</sup>. I will briefly explain these attributions.

(1) To say that the right to health is a fundamental right means first that it cannot be overruled by the public powers (Legislative, Executive, and Judiciary branches), nor can it be stricken from the Constitution by means of a Constitutional amendment; it also means that in the exercise of these powers and within the limits of reality, the Brazilian State must do everything possible to promote health. This is what legal doctrine normally

refers to as a “fundamental right by principle”. Fundamental rights are principles by nature when they order the public powers to do “*everything possible*” to implement and enforce them. As defined by Robert Alexy, they are “*mandates for optimization*” (ALEXY, 1997). The consequence for the AIDS epidemic is that the Constitution orders primarily the Legislative and Executive branches to take the greatest possible responsibility for health care. It means that these branches of government have the duty to develop and implement the most effective and comprehensive public health policies possible. In other words, to exclude or overlook HIV, whether by deliberate action or omission, would mean a breach of the Constitution.

(2) The right to health is both an individual and trans-individual right.

(2.1.) It is an individual right, referred to by jurists as a “public subjective right”, that is, the right of someone to demand a given provision (i.e., health care) from the State. Herein lies the individual dimension, by which someone can enter a legal plea for access to medication, a situation on which the Brazilian Supreme Court has already ruled favorably<sup>5</sup>.

<sup>4</sup> For a broad and original study on health as a right and duty under the 1988 Brazilian Constitution, see Tessler, 2001.

<sup>5</sup> I highlight the following excerpts from the abridgement, referring to the Bill of Exception under Extraordinary Review n° 271.286/RS (2nd Panel, Reporting Judge Celso de Mello, unanimous vote, RTJ 175/1212): “*The subjective public right to health represents an inalienable legal prerogative ensured to all persons by the very Constitution of the Republic (article 196). It expresses a Constitutional safeguard, the integrity of which must be upheld under the responsibility of the public powers, to whom it behooves to formulate – and implement – competent social and economic policies aimed at ensuring for citizens, including those with the human immunodeficiency virus (HIV), universal and equal access to pharmaceutical and medical/hospital care.*”

(2.2.) It can also be conceived as a trans-individual right, with two sub-types: (2.2.a.) collective rights and (2.2.b.) diffuse rights.

(2.2.a.) A collective right is when a given group with relatively precise determination of its members resulting from participation in a basic legal relationship may obtain protection for the entire class, so that there can be no satisfaction or loss in the group's representation except such as affects all the members. Examples: HIV-positive patients enrolled in a distribution program for AIDS drugs, linked through a basic legal relationship to the Unified National Health System (SUS); members of the military discharged from service on the basis of their HIV-positive status<sup>6</sup>. If by chance a necessary drug is excluded from distribution, that is, a drug that can be demanded within the health system, this provides the basis for the defense of this collective right through a public action suit, class action suit, or collective injunction, ruled by the group's representative association or by the Public Prosecutor. In such cases, the ruling covers all members of the group, yet members of the group with individual grievances can still continue to take individual legal action.

(2.2.b.) A diffuse right is when a given group with absolutely unde-

termined membership and whose relationship derives from mere de facto circumstance may obtain protection for the entire group. Example: residents of the same area share the diffuse right to a healthy environment, which may include, for example, preventive measures in the case of epidemics. Such rights can be defended by the same procedural means available for collective rights, by the Public Prosecutor's Office or by associations whose objectives include the issue at hand (health or the environment, for example).

#### FUNDAMENTAL PRINCIPLES PERTAINING TO HEALTH IN THE 1988 FEDERAL CONSTITUTION

Having outlined the main normative traits in the right to health, it is essential to highlight its characteristics as a fundamental right in the 1988 Federal Constitution. First of all, the right to health is a fundamental social right, aimed at freedom from social oppression and need (MIRANDA, 1992).

Second, it is a social right<sup>7</sup> predominantly related to health care. It covers the State's provision of goods and services to citizens. The relevance of this aspect becomes evident when one evaluates the legal response to the AIDS epidemic. Suffice

it to recall the frequent legal disputes over the provision of medicines and the passage of Act 9.313/1996, ruling on the free distribution of medicines.

I say it pertains *predominantly* to health care because the right to health also includes a defensive dimension, that is, it prohibits undue interference by third parties within the sphere of personal freedom. Within this dimension, the right to health implies respect by third parties vis-à-vis individual physical and psychological conditions, thereby ruling out undue requirements or excessive burdens or liabilities (SARLET, 2000). An example of this defensive efficacy is the non-compulsor aspect of HIV testing for commercial sex workers, a situation which led to a public action suit by the Federal Public Prosecutor's Office against a municipal ordinance in São Sebastião do Caí, Rio Grande do Sul State (LEIVAS, 2000), which the 4<sup>th</sup> Federal Circuit Court ruled as breaching the Federal Constitution.

Finally, the right to health is ruled by the principle of "equal universal access" (1988 Federal Constitution, article 196). What does this principle provide for? The equal access principle means respect for and observance by public policies of the different situations experienced by HIV-infected individuals. To enforce

<sup>6</sup> Unanimous ruling by the 4th Panel of the Federal Circuit Court, 4th Circuit (AC 2000.71.00.003339-3/RS, Reporting Federal Justice Edgard Lippmann, RTRF-4<sup>a</sup> 41/196), concerning an individual case, the evidence of which presents the potential for characterizing a collective right.

<sup>7</sup> 1988 Federal Constitution, article 6.

the obligation of providing equal universal access means, insofar as possible, to consider the cultural, social, economic, geographic and other forms of diversity of individuals and groups affected by public health policies, enabling the system for provision of health-related goods and services to serve these same individuals and groups. Along this line of reasoning, one can speak of a diffuse right to a health system combining generic measures and specific measures (considering each group's specificity) to fight the epidemic, as indicated for example by the idea of harm reduction among drug users (BASTOS; MESQUITA; MARQUES, 1998). Other situations also illustrate this reality, as demonstrated by campaigns concentrating on commercial sex workers and homosexuals.

This characterization and these principles provide legal authorities with huge possibilities for a Constitutional basis for health-related initiatives in relation to the epidemic. From the legal point of view, they contribute decisively to the implementation of more effective public policies that can be listed among the many factors in Brazil's response to HIV.

Before concluding this section, I wish to highlight the potential of these Constitutional provisions. They establish a highly valuable legal groundwork for the maintenance of current public policies in health even after external funding expires from the World Bank (referring here to phas-

es I and II of the Brazil/World Bank AIDS Project) (MATTOS; TERTO JÚNIOR; PARKER, 2001). They indicate the legislative and executive duties in upholding the Federal Constitution.

#### THE HIV EPIDEMIC AND THE "LEGAL PERSON" CONCEPT

The reflection proposed in this article relates to the effectiveness of legal responses to the AIDS epidemic. I seek to understand the reasons why Brazil's legal experience can both catalyze and inhibit such responses.

As mentioned above, the Constitutional principles pertaining to health and the characterization of the right to health as both an individual and trans-individual right provide a solid legal basis for leveraging effective public policies to fight HIV. On the other hand, there are challenges to the effectiveness in the sphere of legal practice, ranging from economic hurdles against accessing legal redress all the way to the Brazilian court system's lack of preparedness, in terms of human and technical resources, to properly deal with this task.

In this section I emphasize another fundamental aspect for this reflection, through an analysis of the 'legal person' category. Without going into theoretical disputes that are beyond the scope of this study, one can say that in legal common sense, a legal person is a natural human being, capable of acquiring subjective

rights and contracting obligations. According to Ferraz Jr. (1988), the category defines persons as both human beings and legal entities (which has not always been the case from the formal point of view, as illustrated by the legal status of slaves, defined merely as things or chattels, the objects of property rights).

As with all human knowledge, the understanding of this category is conditioned by history. It is essential to examine the concept from this perspective in order to discuss the legal responses to the AIDS epidemic. In fact, the understanding (whether implicit or explicit, conscious or unconscious, veiled or open) of the legal person concept and its relation to HIV-positive status allows one to understand – from the point of view of legal practice – the qualitative diversity of social responses to HIV, that is, the positive (and especially the negative) responses. In addition, it is important to highlight another aspect, which I merely suggest here and which requires more in-depth analysis: that the legal experience provided by the epidemic can even enrich the overall understanding of the 'legal person' concept and expand its horizons.

The concepts present in society as a whole are obviously reflected in the interpretation of the law by legal authorities (lawyers, public prosecutors, judges, professors and students of law, and law enforcement

officials). Their contents ascribe peculiar meanings to legal norms and subvert some of the judicial and political postulates that are dearest to democratic regimes.

In relation to the issue at hand (the relationship between legal person and HIV-positive status), such hegemonic concepts become key ideas for male supremacy, the centrality of the monogamous family as the stem cell for capitalist society, and the quest for economic efficiency, implying the valorization of self-control and discipline. An overall framework is designed which disapproves of what are considered excesses, especially sexual ones, like masturbation, prostitution, and homosexuality (GREENBERG, 1988; WEBER, 1987; FOUCAULT, 1988), the latter particularly associated with a morbid, abnormal character (HAWKES, 1996; BORRILLO, 2000).

In this heterosexual chauvinist universe, the 'human being' as a legal person is the heterosexual male, in a mental operation that subverts the original inspiration contained in: 1) the legal egalitarianism that supplanted caste society and 2) the notion of an abstract, universal legal person (LOCHAK, 1998). – For all

discordant manifestations, the dominant discourse has reserved repressive treatment (USSHER, 1997), never the dignity of a legal person<sup>8</sup>. This treatment betrays the affirmation of *equality in the eyes of the law*, central to the post-French Revolution formulation characterizing *legal egalitarianism*, a trend towards rational simplification of the legal system (by eliminating the plurality of different forms of subjective *status* and universalization of the legal person concept), which broke with the tradition of the *Ancien Régime*, marked by privileges and particularism (TARELLO, 1995).

Observing how HIV-positive status is historically associated with representations linked to deviations in sexual and social behavior helps understand the ideological roots that challenge – in legal reality – the effectiveness of the rights of HIV-positive individuals. In a phenomenon similar to that of homophobia (BORRILLO, 2000 op. cit.), HIV-positive status becomes a factor for stigmatization (GOFFMAN, 1988), thereby constituting a specific form of inequality and discrimination, in a dynamics fed by a series of metaphors: AIDS as death<sup>9</sup>, as horror, as punishment, as

crime, as war, as "The Other", as shame. All of this leading to a widespread process of social exclusion and oppression (PARKER; AGGLETON, 2001, p. 17-25).

HIV-positive individuals, like homosexuals, are allocated to a subjugated role, in a position similar to that reserved for women, conceived as objects of the "middle-class male legal person" rather than as legal persons in their own right. As demonstrated by Richard Collier (1995), women are treated legally as mothers, wives, sexual objects, pregnant, single mothers, prostitutes; they are effectively not full "legal persons", since the beneficiary par excellence of this category is the male<sup>10</sup>.

In this context, HIV-positive individuals can be conceived as diseased, living threats, culprits, transgressors, infective agents, signs of decadence and shame; in short, the 'Other', not sharing the same dignity with legal persons. As a general rule, they are perceived as the object of outside intervention by a State apparatus or through social reactions. Along this line of thinking, all this perspective represents an explicit violation of the legal content in the Constitutional principle safe-

<sup>8</sup> The feminist movement thus engendered a "feminist theory of law", and studies emerged in legal theory from a gay and lesbian perspective. See, for example, Bamforth, 1997.

<sup>9</sup> In this sense, the Brazilian Supreme Court ruled that sexual intercourse between former lovers and forced by the HIV-positive former partner aware of his HIV status demonstrated "evident intent to kill", subjecting the accused to conviction for attempted homicide (Habeas Corpus n° 9.378-RS, sentence handed down on October 18, 1999).

<sup>10</sup> As a reaction to this male chauvinist approach to law, the feminist movement mobilized a feminist discourse in the legal community, elaborating a "feminist theory of law" (SCHULTZ, 1990; FRUG, 1992; BARLETT, 1990; DAHL, 1993).

guarding human dignity, one of the main pillars of which is prohibiting treatment of human persons as things, as mere recipients of outside intervention, as simple objects of state and social action (BENDA, 1996; SARLET, 2001; RIOS, 2001).

This description allows an understanding of how the legal person category can also act to restrict<sup>11</sup> the adoption of public health policies in relation to HIV, as well as establishing punitive and stigmatizing measures for HIV-positive individuals. Illustrating this issue are restrictions against blood donations by homosexuals or the dismissal of government reimbursement for genotyping tests on the grounds of religious condemnation<sup>12</sup>.

It is thus necessary to unveil the mindset underlying the interventions and formulations by legal authorities in this field. Neither can one overlook the consequences of such interventions for the discourses and practices of activists and public officials who act and

react to the AIDS epidemic; otherwise, one ends up undermining the health policies and reproducing stereotypes and discrimination.

There is the additional risk of confusing vulnerability and victimization. Victimization undermines the principles of equality and solidarity, rooted in the widely acknowledged dignity of all, while feeding on the memory of inferiority and the theatrical performance of unhappiness (ROSANVALLON, 1998). Vulnerability, on the other hand, takes the perspective of equality and dignity, contextualizing them in scenarios of injustice, discrimination, oppression, exploitation, and violence that accelerate the spread of HIV (PARKER, 2000; DINIZ, 2001).

Overcoming the mindset described above helps expand our understanding of the legal person, a process in which the intensity and efficacy of Brazilian responses to HIV have collaborated. The issue is to overcome the stigmas and to find the realities and circumstances in the legal per-

son that go beyond the 'white middle-class heterosexual male'.

To achieve this task is a mission requiring complex development and confrontation of numerous issues, extending beyond the scope of this study (GIACOMO, 1995). I merely indicate that the so-called "rights of recognition" can lead us towards this goal, to the extent that by going beyond the traditional legal techniques of defense of privacy<sup>13</sup> and autonomy or those of redistribution of income, wealth, or access to collective goods (LOPES, 1994), they imply respect for and positive integration of the "different" (TAYLOR, 1994; LOPES, 2000; LOPES, 2001). As Richard Parker describes it, this dynamics requires simultaneously respecting and transcending differences, overcoming the opposition between the notions of *us* and *them*, expanding the meaning of *us* in order to allow the incorporation of the meaning of *them*<sup>14</sup>; in short, it requires solidarity (PARKER, 2000).

<sup>11</sup> In the field of childhood and adolescence and in this same restrictive dynamic in the overall category of "human rights", see Fonseca & Cardarelo, 1999.

<sup>12</sup> For example, I refer to the sentence handed down by the São Paulo State Court, which by dismissing the performance of this test and the provision of medicines, after arguing against the provision of services not recommended by the respective Federal health authority, concluded: "*On the other hand, there is no basis to this [alleged] fear of irreparable or difficult-to-repair damage. After all, we are all mortal. Sooner or later, we know not when, we will all be leaving [sic] - some, based on their merit, to see the face of God. Surely this cannot be construed as 'damage'*" (Case 968/01, 7th Panel, Public Finance Court, São Paulo).

<sup>13</sup> Concerning legal issues relating to the right to privacy and the AIDS epidemic, including the association between homosexuality and HIV-positive status, see Tribe, 1988.

<sup>14</sup> See Knauth, Vítora, & Leal, 1998, in which the authors examine the dynamics of the epidemic in three neighborhoods in Porto Alegre, the capital of the southernmost Brazilian State of Rio Grande do Sul (Vila Dique, Valão, and Partenon) and demonstrate the relative significance of the *myself/other* distinction in familiar situations and according to internal differences in each group and location.

## CONCLUSION

From the legal point of view, the Brazilian response to HIV produced a unique situation, both allowing and leveraging the implementation of health policies for prevention and treatment, providing a broad, effective concept of the right to health and its Constitutional principles. Meanwhile, Brazilian legal practice still expresses countless biases and produces discrimination, in a tense relationship between real progress and insistence on exclusionary stereotypes and world views.

Within this framework, deepening and adequately understanding the right to health under the Constitution and its multiple meanings and implications is an indispensable task, both for legal authorities and civil society. By proceeding in this direction, a fruitful dialogue can be established between lawmaking and jurisprudence, public policies, and initiatives by civil society, all in a virtuous circle. This dynamics can help overcome an exclusionary and stigmatizing culture in relation to the 'different', portrayed here on the basis of HIV status.

The domestic and international recognition of the efficiency and merit of Brazilian health policies towards the epidemic is an important factor for strengthening the Constitutional provisions, as well as for a less discriminatory understanding of the legal person concept. These facts alone

have important consequences and constitute a learning process, and if they are used wisely, they can help improve not only the legal responses to HIV, but legal practice as a whole in the face of contemporary problems.

While legal practices can contribute to a more effective social response to the AIDS epidemic, dealing with the epidemic can also help us overcome exclusionary mindsets and legal categories, making a break with mechanisms of inequality and injustice in both the law and society as a whole.

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## Strategies to promote and guarantee the rights of people living with HIV/AIDS

Miriam Ventura<sup>1</sup>

<sup>1</sup> Lawyer. Founder and executive director of Advocaci-Citizen for Human Rights  
E-mail: venturaadv@easyline.com.br

### INTRODUCTION

Firstly, I would like to express my thanks for the invitation to take part in the seminar, and the special position as lecturer on the theme of Brazil's legal responses to the AIDS epidemic. This participation is especially significant since it recognizes the long, hard work done by many professionals to reclaim the importance of law as an instrument of emancipation, social transformation and individual freedom.

I hope that the brief report on our national experience and a frank, broad debate can contribute to the development and improvement of new forms of political participation by those afflicted by HIV/AIDS throughout the world, and help to ensure human rights for all.

### LAW AND SOCIAL CHANGE

It is both comforting and challenging to realize that it is possible

to make proper and strategic use of the law to intervene in the social processes of exclusion, discrimination and stigmatization on behalf of social segments of the population more vulnerable to violations of rights.

These segments are traditionally seen by the legal system only at the moment when they break rules. They are thus deprived from participating in social welfare and common protection for citizens, which in most cases is offered not within the scope of law but rather in the scope of legal protection refused by law enforcement agents, by individuals, communities and the State of law.

Therefore, intervening on behalf of these groups does not simply mean to ensure legal guarantees and establish diffuse control through existing legal instruments, but rather to contribute and foster a deep transformation in attitudes by claimants and claimees with a real effect on power relations.

The AIDS movement in Brazil managed to extract its transforming potential from the legal component by pushing forward broad structural changes through a strategic use of national laws in the scope of human rights. The successful intervention practices of this movement have helped other movements to reflect upon and redirect their lines of action. In recent Brazilian history, no other movement has achieved such a satisfactory degree of efficacy by existing national generic legislation as the movement of those living with HIV/AIDS.

For example, with regard to human rights of women and the black population, it is noticeable that the extraordinary specific constitutional and legal progress achieved with the 1988 Democratic Charter still has to reach a satisfactory degree of jurisprudence and public policy efficacy.

Despite opinions that attribute the success of legal responses in favor

of people with HIV/AIDS to a merciful, humanitarian sentiment in the face of the tragedy, this analysis fails to take into account that the initial profile of the epidemic did not inspire favorable or sympathetic sentiments, as its first protagonists came from highly discriminated and stigmatized social groups: male homosexuals, sex workers and injecting drug users.

Perhaps the so-called “merciful reasons” are one of the sides of this social process of exclusion that reduces the scope of legal protection to which these “undesirable” elements have a right.

However, the movement in defense of people with HIV/AIDS was clever to propose the discourse of “social solidarity” as a matter of human rights and living with AIDS as a question of citizenship. The movement thus took advantage of the new human rights achievements by certain movements (male homosexuals, women, health) in order to promptly respond to arbitrary value judgements, whether camouflaged in traditional public health measures or in discriminatory actions prevalent in various social contexts.

It is precisely in the conflict area that the movement advances to-

wards setting up a more favorable order to its claims, forging its own identity, redefining and altering social positions and relations. So the national experiences of adopting law as a tool to intervene in public policies for the AIDS movement privileged legal demands to mold the necessary legal guarantees to expand and protect its rights.

However, the promotion, defense, expansion and full exercise of any right depend on guarantees in social, political and legal spheres. Accordingly, evaluating these national experiences calls for a brief contextualization of Brazilian conditions that stimulate and/or obstruct the exercise of participative citizenship and adjust legal expression to new and growing social demands<sup>1</sup>.

#### BRAZILIAN LITIGATION EXPERIENCES

We have a rich history of strategic use of law on behalf of public interest, which has had a defining influence on the new movement's choice of strategies in response to the AIDS epidemic.

Right after the Brazilian military coup d'état, two movements

dedicated to defending human rights were founded by different sectors of society with different objectives and dynamics. The first stems from the articulation in defense of human rights aiming at lending legal assistance to victims of the dictatorship. The second, with the informal organization of sectors such as farmers, neighbourhood associations, health advocates, and so on, created and recreated forms of struggle that would lead to the fulfillment of some of their social demands in the area of health, housing, and rural and urban land tenure<sup>2</sup>.

Legal advisory services were born and proliferated within these organizations, justified by the need to create and recreate intervening ways to break down institutional and legal barriers to guarantee basic civil rights<sup>3</sup> and to present demands before the state structure subjected to the dictatorial regime and suffocated/silenced by the strong censorship imposed on the media, a fundamental tool for the assertion of rights.

In these circumstances, jurists really had to “invent” legal forms that would in certain situations have at

<sup>1</sup> BARRORO, Luís Roberto. A igualdade perante a Lei. In: *Revista de Direito Público*, n. 78, 1986a. p.71. ————. *O Direito Constitucional e a Efetividade de suas Normas – Limites e Possibilidade da Constituição Brasileira*, 3<sup>rd</sup> ed., 1986b, p. 128, RENOVAR; CAPPELLETTI, MAURO. *O Controle Judicial de Constitucionalidade das Leis no Direito Comparado*. 1984. p. 98.

<sup>2</sup> PRESSBURGER, Miguel T. A Construção do Estado de Direito e as Assessorias Jurídicas Populares. In: CAMPILONGO, Celso; PRESSBURGER, Miguel (Ed.). *Discutindo a Assessoria Popular*. Rio de Janeiro: Instituto de Apoio Jurídico Popular/FASE, 1991. p. 29-37 (Seminários, 15).

<sup>3</sup> As above.

least a minimum efficacy<sup>4</sup>. Among other effects, this practice was instrumental in breaking the positivist and formalist rigidity of law professionals who saw themselves challenged by situations that found no response in the institutional framework. In this way, popular movements opened sometimes extremely efficient paths to free up what seemed to be legal impossibilities, leaving an extraordinary legacy to future generations.

“The innovative legal services used to overcome the authoritarian regime were based on a growing politicization of demands by the social awareness of both lawyers and clientele. Formal hermeneutics was replaced by a socially oriented exegesis. In addition, legal assistance goes beyond reacting to violated rights to also adopt a preventive attitude – avoiding the occurrence of lesions – as well as being aggressive, through the use of litigation as an instrument for expanding and conquering new rights.”<sup>5</sup>

With the opening of the democratic process in the country, but without the Brazilian people's being able to trust in traditional channels

for claims<sup>6</sup>, civil society optimized old and constituted new forms of social organization and policies that were autonomous from the State.

New actors appear, ready to intervene in the constitution process by developing political actions and formulating alternative proposals for public policies to make effective important rights until then inaccessible to Brazilians citizens.

Given that in the Brazilian legal system, laws are the main sources for law enforcement, the role of jurists of the social movements in the process of drawing up proposals for the Federal Constitution of 1988, State Constitutions and infra-constitutional regulatory laws were of the utmost importance in the constitution legislative process and in approving legal values to act as guidelines for governmental and social action.

#### THE CONSOLIDATION OF BRAZILIAN DEMOCRACY

In the Brazilian experience, the transition to democracy took place on the political and normative level with the formal reclaiming of citizenship

and democratic institutions, marked by the return of direct elections for Heads of the Executive, resumption of the division of Powers, and an extraordinary national normative production aimed at protecting and promoting a vast array of individual and social rights and guarantees.

Nonetheless, the actual consolidation of the democratic regime on the social level is still underway due to the economic and social difficulties caused by the long period of dictatorial regime and a culture permeated by social and personal authoritarian, dominating and unequal practices.

The current Brazilian scenario clearly shows that civil and political rights have not yet been perfectly assimilated by citizens, and that basic social rights such as health, education and social welfare are not fully guaranteed.

Norberto Bobbio states his concern with the new times of human rights by declaring that the problem we face is not philosophical but rather juridical in its widest political sense, of how to guarantee human rights and prevent them from being constantly violated, in spite of all the solemn declarations<sup>7</sup>.

<sup>4</sup> PRESSBURGER, Miguel T. *Direito Insurgente: o Direito dos Oprimidos*. In: RECH, Daniel *et. al.* (Ed.). *Direito Insurgente: o Direito dos Oprimidos*. Rio de Janeiro: Instituto de Apoio Jurídico Popular/FASE, 1991. p. 9 (Seminários, 14).

<sup>5</sup> CAMPILONGO, Celso. *Assistência Jurídica e Realidade Social: apontamentos para uma tipologia dos serviços legais* In: CAMPILONGO, Celso; PRESSBURGER, Miguel (Ed.). *Discutindo a Assessoria Popular*. Rio de Janeiro: Instituto de Apoio Jurídico Popular/FASE, 1991, p. 16-17. (Seminários, 15).

<sup>6</sup> Before 1964 the Brazilian State organized its social representativity in two ways: parties and unions. According to the observation by Miguel Pressburger in the mentioned work, the military coup dismantled both these ways, which even after being recreated, were in such way linked to the State that ceased to be representative.

<sup>7</sup> CAMPILONGO, Celso, 1991, p. 25.

There is no doubt in our mind that the consolidation of Brazilian democracy has to encompass civil society's awareness of its rights, and especially that this depends on strategies to ensure these rights.

Within this context, it becomes very important to use law on behalf of public interest and to adopt litigation strategies used by the movement of people with AIDS, with special emphasis on expanding the access of the population to legal services, particularly (but not exclusively) those of an innovative nature<sup>8</sup>, as they tend to share with the Judiciary Power a fundamental role in the assertion of the new rights.

The big challenge for social movements in this new stage of the Brazilian struggle – and especially for legal professionals – is to make access to justice feasible, this being understood here as access to legal benefits in general on legislative, administrative and judiciary levels, and to introduce new interpretations on the meaning of the law and specific rights.

Brazil's transition into a democratic state of law was notably conducted by the outgoing authoritarian power. Despite the way it was done, the transition that started in 1985, after twenty-one years of dictatorial military rule (1964–1985), resulted in a good constitutional text (1988).

Many of the yearnings of the population and organized segments

of society were incorporated into the constitutional normative plan that:

- broadened rights on individual, collective, social and economic levels;
- established institutional mechanisms of social control based on strengthening civil organizations, for example by making organic and community participation obligatory in social security administration;
- introduced process instruments for defending rights in public, collective and individual spheres, and fortified the legal system.

The Federal Constitution was based on the prevalence of human rights, guaranteeing automatic incorporation of all the rights expressed in international treaties signed by Brazil, and broadening and integrating the national system to the international system of human rights.

#### STRATEGIES IN DEFENSE OF THE RIGHTS OF PEOPLE WITH HIV/AIDS

Unlike the women's movement and the black movement, the movement of people with HIV/AIDS is very new. It began in 1982 with the detection of the first case in the country and the coordination of social scientists, health professionals, media, gay militants, artists and others in an attempt to alert the govern-

ment and the population as a whole about the seriousness of the epidemic that loomed ahead.

The powerful social reaction and the violation of the basic human rights of individuals initially identified as bearers of the new disease – gays and hemophiliacs – led to the rise of a new condition of social exclusion that marked many persons as bearers of a disease that affected “deviants”.

Because of the strong social reaction and the infection's dynamics itself, the language of human rights was adopted on the international level, either to guarantee human dignity against arbitrary State and individual actions, or because of the understanding of public health specialists that vulnerability to the disease extends far beyond a biological dimension and seriously reflects the situation of structural imbalance in which we are living. Therefore, it was definitively accepted that promoting and protecting health are intrinsically linked to promoting and protecting human rights.

The first NGOs to work with AIDS in Brazil date from 1985. Special mention is due to the AIDS Support and Prevention Group (GAPA) in the State of São Paulo, which has from the very beginning included in its proposal a legal-aid service for people with AIDS and their families, with actions geared to fight discrimi-

<sup>8</sup> As above.

nation and to general prevention campaigns. It was also in São Paulo that the first governmental response was set up, with the founding of the AIDS Reference and Training Center (CRTA), centralizing attendance and information, promoting continuous prevention campaigns and launching the pioneer community handson work in Brazil that served as a stimulus for the appearance of the first NGOs dedicated to working with AIDS in São Paulo.

The response in the State of Rio de Janeiro was very different from São Paulo. The first initiatives in the community field were led by Herbert de Souza (Betinho) and Herbert Daniel, both recently returned from political exile and both carriers of the HIV virus, who brought their opposition stand and markedly reformist traditions to the fight against AIDS. In December 1986, the alliance of the two Herberts<sup>9</sup> and the adhesion of researchers from various areas produced the Brazilian Interdisciplinary AIDS Association (ABIA), a totally professionalized organization that set out to place the AIDS theme in the larger context of public policies by

facing prevention and care within a strategic view of democracy.

In early 1989, Herbert Daniel and a group of friends set up the Group for the Valorization, Integration and Dignity of the AIDS Patient (“Grupo Pela Vidda”), considering the need for people with HIV and AIDS, their friends and family members, to play an active and determining role in public AIDS policies, thus abandoning the traditional passivity and victimization that characterize certain forms of discourse.

The proposal to make people with HIV/AIDS protagonists, thus denying the immobilization caused by the fear of living with the disease, involves innovative legal assistance to politicize the demands, to touch legal professionals and activists and to propose actions that go beyond reacting to violated rights, but that also formulate alternative proposals in the field of public policy and turn important rights, recognized in the recently approved Federal Constitution and until then inaccessible to Brazilians, effective.

These initiatives<sup>10</sup> basically shaped the hundreds of NGOs set up

in different Brazilian States, struggling for a minimum proposal for an AIDS program in Brazil. The many different non-governmental organizations that deal with the question of the AIDS epidemic<sup>11</sup> have served as privileged forums for the discussion and demand of these “new rights” and for the formation of more participative citizens, thereby contributing to strengthen human rights.

At first the new movement rose up against the omissions and inadequate actions imposed by official institutions, organizing a response that involves different levels of action, such as:

- prevention and education by means of campaigns with the population and the media;
- integral assistance and physical and mental care for AIDS patients;
- activism through pressure and discussions with the government to demand effective measures against the epidemic; and
- specific legal advice in cases of clear discrimination or arbitrary conduct, or in the absence of social and health assistance.

<sup>9</sup> These public characters and others such as Henfil, Chico Mario, Markito, Cazuzu, provided higher visibility to the actions and sparked the interest of the press.

<sup>10</sup> The Ford Foundation, following its tradition of providing incentives to innovative social experiences in Brazil, since the beginning of the 70's, even before the country's re-democracy process, assisted these differentiated projects (ABIA, GAPA and Pela Vidda Group), immediately allocating resources and serving as a reference point to other international funding agencies from the US and Europe.

<sup>11</sup> The first NGO/AIDS catalog published by the Ministry of Health in 1995 listed 400 entities. The current mailing list of the sector responsible for articulation with NGOs in the Ministry of Health's National STD/AIDS Prevention Coordination stands at 600 addresses, including organizations that, despite working with the AIDS issue, cannot be considered typical AIDS NGOs, such as feminist groups, homosexual groups and the AIDS commissions in unions.

Since 1992, this Brazilian response to the HIV epidemic, marked by the leading role played by civil society, resulted in the formation of important partnerships with Professional Boards, Trade Unions, other social movements and governmental agencies.

The first mobilizations took place within the sphere of the Legislative Powers, resulting in two important legal markers. Law 7670 of September 8<sup>th</sup> 1988, which extended to AIDS carriers benefits such as health treatment leave, retirement and military reform, and Law 7649 of January 25<sup>th</sup> 1988, preceded by State Laws 5190 of 20/06/86 (São Paulo) and 1215 of 23/10/87 (Rio de Janeiro), making tests for detection of anti-HIV antibodies in the blood to be used in transfusions obligatory, were the result of the coordination and mobilization of the AIDS movement and the Brazilian health movement.

Although the movement did not have a direct active participation in the pre-constitutional process, it quickly put to good use the constitutional advances in defense of its interests, the driving axis being associating the AIDS problem with health questions in general, as a fundamental right of human beings that the State must provide through economic and social policies and not just through actions in the area of health care.

So, the gains obtained benefited the whole population, as is the case of

regulating the control of blood, health plans and access to medications.

There have been few conquests on the federal legislative level. As a matter of fact, the movement, considering the urgency of issues related to the AIDS epidemic and the Brazilian experience of not implementing various specific laws, has privileged a legal path for demands by sustaining the self-applicability of the constitutional provisions and action before the Executive Power through participation in different projects, boards and committees.

On the federal legislative level, Brazil did not adopt measures that violated individual rights, such as compulsory testing. Nevertheless, this does not mean that violations do not exist, which has sometimes allowed the Judiciary and the Public Ministry (law enforcement inspector) to issue statements about testing for child-adoption, inmates, the Armed Forces, employees, etc. The legal decisions and expert opinions are ambiguous and very diversified, particularly when it is a matter of testing in segments with less capacity to demand and protect their rights.

In fact, what has guaranteed advances and stability in health policies with regard to the AIDS epidemic is the social control exercised by non-governmental organizations that work in this area, the international pressure – through International AIDS Conferences – and the legal focus in advocating for major issues.

It is interesting to observe that the strategic use of national laws by these groups achieves significant jurisprudence progresses that altered the interpretative attitude of the courts without altering or creating new laws, and served to stimulate adoption of urgent measures in the sphere of public and even private services. Only now are legislative advances being stimulated, with various bills being discussed, designed to give legal guarantee to the advances obtained.

To illustrate the matter, it is enough to recall the construction of universal access policy to medication for treatment of people with HIV/AIDS. Claims in the Judiciary started in 1990, designed to pressure the Executive Power to establish a policy of integral and universal assistance to people with HIV/AIDS. Legal actions constituted considerable jurisprudence that established the State's obligation to offer integral, free and universal treatment to carriers of the HIV virus.

Legal decisions were the key incentives to public administration, added to the advances made by the Brazilian sanitary movement that formed the Integrated Health System (SUS) and the new concept of health in the Federal Constitution. These decisions helped to establish a broad policy of universal access to medication, which began in 1991 with the distribution of AZT in the public health network and was expanded as of 1995 with the supply of differ-

ent medications that make up the so-called “cocktail”, periodically reformulated by a technical consensus that establishes the anti-retroviral therapy to be adopted and provided by the SUS. Only in 1996 was the medication policy made legitimate by the Legislative Power with the approval of Law 9313 of November 13<sup>th</sup>, 1996, which declared that SUS was obliged to supply all the medication necessary for the treatment of people with HIV/AIDS.

Other significant examples are: the right for workers who have the HIV virus to withdraw their “Length of Service Guarantee Fund” for health treatment, (now done by administrative request, formerly only allowed in cases of dismissal or retirement); the obligation of group-medicine and health-insurance companies to cover the cost of AIDS treatment, thereby requiring specific legislation that incorporated this obligatory attendance to all diseases; making the Union and States responsible for blood contamination via transfusion or through use of hemoderivates, condemning the government to pay indemnity in the form of food support for transfused people and infected hemophiliacs; re-admission of workers dismissed due to discrimination and condemnation of the company to pay indemnity for

moral and material damage; re-admission of military personnel excluded from the Armed Forces because HIV; supply of medication by the government (universalized by Law 9313/96) and specific high-technology tests. Other questions can be added of a less demanding nature, but which show the change in the interpretative attitude of Brazilian law courts, such as: making it obligatory for schools and kindergartens to accept sero-positive children; prohibiting compulsory testing in inmates and sex workers; obliging family members to provide financial and material support to needy AIDS patient relatives; prohibiting testing in children in cases of adoption and foster regime.<sup>12</sup>

As legal conquests were obtained, activists tried to gain more visibility through the media, allowing other segments of society to realize the importance and possibility of claiming social rights such as the right to health, education and work before the Judiciary Power. No doubt these legal questions made a great contribution to public policies on health and assistance to carriers of deficiencies, and today there are more and more claims of the same nature presented before the Judiciary.

But the process of rights assertion does have its onstacles. If the legal decisions were almost always favorable in first hearings, inspired by a feeling of compassion, they became fragile in the upper courts, after the emergency situation had passed, which called for powerful mobilization of activists to guarantee the initially recognized right. Certain requests, due to their lower tension (for example, pharmaceutical assistance, indemnity for transfusion infection) received more positive responses, since these questions involved private health companies, despite the concessions in lower-court decisions, fearing that the patient might die, depended on strong social pressure to finally form a jurisprudence favorable to protecting human rights. Nevertheless, the end result was positive and encouraged other groups.

The legal-advice model initiated by GAPA/São Paulo and Grupo Pela VIDA in Rio de Janeiro<sup>13</sup> was repeated in several Brazilian States. At present, various NGOs that work with AIDS offer legal-assistance services to the target-public. It is estimated that there is a total of 36 projects developed and financed by the National STD/AIDS Program of the Ministry of Health, distributed all

<sup>12</sup> See *HIV nos Tribunais*, organized by Marcelo Moscolgiato, published by the Brazilian Ministry of Health, Office of Health Care, National STD/AIDS Prevention Program, 1995, also available at: [www.aids.gov.br](http://www.aids.gov.br).

<sup>13</sup> In 1993, with the support of the Ford Foundation and Sociedade Viva Cazuza, the Pela VIDA Group published the first work in Brazil about the subject Rights of People Living with AIDS/HIV (*Direitos das pessoas vivendo com HIV/AIDS*), organized by Miriam Ventura, that compiled the legal basis supporting judicial actions.

over the country. These initiatives were and are still of crucial importance, whether from the social and political point of view or because they enable people with HIV/AIDS to have access to the State structure as active subjects.

The known obstacles to the continuity and improvement of these free services are: the slowness of the legal framework, which causes processes to build up in these areas; the constant alterations of professional cadre involved, most of them volunteers or with very low remuneration; the slowness of the legal system and the urgency imposed by certain demands; the limitations of the legal decision itself, which, despite ruling certain relations, fails to interfere in the logic of some policies, and the questions are solved as a general issue (such as re-admission of workers, non-access of sero-positive persons to work, the criterion used by medical-welfare inspectors to grant illness benefits, retirement, life-time monthly income, among others).

The alternatives being implemented are agreements and partnerships with Law School model offices. This allows for fuller assistance and gives law students the opportunity to develop specific knowledge on the matter, as well as offering training and awareness courses<sup>14</sup> for lawyers, Public Min-

istry and Labor Inspectors to stimulate and sensitize these professionals to advocate for these new issues.

Although litigation has had a great social impact and made it possible to change some policies, legal actions concentrate on access to health and welfare goods and services and on guaranteeing employment for workers with HIV who are part of the formal economy. However, the strategy proves insufficient to solve serious structural problems such as access to work and/or alternative economic placement for infected persons with little schooling or who are unemployed, support programs for orphans, pregnant HIV+ women, etc.

The results demonstrate that new strategies should be introduced in the movement to increase activity before the Legislative Power and expand social policies beyond the health sector in the Executive Power sphere.

Today, therefore, the big challenge for the movement is to restructure its legal advisory activities by transferring the high volume of demands from assistance to public defendants, and also, based on the accumulated knowledge and the great capacity for political coordination in the national and international arena, by working on proposed State-restructuring projects that reach core development problems revealed by the epidemic, con-

sidering the new epidemiological profile - mostly women in reproductive age and young people from the poorer segments of society.

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<sup>14</sup> Promoted by the Human Rights Network of the National STD/AIDS Prevention Coordination, Ministry of Health.



## The experience of providing universal access to ARV drugs in Brazil

Marco Antônio de Ávila Vitória<sup>1</sup>

<sup>1</sup> National STD/Aids Program – Ministry of Health – Brazil

E-mail: vitoriam@who.org

### INTRODUCTION

The Brazilian HIV/AIDS drug policy has been extensively discussed and even criticized, particularly at the time of its implementation by the Government in the early 90s. However, after a decade of action, the success of the Brazilian response to HIV is evident and achieved worldwide recognition, based on a concerted early governmental response, a strong and effective participation of civil society, a multi-sector mobilization, a balanced prevention and treatment approach and the advocacy of human rights in all strategies, particularly with the policy of wide access to antiretroviral (ARV) drugs.

In order to improve quality of life for people living with HIV and AIDS, the Brazilian Ministry of Health (MoH) implemented a policy of universal free of charge access to antiretroviral therapy in the mid 90's. This effort was

initiated in the early 1990's with limited distribution of the ZDV capsules, and was strengthened with a 1996 presidential decree that ordered all HIV-infected citizens to have free access to essential medication to combat HIV. The distribution of protease inhibitors began between December 1996 and January 1997. The same presidential decree stipulated that the criteria for dispensing HIV treatment would be established by the Ministry of Health, which had two task forces working on the problem, one focusing on HIV therapy for adults and adolescents and one for children. The two task forces gathered at least once a year to review established criteria and to discuss new medical breakthroughs and the availability of new treatments.

### BRIEF OVERVIEW

By the end of 2001, approximately 113,000 patients received ARV

through the public health system, representing roughly US\$ 232 million in expenditures to buying a list of 14 drugs that make up the so-called "anti-HIV cocktail". These expenditures with antiretroviral drugs represent 1.6% of the total budget for the Ministry of Health and less than 0.05% of Brazilian GDP in 2001. In addition, the Brazilian Government established national HIV treatment guidelines for adults, children and adolescents and implemented a logistic control system of these drugs in more than 400 ARV dispensary units throughout the country and, in order to adequately monitor treatment, it also established a National Network of Viral Load Laboratories and a Network of TCD4+TCD8+ Lymphocyte Counting laboratories, with 73 and 65 units, respectively. Concomitantly, a network of approximately 900 public alternative HIV/AIDS care services was built up based on

regional and administrative divisions according to the complexity of the care needed, in order to improve the monitoring of HIV infection and for diagnosis and medical observation of opportunistic diseases. It is also important to say is that the acquisition of drugs to treat AIDS-related opportunistic diseases was established as an attribution of states and municipalities.

### FIRST RESULTS

After five years, the results of these strategies were impressive. From 1996 until now we have observed a striking reduction on mortality, morbidity and hospitalization rates for HIV+ patients in Brazil, with cost-reduction for this antiretroviral therapy policy.

The occurrence of HIV-related opportunistic infections decreased by 60-80%. Tuberculosis in HIV+ patients, for instance, dropped 75% in the last four years, in the State of São Paulo, which accounts for roughly 50% of all AIDS cases reported in Brazil. Moreover, a change in the profile of HIV health care services was observed, with a significant demand increase for outpatient, home care and a decrease for in-patient and day-hospital services.

Another figure that reflects the impact of the Brazilian policy of universal access to antiretroviral drugs is the phenomenon of partial immunological reconstitution promoted by

the treatment. This was demonstrated by the evolution of the mean TCD4+ cell count in HIV+ patients on ARV therapy after widespread use of HAART in Brazil. In a small study conducted by MoH in 2002, we observed that the mean cell counts rise progressively from 267 cel/mm<sup>3</sup> to 426 cel/mm<sup>3</sup> after 24 months of treatment with combined ARV regimens. This improvement seems to significantly contribute to the reduction in frequency and severity of opportunistic diseases associated to HIV and to be a good indicator of the better quality of life of patients treated in the public health network.

### RECENT DATA

All of these aspects are consequences of an evident reduction in the number, time of duration and complexity of treatment in hospital admission episodes, suggesting a significant welfare profit for these patients after a more disseminated use of antiretroviral combined therapy. It is also worth noting a reduction of more than seven fold in hospitalization rates and 358,000 avoided AIDS-related hospital admissions, resulting in an overall saving to the Government of more than US\$ 1.1 billion for the 1997-2001 period.

By the end of 2001, the Brazilian MoH distributed 14 antiretroviral drugs of three different pharmacological classes to all HIV infected patients that meet the criteria estab-

lished by national guidelines. Of these, we have eight locally produced anti-retroviral formulations, with pharmacological specifications for generic versions of these groups. A new drug, an association of Lopinavir/ritonavir (LPV/r), was added to this MoH list in March 2002.

Furthermore, prices of antiretroviral drugs purchased by the Brazilian MoH have been declining quite significantly over the last few years. This is mainly thanks to, firstly, investments made by the MoH to set up domestic national laboratories and, secondly, effective negotiation of drug prices with international pharmaceutical drug companies that are exclusive producers of certain anti-AIDS drugs. At this moment, we have 6 federal ARV pharmaceutical producers and one of them, the Farmanguinhos/Fiocruz Pharmaceuticals (from Brazilian MoH), is responsible for approximately 40% of the total amount of antiretroviral drugs used in Brazil. In fact, prices of drugs produced within Brazil, fell on average 82% between 1996 and 2001, however, imported drugs fell only 25% during the same period. In 1999, the expenditures with imported ARV drugs represented 81% of total MoH budget for ARV drugs, but in 2001 it has dropped to approximately 57% and 63% of ARV consumption in the Public Health System are locally produced versions of these drugs.

## NEGOTIATION STRATEGIES

To avoid the use of compulsory licensing in certain situations, the Brazilian MoH also has used a negotiation strategy with some exclusive producers based on tiered or differentiated prices. An agreement with Merck Sharp & Dhome Laboratories to reduce the prices of two anti-retroviral medicines produced by that company was announced in April 2001. Indinavir underwent a price cut of 64.8%, Efavirenz had its price reduced by 59% and another negotiation occurred in 2001 with Roche Laboratories which cut Nelfinavir prices by 40%. Recently, an agreement with Abbott Laboratories has also reduced the price of its new protease inhibitor (LPV/r) by 46%. With these strategies, the average cost for patient/year in antiretroviral therapy decreased by half in recent years, in spite of the proportional increase in the number of patients needing more expensive, complex treatments.

The average cost for patient/year in antiretroviral therapy decreased a full 48% between 1997 and 2001 (from US\$4,860 in 1997 to US\$2,530 in 2001). It is also important to emphasize that local production of HIV-drugs is being done only for domestic consumption. Negotiations are the Brazilian Government's first option when dealing with drug companies. The compulsory license is only a safeguard and last option in order to provide

access to medicines for the Brazilian people and has never been used, up to now.

## ARV ANTIRETROVIRAL DISTRIBUTION AND CONTROL

The Brazilian MoH also has implemented a specific computerized system for logistic distribution and control of anti-retroviral drugs named SICLOM. At this moment, SICLOM is fully implemented in 111 antiretroviral dispensary units, and covers around 65% of total patients on ARV treatment in the Public Health System. The major objectives of this logistic control system are:

- to control drugs stock at national, state and municipal levels;
- to assure efficiency and safety in the provision of drugs;
- to plan the purchase of drugs; and
- to assure general management of drugs.

All these strategies and tools certainly contributed to promote sustainability and maintenance to the universal access to ARV policy adopted and when we analyze the final costs of ARV expenditures and the savings of hospitalizations/opportunistic infections treatment avoided, we can see that the Brazilian ARV access policy is cost-effective.

We estimate that the Brazilian policy for national production of ARV drugs has represented an economic

saving of approximately 490 million dollars in the 1996-2000 period. With the start of local production of Nevirapine and Indinavir, the Brazilian Government has saved approximately US\$ 80 million in a one-year period, which represented 30% of global expenditures in 2000. Another new strategy that we are now evaluating is the local production of a generic version of new co-formulation and presentations of ARV that will reduce the daily pill burden, which will improve adherence to treatment and can promote an additional cost reduction.

## ADHERENCE TO TREATMENT

The Brazilian MoH has also created an advisory committee to establish the official recommendations for treatment with antiretrovirals. Accordingly with the most recent review of Brazilian antiretroviral guidelines, the use of potent antiretroviral therapy was established as standard of care. Antiretroviral treatment is recommended for all symptomatic (AIDS) individuals, regardless of laboratorial parameters, and if patients are asymptomatic, it is indicated only if the CD4 cell count is lower than 200/mm<sup>3</sup>. However, these guidelines consider the use in asymptomatic patients if the CD4 cell count is between 200 and 350/mm<sup>3</sup>.

Another important topic is adherence to antiretroviral treatment. Recently we conducted a multicentric trial in 27 care units in the State

of São Paulo, with a follow up of almost 9,000 HIV+ patients. The study considered the capacity to take more than 80% of prescribed pills as a definition of good compliance. At the end of the study we calculated an adherence rate of 69%, which is very similar with the results found in international studies. In this study, the major factor associated with good adherence was the quality of medical service. Now, we are starting a new complementary study, in order to evaluate the quality of care in AIDS outpatient services and its relation to patient adherence to antiretroviral therapy.

Until this moment, the prevalence and profile of drug resistance mutations in Brazilian patients under HAART has been very similar to what have been found in international studies. However, the prevalence of primary resistance in first time drug patients is less than 8%, significantly lower than the rates seen in Western Europe and the US. Together with striking reduction on mortality, morbidity and hospitalization rates for HIV+ patients, the quality, safety and efficacy of generic antiretroviral drugs are reinforced and so is the policy of universal access to ARV therapy adopted by the Brazilian Ministry of Health in the last decade. However, considering the impact that this aspect can have on the Brazilian HIV treatment policy, the MoH decided to establish a National Network of Genotyping Test

(RENAGENO) able to perform and interpret the results of HIV-1 resistance tests using an adequate and rational criteria. For the initial implementation of this network, 12 laboratories were accredited and 60 reference genotyping expert physicians from different parts of the country were trained to act on a regional basis.

#### EXPRESSIVE MEASURES TAKEN BY BRASIL

It has been a long process to arrive at these achievements, and some lessons were learned. Firstly, some adherence strategies to optimize the antiretroviral therapy are needed. Pilot studies in Brazil have demonstrated that feasibility, efficacy and adherence rates with antiretroviral treatment are similar to those obtained in high-income countries, even among patients with low education or with important social limitations. Training projects for health care workers and organization of patients groups to improve adherence also have been identified as important factors that explain the success of this process, that used simple clinical and laboratorial tools for diagnosis, treatment monitoring and approach.

Secondly, the participation of civil society at every level of decision-making and during the elaboration of relevant strategies is of paramount importance. I have to emphasize that this is one of the key as-

pects of the Brazilian STD/AIDS Program and has served to help guarantee the human rights of patients with HIV/AIDS and other STD, and the execution of community projects and the building of partnerships with the private sector.

However, some challenges are coming. In the near future, the Brazilian Government must improve the diagnosis of HIV infection in early stages, ensure mother to child transmission prevention for all pregnant HIV+ women around the country, expand the CD4 and viral load laboratory networks so as to decentralize it, and better monitor adherence and viral resistance, particularly in 'hard to reach' groups.

Brazil also has made its voice heard in several international forums worldwide promoting the expansion of access to ARV. Among them, it is worth highlighting the Brazilian participation at the 57th Session of the United Nations Commission on Human Rights, held in April 2001, advocating the provision of treatment and care to HIV/AIDS patients as a fundamental human right. Brazil has also consistently pushed for the flexibility of the WTO-based TRIPS (Trade Related Aspects of Intellectual Property Rights) Agreement, and the IV Ministerial Meeting of the World Trade Organization, held in November 2001, is a cornerstone example of success of the Brazilian policy. As a member at the Transitional Working Group of the Global

Fund to fight Aids, Tuberculosis and Malaria, Brazil has also played a very important role to ensure the participation of developing countries and civil society actors in its decision-making structure. Finally, it should be said that Brazil articulated and collaborated, in partnership with the Horizontal Technical Cooperation Group of Latin America and the Caribbean, in the elaboration of an international Databank of Prices of Aids Drugs.

Considering all aspects described above, it is now clear that past objections to HIV treatment in developing countries is not persuasive anymore and there are strong arguments in favor of the effort for widespread treatment access. A considerable amount of evidence suggests that an effective Aids treatment is possible even in low-income countries. Contrary to what the World Bank expected in early 90's, that 1.2 million people would be infected by the year 2000 in Brazil, recent estimates have placed the figure at 597,000 HIV carriers, or in other words, approximately half the number predicted some years ago. This performance is highly significant, even taking into account possible statistical errors and epidemiological trends, and represents a result of balanced efforts in prevention and care. Reducing prices of antiretroviral drugs and promoting other strategies to expand effective access to them can dramatically alter the economics of

HIV/Aids treatment, and possible obstacles to adequate treatment such as poor infrastructure can be overcome through a well designed and supported international effort to improve the approach to Aids both in rich and poor nations of the world.

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## Non-governmental organizations and access to anti-retroviral treatments in Brazil

Carlos André F. Passarelli<sup>1</sup> & Veriano Terto Júnior<sup>2</sup>

<sup>1</sup> M. A. in Social Psychology, ABIA Project Officer  
E-mail: [passarelli@abiaids.org.br](mailto:passarelli@abiaids.org.br)

<sup>2</sup> Psychologist, Doctor in Social Medicine, ABIA General Coordinator  
E-mail: [vterto@portoweb.com.br](mailto:vterto@portoweb.com.br)

### INTRODUCTION

Some authors who studied the response of Brazilian non-governmental organizations (AIDS/NGOs) to HIV infection note the scarcity of analyses and reflections on the role played by organized civil society in establishing a collective agenda to deal with the problems produced by the AIDS epidemic (GALVÃO, 1995). Even today there is a need for more analytical studies, and the vast majority of the texts published on the matter are more concerned with the future scenarios (sustainability) of the AIDS/NGOs than with the analysis of paths traveled so far. This article aims at a reflection on the importance of activism by organized groups in the achievements related to treatment access for people infected by HIV/AIDS.

Accordingly, in this text we shall concentrate on recent years, more

specifically from 1996 onwards, year of the 11<sup>th</sup> International Conference on AIDS held in Vancouver, Canada, where new therapeutic alternatives were announced that used a combination of anti-retroviral medicines. Even taking into account possible technical, political and operational divergences regarding access management and use of anti-retrovirals and the fact that new therapies never cease to emerge, there does seem to be a unanimous understanding that the epidemiological profile seen today in countries where the population has access to anti-retrovirals contradicts all the expectations formulated in the late 1980s, when only Zidovudine (AZT) was available for the treatment of AIDS. In Brazil, for example, the prediction was that there would be over a million people infected in the year 2000, whereas today the most pessimistic estimates point to just over

half that figure (BRASIL, 2002). According to the Ministry of Health, up to September 2001 the country had 222,356 cases of AIDS, of which 73% (162,732) were in men and 27% (59,624) in women (BRASIL, 2001). The National Coordination for the Prevention of STDs and AIDS (CN-DST/AIDS) estimates that there are 597,000 Brazilians infected by HIV, and that 105,000 of this total received medicines for the treatment of AIDS in 2001 (BRASIL, 2002 b. p. 5). In addition, the savings as a result of reducing the number of hospital admissions and the lowering of mortality and morbidity rates due to opportunistic diseases is an indicator of success by these new treatment modalities, despite the fact that we still lack data on this matter in developing countries. According to data by the CN-DST/AIDS, there was a decrease of about 50% in deaths as a result of AIDS throughout the country, a fig-

ure that rises to 71% in the State of São Paulo. With regard to hospital admissions due to opportunistic diseases, from 1997 to 2001 there was a reduction of approximately 80%, which in terms of resources represents an economy of approximately US\$1.1 billion (BRAZIL, 2002 b. p. 28).

On the other hand, by increasing the length and quality of life for patients with AIDS, universal access to treatment generates social gains, that is, the possibility of restituting the working capacity of affected individuals, since the HIV infection impacts segments of the population in the age bracket considered economically active. At the same time, furthering the integral health of those suffering from AIDS makes it possible to lower the appearance of new cases, since patients become engaged in an active process of prevention of opportunistic diseases and other sexually transmissible diseases, and take more care as regards their own sexual health.

Today there remains no doubt about the causal connection between the policy of distributing medicines, the stabilization of the number of new cases, and the enhancement in quality of life of people living with AIDS.

Nevertheless, we know that this success is not only due to the discovery of new therapies and expanding access to treatment. The numerous efforts made and the amount of resources involved in primary prevention of HIV infection, whether by

means of informative campaigns or actions by NGOs and health services, serve as an example for the multifaceted, intersectoral and interdisciplinary nature of the responses that civil society and the Brazilian government have been giving to the problem (GALVÃO, 2000).

However, the success of the Brazilian experience in the field of AIDS cannot be analyzed without taking into account the context of public health in our country. It is undeniable that what makes the Brazilian case exemplary in comparison with other developing countries is precisely the fact that the federal constitution presupposes health as a universal right and a duty of the State guaranteed by the Integrated Health System (SUS). The principles of SUS are integral assistance, universal access and social control (Federal Constitution, title VIII, chapter II, section II, articles 196 to 200); and with specific regard to AIDS, SUS also adopts a policy of distributing medicines to meet the needs of those who live with HIV/AIDS, have access to health services and satisfy the criteria established by national guidelines for anti-retroviral therapy, regulated by specific legislation. In accordance with Law 9.313/96, a group of specialists meets at least once a year to define and update guidelines for use of anti-retroviral medicines in adults, children and pregnant women. What we aim to present in this text is an understand-

ing of the trajectory that shaped the social response to the epidemic, a response that gained international recognition in the area of public health, which had always been an embarrassing matter. Our objective here is to discuss the way that popular participation in questions concerning access to anti-retroviral treatment has influenced the public health policies for controlling and confronting the AIDS epidemic.

#### SOME FACTS RELATED TO DISTRIBUTION OF MEDICINE IN BRAZIL

In 1991 began the free nationwide distribution of Zidovudine (AZT), which started to be manufactured in Brazil in 1993. However, since 1989 the Secretariat for Health of the State of São Paulo already distributed it cost-free to AIDS patients in that State. By means of a ministerial resolution (Resolution 21, of March 1995), the Ministry of Health established that it would provide the available anti-retroviral drugs (AZT and Didanosina/ddI) and some medicines for opportunistic infections (Ganciclovir, Fluconazol, Pentamidine, Aciclovir and Anfotericine B). In March 1996, the Ministry of Health set up a technical committee to prepare guidelines for the use of anti-retroviral drugs, including protease inhibitors (BELOQUI, 1998 a).

After considerable pressure from the government of the United States on the member-countries of the

World Trade Organization (WTO), the Brazilian government passed its patents law on 14 May 1996 (Law 9.279/96), regulating issues related to intellectual property of industrialized goods and the length of validity (20 years on average) of the exclusive rights of production and commercialization of a patented product by the patent holder. Many analysts consider that such a situation eventually creates exclusivity in the commercialization of certain goods (monopoly), which are then sold at excessively high prices, and through imprecise definition criteria (OXFAM, 2001). As a result, public access to the medicines is far more limited.

Nonetheless, the article 68 of this law stipulates that if the holder of the patent does not manufacture the product patented in Brazil, within a period of three years after patent registration, without plausible justification, the government may authorize the manufacture of that product by another company (which is called compulsory licensing) or else import the good from the producer country (parallel importing). Article 71 states that compulsory licensing and parallel importing of goods may be determined in cases of national emergency or public interest.<sup>1</sup>

At the 11<sup>th</sup> International Conference on AIDS held in Vancouver in

July 1996, the positive results of research using a combination of anti-retroviral drugs were announced. In November of the same year, a presidential decree (Law 9.313/96) guaranteed free distribution of medicines for AIDS.

In May 1999, the 52<sup>nd</sup> World Assembly on Health approved a resolution calling on countries to explore and review their options on international agreements, including trade agreements, in order to safeguard access to essential medicines.

The fact that Brazil has a specific law does not mean that the distribution of medicines is already a consolidated right. In August 1999 the Ministry of Health revealed the need for a budget supplement to correct the lag of resources caused by the devaluation of Brazilian Real vis-à-vis United States dollars in the purchasing of medicines. The mobilization of NGOs all over the country in September resulted in resources being issued by the Ministry of Public Finances. The same fact occurred in November 2000, with the same solution. These situations show that maintaining the free distribution of the medicines depends on the local manufacture of these input materials, so that the current policy is not kept at the mercy of exchange fluctuations or foreign technology.

Still in 1999, Presidential Decree 3.201, of October 6, defined the cases of national emergency and public interest as criteria for the compulsory patents licensing.

In 2000, public and private laboratories in Brazil already had capacity and technology to produce 7 of the 12 anti-retroviral drugs distributed through the public health network. In July of that year, the 13<sup>th</sup> International Conference on AIDS held in Durban, South Africa, in addition to disclosing the devastation wrought by the epidemic on the African continent, stressed the issues related to the cost of the medicines and access to treatment for the populations of developing countries. The Brazilian AIDS program was highlighted due to its policy of free distribution of medicines to all patients.

In 2001 we witnessed the international dispute on foreign trade laws and the intellectual property rights (patents) of international drug companies that make essential medicines and anti-retrovirals. Brazil played a leading role in this discussion, on account of its national production of medicines that make up the combined therapy for AIDS patients, the positions assumed by the Ministry of Health towards foreign laboratories, and the mobilization of

<sup>1</sup> Much of the information contained herein on questions involving patents and medicines was extracted from the material produced by the Brazilian office of the British NGO OXFAM, engaged in a worldwide campaign (*Cut the cost of medicines*) to increase access to these medicines (see <http://www.oxfam.org.uk>).



organized civil society in alignment with international activism.

In January 2001 the government of the United States presented to the WTO a complaint (*painel*) against article 68 of the Brazilian Law of Patents. Their argument was that this article is in violation of the Treaty on Commercial Aspects of Intellectual Property (TRIPS) and deters patent-holders from developing their products on Brazilian territory. The discussions on this panel lasted until the month of July, when a joint note from the United States and Brazilian governments declared the agreement whereby the former withdrew the complaint against Brazilian in the WTO without this affecting the differences of interpretation of either party with regard to article 68 of the Brazilian Law of Patents' conformity with the TRIPS agreement. The Brazilian government, in turn, agreed – should it deem necessary to apply article 68 to grant a compulsory license of patents not held by North-American companies – to notify the government of the United States beforehand and offer appropriate opportunity for prior talks on the matter, which almost happened during the negotiations between the Brazilian government and two multinationals responsible for manufacturing medicines that make up the combined therapy against AIDS, as we shall see below.

In February 2001 the Brazilian Ministry of Health announced its

intention to license compulsorily the Nelfinavir and Efavirenz patents, for alleged public interest reasons, until the month of June, if the laboratories failed to bring down their prices. An agreement signed in March between the Brazilian Ministry of Health and Merck Sharp & Dohme allowed for a significant reduction in the prices of Efavirenz and Indinavir. On August 22, after six months of negotiations with the Swiss company Hoffman-La Roche, holder of the Nelfinavir patent, the Ministry of Health announced that it was to compulsorily license the patent of this medicine so that its generic version could be produced by the Far-Manguinhos laboratory of the Oswaldo Cruz Foundation. It was the first time since the patents law was passed in 1996 that the Brazilian government applied article 68. After this, the Swiss laboratory backed out of its position and offered a significant reduction in the price of the medicine, which led the Ministry of Health to abandon the compulsory-licensing process.

On the international level the positions by the United States government and pharmaceutical companies caused considerable discontent in various parts of the world. In early 2001, 39 drug companies opened a lawsuit against the South-African government to prevent it from engaging in parallel importing of anti-retrovirals. Debates on patents and activist demonstrations began to pop

up all over the world. On March 5<sup>th</sup>, the date of the trial in South Africa, there were protests in many countries and the day was declared “World Day for Action.” In Brazil the AIDS/NGOs Forum of São Paulo organized a demonstration in front of the United States consulate in the State capital. In April, fearing even more criticism from public opinion, the laboratories withdrew the complaint against the South-African government.

In May a new demonstration of all the Brazilian non-governmental organizations active in the field of AIDS was held in Recife, thus strengthening national mobilization on the question. Next, Brazil presented a resolution to the Human Rights Committee of the United Nations on the right of access to medicines at accessible prices, in the context of the AIDS epidemic. The motion was supported by 52 countries, with one sole abstention: the United States. In June, on the occasion of the Special Session of the UN General Assembly on HIV/AIDS, the question of access to treatments in developing countries was given priority rating. The Global Fund for Combating AIDS, Tuberculosis and Malaria was launched with the aim to help the governments of poor countries to confront these diseases.

At the 4<sup>th</sup> Ministerial Conference of the World Trade Organization held in Doha, Qatar in November 2001, unanimous approval was given to the declaration put forward by Bra-

zil, that the TRIPS agreement should not relegate the interests of public health in member-countries to a secondary position. It should be stressed that numerous demonstrations took place all over the world to pressure governments to make the TRIPS prerogatives more flexible on behalf of public health in developing countries. The Brazilian production of generic and similar versions of anti-retroviral medicines and the situation of the African countries served as a slogan for all this mobilization.

### THREE PRINCIPLES: UNIVERSALITY, INTEGRALITY AND SOCIAL CONTROL

While Brazil and its policy of distributing anti-retroviral drugs attracted international attention, the challenges of prevention and care nonetheless remained present and often lacked effective responses. If on the one hand epidemiological indicators pointed to an epidemic in the process of stabilizing, some behavioral studies detected a resurgence of unprotected sexual practices, especially in less informed and economically excluded groups, not to mention the small amount of studies to enable the mapping of HIV infection in the country (PIMENTA *et al.*, 2002).

So, despite the success of Brazil's medicines policy, the maintenance of which is still one of the banners of organized social movement, it has not been possible to reduce some

major deficiencies in the area of treatment. Discontinuing the offer of CD-4 and viral-load examinations has become emblematic of the difficulty faced by the decentralization process, leading to conflicts between the federal, state and municipal levels of SUS management and to reformulation in the technical consensus on anti-retroviral treatment, in addition to demanding constant and arduous vigilance on the part of civil society.

The way that financial resources are raised and allocated has also steered the debate on the direction of social response to the AIDS epidemic. Through its Ministry of Health, the Brazilian government signed two loan agreements with the World Bank to finance prevention and control actions for the AIDS epidemic. The first project (known as AIDS I) was performed between 1993 and 1998 with US\$ 250 million (US\$ 160 million from the loan and US\$ 90 million in national resources). The second agreement (AIDS II) was signed in 1998 and performed through the end of 2002, using US\$ 300 million (US\$ 165 million from the loan and US\$ 135 million in national resources) (GALVÃO, 2002). The imminent end of the second loan by the World Bank (AIDS II) forced us to discuss AIDS prevention within SUS, and its financing with its own resources. Decentralization and sustainability became the slogan of the social movement, governmental agencies and other sectors involved with the epi-

demio, but there was still little discussion on a deeper level.

If, as we see, there are serious obstacles to the continuity of care and treatment actions in a system that has a markedly care-and-curative nature, what can be expected when the plan is to offer prevention work by SUS? In such a scenario, how to assess and assure the work performed by community organizations? What concrete, programmable interfaces can be formed between NGOs and SUS? What are the perspectives and proposals for achieving political, institutional and financial sustainability of social responses to HIV/AIDS? What development models in the health field effectively aim at integrating actions without separating prevention from care? Which actors should play a leading role and face the epidemic from an intersectoral perspective?

The purpose of this paper is not to find answers to all these questions. However, its formulation is based on the premise that one of the possible perspectives for maintaining and improving Brazil's response to HIV/AIDS is through SUS and bringing the organizations that work with AIDS closer to the sanitary movement. This assertion is made because many of the conquests in gaining access to treatment have been due to complying with and carrying out (often through judiciary means) the prerogatives and principles that base SUS. It is therefore appropriate

to analyze better the way that public health is organized in Brazil and how AIDS fits into this proposal.

When the Federal Constitution was promulgated in 1988, and when Federal Law 8.080/90 was approved, thereby regulating the implantation of SUS, social movements celebrated the possibility of making the dream of an integrated health scheme for all come true, with quality and social participation. A great deal remains to be done before this dream comes true. After all, if we consider that Federal Law 8.080, which deals with the SUS regulations, was passed in September 1990, we are dealing with a public institution only 12 years old that came to replace an extremely centralized, corporate, rigid and assistance-oriented health-care model. But SUS is now effective, and with all its drawbacks has proved to be the space where public health articulates with democratic ideals.

The existence of and respect for a principle that fosters universal access to health is precisely what the World Bank technicians saw as the possible failure of the Brazilian AIDS program at the time the Brazilian government decided to distribute medicines to all HIV/AIDS patients according to criteria established by a medical consensus. As early as the beginning of the 80s, forecasts of this same institution claimed that it was suicide for health in Brazil to enjoy the value of a universal right. In these technicians' view, a health sys-

tem based on this principle could lead to disaster in the country's public accounts (MATTOS *et al.*, 2001). And in yet another report published in the second half of the 90s, the World Bank advised against distributing anti-retrovirals, following a cost/benefit logic according to which it was cheaper to invest in prevention, and claiming that it was economically and structurally unfeasible to distribute drugs in developing countries (WORLD BANK, 1997).

This is the policy in effect in many developing countries. Even India, with its impressive production of anti-retroviral medicines, does not have a program for distributing them to the infected segment of the population. It is claimed that expanded access could stimulate the demand for diagnosis and treatment. But is that not precisely what is meant by promoting early diagnosis? For Brazilian activists, any evaluation of a cost/benefit nature that can simply let those suffering from AIDS die from lack of medicine is utterly unacceptable. One cannot forget that in some African countries, such as Botswana and Zimbabwe, people infected by HIV now number 20% or more of the adult population (UNAIDS, 2000).

In other words, the Brazilian conquest of treating HIV/AIDS patients according to medical criteria previously defined and ratified by a law (Federal Law 9.313/96), runs contrary to the expectations of the World Bank and other international agen-

cies, and even so is hailed as a successful experience within the struggle against the AIDS pandemic. The confrontation in this case is on the one hand to protect a constitutional right and imbue the State with the pledge to offer a quality health program, and on the other hand the neoliberal model of minimum State, that delegates to private initiative the responsibility to offer of social security, health and education services.

It is not only universal access to health, as one of the fundamental principles of SUS, that - by being respected and complied with - manages to guarantee the policy of distributing the medicines that make up the treatment of HIV/AIDS patients. Integral care is also a fundamental principle of what is being seen as the field of promoting health. But it is in the principle that presupposes the existence of social control instances in SUS that we come across the possibility of making public-health policies effective. Public participation, whether by means of municipal, state or federal health councils or in the sphere of civil-society entities, or even within human rights movements (workers' movement, landless movement, feminist movement, gay/lesbian movement), is the condition that not only brings legitimacy but also and especially makes success feasible. The struggle of those living with HIV/AIDS has, with considerable difficulty, become the depository of expectations by countless actors. From

segments of the population barely benefited by health services to the most active instances of the government, NGOs receive in their offices and reach through their community interventions an enormous contingent of people seeking legal aid, opportunities for social interaction, skill building, or mainly a space for political expression.

Our objective is not to delve into the responses that civil society has been giving to the AIDS predicament. Nonetheless, we believe that it is important to show how issues and facts related to access to medicines, as with the patents, have helped to define the position of NGOs that work with AIDS and their dialogue with other sectors of society, especially government agencies, the market, the pharmaceutical industry and also scientists and their production. As a matter of fact, in the area of science and technology the relation between research institutes and the social movement on behalf of AIDS both in Brazil and abroad has been contradictory and full of conflicts throughout the history of the epidemic. If on the one hand the scientific discoveries concerning AIDS are hailed and stimulated, on the other hand the ethical standards of clinical research and broader access to these findings have been the target of constant debate and are included in the agenda of a significant part of the AIDS movement all over the world (EPSTEIN, 1996).

## ARENAS OF POLITICAL CLASHES

One of the ways that AIDS patients, in isolation or through associations such as AIDS/NGOs, have tried (and still try) to fight for their rights related to integral care, including the offer of medicines and complementary examinations by the public-health network, is to resort to the Judiciary Power through collective lawsuits or injunctions petitioned by the Public Prosecutor's Office or by organizations, to ensure the human rights of those living with AIDS. The aim is to defend what legal professionals define as collective right: "there is collective right when a certain group, with relative determination, resulting from participation in a legally based relation can obtain protection for the whole class represented, and there can be no satisfaction or jeopardy except when it affects all members of that specific class" (RIOS, 2002, p. 25, as highlighted).

From the late 80s on, ever since AZT began to be used on AIDS patients, many lawsuits have been opened in order to guarantee access to medication. Oriented by NGO advisory bodies, AIDS patients succeeded in having their right to care recognized and began to receive treatment and medicine in the public-health service. As Ventura sees it,

*the initial lawsuit in the Judiciary Power against all unjustifiable and unconstitutional measures and/or*

*attitudes that invaded the intimacy of and denied any right to the seropositive citizen (the right to work, access to public places and to medical-hospital care) was decisive for the social inclusion of people with HIV/AIDS, for the introduction of the language of human rights in our daily practices, and to stimulate the fight for social efficacy of legal standards for all. (VENTURA, 1999. p. 288)*

So this modality of activism was not promoted and organized only from the moment that obtaining medicines or complementary examinations for AIDS patients became a possibility. From the early days of the epidemic to the present, NGO legal advisors have struggled hard in the courts to thwart and denounce situations involving compulsory testing for AIDS in certain social groups (for example, sex workers) and as a prerequisite for admission to jobs and public exams. All this because "the right to health also has a defensive dimension, that is, (the assurance of) respect of third parties with regard to each individual's physical and psychological conditions, without unreasonable demands and unjustifiable charges" (RIOS, 2002. p. 26, as highlighted).

But in addition to these mobilizations aimed at provoking responses within the Judiciary Power, other lawsuits are directed towards formulating and approving bills that deal with the needs of those who suffer from AIDS. An example of this

can be found in the way social movements coped with the issue of the relation between users and administrators of health insurance plans. In this case the leading role of AIDS patients was demonstrated in an issue that afflicted a whole range of users who suffered from other diseases. In 1997, when the new legislation on health plans had not yet been regulated, many insurance companies did not offer benefits for appropriate treatment of their users' health needs. Many of the conquests in this arena are due to activism in the area of AIDS, which had included the issue in the sanitary movement agenda and the National Congress:

*the systematic inclusion of the discussion on health plans in national, state and municipal Health Conferences, and efficient political articulation with the Federal Board of Medicine enabled the latter to launch a resolution obliging health insurance plans to provide assistance to every pathology.* (VILLELA, 1999. p. 217)

In the campaign for more integral care that includes not only medication but also all the necessary examinations for a proper follow-up of clinical evolution, a recent episode illustrates the way that access to Judiciary Power can change situations that go against the interests of users. In July 2000, community organizations in the State of São Paulo opened a suit in the Federal Public Prosecutor's Office requesting that genotyping laboratory tests be

performed by the public-health network. Genotyping examinations are carried out to identify genetic mutations of HIV in order to assess the resistance of the virus to drugs and to guide new therapeutic approaches. Since then the federal government set up a national network of laboratories to perform these examinations (RENAGENO), establishing technical criteria that determine which patients can benefit from the test. In other words the Ministry of Health recommends the genotyping test for patients with primary therapeutic failure, with a drug scheme that includes the use of a protease inhibitor, whereas the users petitioned to see this examination made available to patients with repeated therapeutic failures, even if they did not use a protease inhibitor. During the legal procedure, which lasted more than a year and a half, hearings were held with representatives of the users and the defendants, including the Union, the government of the State of São Paulo and the São Paulo city government. As can be read in an extract from the sentence passed by Judge Aroldo José Washington, of the 4<sup>th</sup> Court of Federal Justice in São Paulo, in Process 2001.61.00.027898-6, it was determined that the three levels of SUS administration (the Ministry of Health, the São Paulo State Secretariat for Health and the São Paulo Municipal Secretariat for Health) should implement "genotyping test

of the human immunodeficiency virus (HIV-1) within the scope of the Integrated Health System, for all bearers of this virus."

Of interest to our discussion is the fact that the sentence is based on the prerogatives provided by the laws that regulate SUS (Law 8.090/90) and care for AIDS patients (Law 9.313/96), with the justification that the criteria defined by the Ministry of Health to recommend the examination abide to constitutional principles, as we can read in the extract of the endorsed document complementing the advance protection on which the legal decision of the case in question is based:

*the criterion and method adopted within general principles of law and all principles that guide the health program, in particular the right to life, as established in the preamble to Article 5 of the Federal Constitution, this being the primary fundamental right of human beings, fail to attend to it fully.*

Although the legal decision goes against to the criteria defined by the Ministry of Health, it had to be accepted by the three instances of SUS administration involved in the lawsuit. The right to life and the principle of universality of SUS are predominant against the recommendations of a technical or economic nature, but they are only complied with if organized civil society bears influence on public opinion and appeals swiftly to the competent bodies.

Based on these facts and progresses, we can draw the conclusion that legal conflict on matters raised by the epidemic is not new for the AIDS social movement, as might seem from analyses of facts related to discussion on patents and generic drugs for AIDS. On the contrary, lawsuits involving the human rights defense for those living with AIDS have “overcome exclusionist mentalities and legal categories, breaking down mechanisms of inequality and injustice spread throughout law and society” (Rios, 2002. p. 28).

Nevertheless, the legal arena is not the only place where battles of those living with HIV/AIDS are fought. As mentioned earlier, the mobilization of NGOs also takes up public spaces in order to lend visibility to issues that involve disrespecting the rights of, and discriminating against, AIDS patients. Some dates have already been set on the social movement calendar, such as demonstrations that take place on World AIDS Day (December 1<sup>st</sup>), the distribution of condoms on national holidays such as Carnival, and in some cities like Fortaleza, vigils held in the month of May in memory of people who have died of AIDS. Besides these events, there are meetings with militants, activists and patients, such as the National Encounter of AIDS/NGOs (ENONG) every

two years, and the National Encounter of People Living with AIDS.

However, we would like to highlight some specific mobilizations directly related to the distribution of medicines or to care on a broader level. As mentioned in the second part of this article, the AIDS/NGOs held demonstrations in September 1999 and November 2000) to draw public attention to the need for budget supplements in the Ministry of Health so that drugs and input materials could be purchased and distributed without interruption. Both events were held after community organizations gathered information from the press (the communications division of the Ministry of Health made it known that its stock of medicine was running out), and in a very informal way from technicians of the Ministry itself. The most impressive thing about these events is precisely the closeness of social movement and government agencies (albeit not immune to conflicts, as seen in the case concerning genotyping examinations, to give just one example), as well as the speed with which the groups organized the demonstration in different cities.<sup>2</sup> If on the one hand we might suppose that the action of the social movement acts on behalf of the interests of certain segments of the government (which is not an entire-

ly unreasonable interpretation), on the other hand we see that the joint, articulated work of AIDS/NGOs managed to guarantee effective answers to their demands, because on the two occasions that the activists took to the streets to protest against the lack of resources to buy drugs, they had their complaints resolved.

In this way, the action of the Brazilian AIDS/NGOs in the episodes involving questions concerning patents was decisive in mobilizing public opinion and clarifying facts that seemed too abstract for the man in the street, as we shall further ahead. Some fronts of action were opened so as to transform the “intellectual property” issue into something that concerned everybody.

To this end, seminars were held to show to the AIDS/NGOs themselves the full importance of the matter. Demonstrations took place in harmony with the international movement, as was the case of March 5<sup>th</sup>, 2001, as seen above. In addition, international groups based in Brazil, such as OXFAM and Doctors without Borders, strengthened their partnerships with active Brazilian groups in the AIDS movement in order to involve the population in their campaigns for access to essential medicines, with anti-retrovirals being used as a kind of emblem of the struggle.

<sup>2</sup> This calls for an analysis of the role played by information technology tools, since a great deal of the communications among the groups responsible for these mobilizations made use of the Internet and e-mail.

These are the reasons why we see the discussion on patents and the national production of medicines as one of the facets of the fight to offer people with HIV/AIDS access to more efficacious treatments or, to put it more dramatically, the fight for life, as Brazilian groups have been claiming for so long (BELOQUI, 1998 b). We are not, we repeat, witnessing a new theme or even a new war, to resort to a bellicose metaphor so often used to speak of the relation between State and civil society, or between pharmaceutical industry and governments, at some moments in the social history of AIDS. To state it more radically, for activism in AIDS the questions are the same as before, except that now they are dressed in clothes that may make them look more complex or elaborate.

With the discussion on the law of patents, we suddenly began to observe intense debates filled with new terminology (article 68, the TRIPS agreement, WTO) with which we were not quite familiar, given the scarcity of opportunities to gain skills in these matters, plus the fact that most of the publications and texts have restricted access as they are written in English.

As usual in debates that involve trade relations among countries, the whole discussion seems to take place in a space that not even remotely affects the daily life of those poor mortals who do not attend the tables where these matters are aired.

Faced with the threat of no medicines on the shelves, the user immediately feels what his/her real needs are. But when it comes to understanding how the political discussions held in the international sphere are to bear influence on the quality of his/her treatment, the elements are lacking to lend consistency to the debate and his/her opinions, and this can lead to a certain immobility. Nevertheless, the user has the experience and in a visceral sense knows the impact of trade policies and agreements. This knowledge and this experience are what make up the main argument by the user, who, despite resistance from some sectors, should be taken into account and be present and active in the debates, negotiations and decisions taken on the issue of access to treatment on all levels.

There is clearly a gap between the reality lived by civil-society organizations and users of the health system, especially in developing countries, and what is debated and decided in the international forums that define policies and implement trade agreements. If on the one hand this situation expresses how far we have to progress in preparing leaders and social movements, on the other hand we are faced with new challenges and dilemmas determined by globalization. In other words, at the same time that it is necessary to create strategies that enable more proximity and exchange among people and groups living in a global-

ized world, the struggle for access to medicines, expressed in the vocabulary of patents and international trade, also shows us the processes of exclusion, ignoring borders between countries.

To judge from the heat of the international debate on patents and the price that many countries and individuals pay for their treatments, precisely because of questions involving intellectual property and trade, our assessment is that we are still faced with obstacles that call for immediate solutions. After all, how will the new drugs that make up anti-retroviral treatment be bought and distributed? What will become of those drugs that are still patented and therefore still constitute a burden on public accounts? Which strategies will be effectively adopted to minimize or treat side effects caused by anti-retroviral drugs currently available? What kind of answer can the HIV/AIDS social movement expect from the national area of science and technology, given the rules on the table? How can a greater number of patients come to benefit from the most up-to-date tests, access to which has been restricted due to a combination of technical questions and economic factors? How are activist groups to position themselves vis-à-vis the alternatives set before poor countries, such as the Global Fund for Combating AIDS, Tuberculosis and Malaria, for example? The existence of such a fund certainly

does not belittle the importance of other alternatives that aim to significantly lower the impact of foreign trade and intellectual property agreements on the situation of AIDS patients in developing countries.

#### DELICATE RELATIONS: DIALOGUING FOR SOLUTIONS

Although this does not seem to be a unanimous opinion, the recent progress in a variety of international forums depends on the quality of the dialogue between civil society and government. But we cannot afford the illusion that this is an easy relationship, especially if we take into account the policies of structural economic adjustments that impose cuts on public spending, and programs to privatize national public assets and reduce the presence of the State in the compliance of its social responsibilities.

This relationship grows all the more delicate and filled with contradictions when we take the case of the Brazilian government obeying the dictates of international economic policies by cutting social spending and privatizing public companies while at the same time defending positions such as the implementation of anti-retrovirals universal distribution policy and production of generic medicines for various diseases, including AIDS.

Brazil has yet to review its patents law and also participate more

actively in future revisions of agreements in the sphere of TRIPS, always in the sense of assuring priority to national public interests against international pressure from rich nations and multinational corporations. This is a great challenge that can only be faced with the mobilization and participation of different sectors of the government and society, including academia and the private sector, rather than just one or two social movements in isolation. The discussion on patents concerns not only AIDS/NGOs and the Ministry of Health but also affects other social sectors such as agriculture, the environment, and the country's scientific and technological development. It is necessary to articulate and promote democracy in order for civil society to incorporate this discussion all the more. The success of defending the interests of Brazilian citizens in the spheres of international trade negotiations depends on an organized civil society, an increasingly more democratic State, more committed to public interest and less to private interests and to interests of companies and international financial agencies or other countries' governments.

Just as the questions related to patents and intellectual property should be dealt with through a dialogue between different actors, the responses to AIDS should also spring from a collective project based on interaction between different sectors

directly or indirectly affected by the epidemic. To a certain extent this has been happening, but the quality of this intersectoral debate should be refined. As we have tried to show in this paper, activism in AIDS appeared in synergy with the re-democratization in Brazil and with the organization of SUS, a model conceived and born in the core of various social movements (PARKER *et al.*, 1999). Likewise, the policy of universal distribution of anti-retroviral drugs in Brazil is not a privilege of AIDS patients but rather a conquered right that can and should be extended to all epidemics and diseases assisted by public health.

Nonetheless, the battle against AIDS has shown that doses of creativity, daring and determination are necessary in order to construct effective responses. To do so it was necessary for the government to disobey the advice of international experts in public health who claimed that it was unfeasible to distribute anti-retroviral drugs in a poor country with so many structural problems (ATTARAN, 2001). But it was also important that in several instances civil society and people with HIV/AIDS took to the streets to claim their rights in a fight that is far from over. AIDS has proved to be a dynamic epidemic that presents frequent challenges, and so the responses and initiatives to face it have to consider the dynamism and urgency of the epidemic. The discussions and deci-



sions on the course of the epidemic and its determinants (foreign trade, intellectual property, social inequalities, sexual and reproductive health, forms of pleasure), instead of limiting, should in fact stimulate creativity, authenticity and solutions to problems, thereby guaranteeing life as a non-negotiable objective.

Let us repeat that it may seem that the struggle today in Brazilian is over and has been crowned with triumph, and that all that remains to be done is to set up a plan for action that can maintain the laurels of this conquest within the moulds of neo-liberal pragmatism. The success of the Brazilian policy for combating the HIV/AIDS epidemic can only be understood as such if we keep aware of the fact that as the disease spreads throughout the poorer and more vulnerable communities (and consequently those least capable of confronting the problem), the government and organized civil society will have to review, in a continued and creative spirit of solidarity, their positions and possibilities for dialoguing on the long road that still lies ahead.

This road, however, must be shared by a growing number of actors and be sensitive to the problems that the epidemic causes for the international community. One of the facets revealed by the debate on access to treatments and intellectual property laws is the importance of opening up mobilization fronts that include organizations from differ-

ent countries so as to create a network of international solidarity. This is important because the inequalities between rich and poor countries have been growing so dramatically that developing countries are obliged to create common solutions for the conflicts caused by these economic disparities. The exaggerated profits by large drug companies, the neo-liberal policies that privatize public health, the priority given to unfair intellectual property laws that go against public and community interests, and the omission of many public authorities in handling social inequalities that mark the history of developing countries, all these factors are killing people who suffer from AIDS in Latin America and the rest of the world. As part of the international community, we must find solutions to these questions and fight, through transnational activism, the determining factors behind social and economic exclusion that lie at the bottom of the AIDS epidemic in the developing world.

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Adriana Carvalho & Carlos Fernando Reis da Costa

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