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RESPONDING TO AIDS IN BRAZIL: the very early years[1]

As in most places other than the United Sates, AIDS became an issue in Brazil before there were any reported local cases. It was a media issue, a subject matter for discussion, for fear, for writing, for statement making, for either denial or morbid interest, independently of the actual cases that in fact were or were not coming up in medical settings. Around the world, AIDS was often taken as a foreign disease, be it a man-made genocidal device, like a cold war weapon out of control (Panos 1989, Sabatier 1988), a sabotage against the third world populations (Chirimuuta and Chirimuuta 1989, Panos 1989, Sabatier 1988), or simply something intrinsically associated with the decadent life-styles of America. In any ways, it was highly talked and feared before it became an actual matter of private and public health. Brazilian activist Herbert Daniel suggested the distinction between "aids" and “AIDS”, the former applied to "a significant that means far more than the disease referred by the acronym AIDS" (Daniel 1990:11). Along the same lines, Silvia Ramos described that

> *AIDS arrived to Brazil before the first cases of AIDS. An epidemic (the third) [of prejudice] starts to circulate in Brazilian society with a large impact right in the beginning of the early 1980s. The expectations and excitement of the national soul were bigger than the effects caused when the disease arrived, grew among the population and, now, explodes... a few years later. (Ramos 1990:8)*

Contrary to the other countries with Latin-rooted languages, where AIDS became SIDA (for Syndrome de l'Immuno-Déficience Acquise, in French, Sindroma de la Imuno-Deficiencia Aquirida, in Spanish, or Síndroma de Imunodeficiência

Adquirida, in Portuguese), Brazil created its own vocalization of the international English-based term "AIDS" [A-ii-d-e-sh] to refer to the epidemic. In the first series of manuals edited by the government, setting guidelines to treat and prevent the epidemic, it was referred as SIDA/AIDS (Ministério da Saúde, 1987, 1988a, 1988b); in clinical settings the disease was and often is referred to as SIDA, as in other Portuguese-speaking countries. Publicly, however, the disease came to be known as AIDS; government, activists, media and health professionals alike transformed what was originally an English acronym into a noun. This fact is not unrelated to its repeated use by the media.

In Brazil, like in many other non-U.S. settings, AIDS become news for the simple fact of being from the United States Ramos (v. Ramos 1990:9-10). Just as a hurricane in Miami was more likely to make news than one in the Philippines, a lethal epidemic in the developed countries became world news. This was even more so as this mysterious disease seemed to affect famous people and gays. The most morbid expectations were raised in the Brazilian media. Was it going to arrive to the country? Was Brazil that modern? In a country split in the double identity of developed-while-underdeveloped, it is not uncommon for the media to explore the ambiguities of collective identity. If Brazil were to have AIDS, it meant that at some level it was a developed country; after all, AIDS was a "first world" disease. As a consequence, some of the early cases of AIDS attracted the spotlight, in contrast to the shameful silence given to the endemic diseases that affected and affect the population by the millions; those were not fit to print or make glossy covers. Readers do not want to know about the 8 million people with Chagas disease, the 13 million with schistosomiasis, or 460,000 new cases of malaria in 1987 alone (v. Cohn 1995:85-86).

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AIDS, however, was not the regular shameful trivia; it deserved media attention as a *Doença de Primeiro Mundo* (disease of the first world), popularly referred as *doença de rico* (disease of the rich). As Moraes and Carrara (1985a) note, the symbolic opposition between "third world" and "civilized world" was the most complex one within a repertory of imageries used by the media to portray the epidemic, and that included gender, sexuality, and death. Coming from the "primitive heart of Africa" to "slash" New York, the "capital of the world," the new epidemic was portrayed as a "revenge of the oppressed"; passing from the monkeys to Africans, from those to Cubans and Haitians, the virus was transmitted to U.S. gays on vacation; from primitiveness to modern decadence, a range of symbolic connotations loaded the account (Moraes and Carrara 1985a:17). The epidemic in Brazil was portrayed in the media as the encounter of both the "civilized" and "primitive" extremes, the authors note.

> *It gets delirious when the presence of the disease among us is seen as a sign of distinction and civilization. When [the magazine] Manchete publishes in the first page the title "AIDS: Brazil is already the vice-champion," it is not just a morbid joke: there is also a certain amount of pride in there. AIDS becomes the proof that among us exists the life-style of the big American metropolises, that we are also "civilized," that the "sexual revolution" happened here also. (Moraes and Carrara 1985a:17)*

The representation of AIDS as an affliction of the rich was there to stay for a few years. This was by and large due to the way the media treated AIDS, which was almost exclusively centered on the celebrities who had the disease. We know now that the epidemic probably affected the different social strata evenly since its early years (Granjeiro 1994), but this fact remained unnoticed back then. Only after the question of AIDS and poverty attracted theory and media coverage in the United States was the issue of AIDS among the poor in Brazil treated by local media (see *Estado de São Paulo*, May 18 1991). In the year 1991, the words "pauperization" and "Africanization" became media favorites in the description of

the epidemic trends in Brazil. Behind that picture was dual frame used by the World Health Organization to interpret the worldwide epidemic contrasts: a pattern I for the developed countries, with high incidence among gay men and drug users, and a pattern II for the developing world, mostly Africa, where the epidemic was evenly distributed by men and women. When some women came up in AIDS statistics in Brazil the media portrayed it as a move from pattern I to pattern II, and named the tendency as "Africanization." The topic appeared already in 1987 in the daily *O Globo*, as part of an interview (November 15, 1987) and was often attributed to the international agencies like WHO (*Folha de São Paulo*, August 8, 1991) or PAHO (*Folha de São Paulo*, October 3, 1991). It would also become a speculative motive for general confusion, misinformation, and the repetition of stereotypes. This was the case with an article from *O Globo* in April 13, 1989, which combined the presence of HIV-2 in Brazil with the stereotypes on poverty like undernourishment, poor hygiene, and promiscuity, as

> *the ideal conditions for the explosion of AIDS, through a change in the patterns of transmission: instead of the propagation by risk groups (homosexuals, injecting drug abusers), today dominant all over the world except in Africa, the passage to the heterosexual transmission (O Globo, 4.13.1989)*

Giving to the topic a racial connotation that is rarely made explicit, the article further suggested that it was the concern with the Africanization of AIDS in Brazil that had led FIOCRUZ to send its leading AIDS scientist Bernardo Galvão to Bahia, in order to create a front research laboratory for the surveillance of the epidemic, because

> *the area, besides having a large number of people of African descent, has the basic conditions for the propagation of the virus in the heterosexual population (Globo, 4.13.1989)*

Virtually all the researchers I interviewed dismissed the notion of "Africanization," both on its ideological terms and on biological ones. In fact, the variants of HIV found Brazil belong to the same "clade," or group of variation, as those of United States and Western Europe, which is HIV-1-B. Also, the dominant mode of transmission is sexual and from men to men, followed by men to women, and with fewer, but existing, cases of women to men transmission.[2]

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The association of AIDS with privilege in the beginning of the epidemic in Brazil had two sorts of impact: on the one hand, it was used as an excuse for the government's lack of attention to the disease(Ramos 1990:13), with the claim that AIDS affected a very small minority -- the "First World within" -- who could afford their own health care abroad, while the government should use its resources for the massive endemic diseases affecting the deprived in massive numbers, like malaria and tuberculosis. In a page length article of the daily Globo, in September, 8, 1985, Health Minister Carlos Santana declared that even though his office was taking a series of measures against AIDS, this disease could not really be considered a priority. There had been only 415 confirmed cases of AIDS, when Chagas disease alone had 4.5 million, schistosomiasis had 7 million,

[2] The female-to-male HIV transmission raised intense debates in Brazil. Based on a small universe of research, physicians from the AIDS unit of the hospital Gaffrée e Guinle sustained publicly that there was no evidence of women-to-men transmission. Even though the claim was dismissed by a number of local doctors and activists, as well as by the literature, it remained as an ideological contribution to the already strong resistance regarding the practice of safer sex. This translated in men, oblivious of their own serostatus, avoiding condoms when having sex with women, to the later's blatant disadvantage in a context where gender empowerment is unbalanced to begin with. As a pragmatic choice, most prevention campaigns focused on the use of condoms as the only way to avoid HIV infection. Easier to manage than issues like power, negotiation, gender, and alike, the focus on condoms had its own problems, particularly giving their high cost: in 1991, one unit costed more than the equivalent to one U.S. dollar, while the minimum monthly wage was below U.S.$ 100.

malaria had 385,000, leprosy had 206,000, and the Ministry of Health was treating 88,000 cases of tuberculosis -- not to mention the 1,5 million cases of sexually transmitted diseases like syphilis and blenorragia. On the other hand, the publicity brought by celebrities to AIDS helped mobilize solidarity campaigns and fund raising. After some pop stars and TV idols got sick or died,[3] support from the performing arts community for the AIDS cause in Brazil increased significantly.

The first publicized case of AIDS in Brazil reinforced its stereotype of a disease of the rich and famous; it happened with São Paulo's gay designer Markito in 1983. He was seen as a cosmopolitan gay traveler who got AIDS in New York. He was also portrayed as the irresponsible type who went back to the metropolis for fun and party instead of getting treatment (*Isto É* 6.15.85, *apud* Moraes and Carrara 1985b:25).

Cosmopolitanism contributed at least as much as homosexuality for the initial symbolic imprint of the new epidemic, and Markito's case was used as evidence that Brazil shared the international jet-set phenomena perceived as AIDS. Contrary to the homophobic censorship that in the United States prevented the publication of early notices on AIDS, in Brazil the disease turned into a mediatic show. While in the United States the rampant number of cases could

[3] Two contrasting examples from the year 1989 are those of rock singer Cazuza and TV-Globo actor Lauro Corona. The young and handsome Corona hid his condition and kept acting in a soap opera until he could no longer stand yp; he died in denial, appalling a multitude of fans and friends. In his memory, other actors and actresses campaigned against the prejudice that surrounds AIDS, so that no one else had to endure the same type of solitude. At about the same time, and yet counting on a different personality and social support (his own family ranked higher in Globo itself) Cazuza came out as a PWA; his disclosure was used as a tool against the disease, which he fought with all possible strategies. He became the local AIDS-poster-boy, lend his face to front pages of mainstream magazines and to serve as a role model for disclosure and fight. His mother Lúcia Araújo got involved in anti-AIDS activism and created a foundation after his death, in 1991, *Sociedade Viva Cazuza*, that provides support and health care to children with AIDS.

hardly get any coverage, in Brazil the few initial cases had to struggle with an excess of morbid attention.[4]

A second basis for public awareness, and one that mobilized a more political type of attention and action, came with another of the early publicized cases: that of Henfil, the well-known and beloved political cartoonist who had criticized and fought the military dictatorship with his art. Henfil had hemophilia and had been iatrogenically contaminated with HIV through hemotherapy, as were his brothers Chico Mário, a musician, and Betinho, a politically engaged sociologist widely known as a community organizer.[5] Betinho (Herbert de Souza) helped shape a politicized perception of the epidemic as a public issue that involved empowerment, citizenship, social compromise, disclosure of government policies, social control, and the fight for basic rights. The issues of illegal blood banks, corruption and government inefficiency were made visible through the commentary on Henfil's disease and painful death, and helped mobilize wider agendas.

The fight for citizenship in a country that was emerging from an authoritarian military rule (1964-1985) provided a larger and better umbrella for anti-AIDS social organizing than a gay-based movement might have provided,

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[4] Media's morbid attitude included an eager search for the "aidético" (the medical name given to AIDS patients, later doomed as politically incorrect by the PWA organizations) even in hospital settings. Once a doctor commented on how she had disappointed a journalist just by referring that she handled AIDS as if it were any other disease. While the health professionals tried to build a pattern of normality in the treatment of AIDS, the media insisted on its "abnormality". The magazine ended up not publishing the story of "normality" in the professional care of AIDS. For a lenghty analysis of AIDS treatment in Brazilian media, see Galvão 1992a).

[5] Betinho (Herbert de Souza) headed the large umbrella-NGO IBASE, the Brazilian Institute for Social and Economic Research, which hosts a number of applied social research projects. IBASE pioneered the management of updated and large-scale documentation, electronic networking and international conferencing, public intervention on social causes and critical dialogue with the governments about specific issues. Betinho was often consulted by progressive ministers and presidents. A charismatic figure, in 1994 he led the campaign of "citizens against famine", which almost brought him the nomination for the Nobel Prize on Peace (the candidacy was jeopardized by his past acceptance of illegal gambling money as emergency funds for the AIDS organization ABIA at one of the times it was at the verge of bankruptcy). Betinho lived productively and joyfully in spite of his declining health. He

many activists argued.[6] There was no distinct and established gay community[7] in Brazilian cities as there were in New York and San Francisco. Moreover, there is a pervasive ideology that denies the existence of homophobia in Brazil, similar to the denial of racism -- which, naturally, takes other and more insidious forms.[8] If there is no homophobia, the argument goes, there is no sense for a gay movement or gay-based actions.

The situation is actually far more complex. Scholars have portrayed the subtleties of Brazilian sexual culture in a number of diverse ways, from a "closeted" gay life under a repressive homophobic culture (Mott 1995) where original categories like that of *entendidos* develops (Guimarães 1977, Whiten 1979), or an incipient gay movement comes to struggle (MacRae 1990), bringing a shift from hierarchical to egalitarian relations (Fry 1982), to a *sui generis* sexual culture where the categories of "gay" and "straight" are subverted by floating erotic meanings, like *sacanagem*, structured around transgression (Parker 1987, 1991a, 1992, and also Fry and MacRae 1985, Perlongher 1987); there are also

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welcomed enthusiastically the triple cocktail, even though his body did not accept the treatment for too long. He died in 1997.

[6] The interviews and exchanges on which this statement is based were collected in the years 1989-1992, and mostly in Rio de Janeiro. People who had participated years before in the extinct gay groups like SomoS, or people who were gay but had never participated in any gay group, argued that the participation in a larger platform, including hemophiliacs, blood recipients, and women under the banner of citizenship, was a better strategy for fighting AIDS and spreading prevention messages. Some members of the existing gay groups, like Grupo Gay da Bahia and Atobá, preferred to include AIDS in their many activities as gay-identified groups. G.G.B. remained very critical of what became the mainstream in AIDS activism, particularly the large agency ABIA, from Rio.

[7] For many of my "informants" the notion sounded alien and very (north) "American". In their analysis of the early media responses to the new epidemic, Moraes and Carrara (1985b) criticize the rapid adoption by the media of the term "gay community". The authors considered the literal translation of the term as culturally inadequate in the Brazilian context at the time. However, with the implementation of the fight against AIDS and the strengthening of community-based organizations, the term comunidade homosexual (gay community) became more frequently adopted. In 1995, Rio de Janeiro hosted the annual International Lesbian and Gay Association (ILGA) meetings, an event in which federal and state government officers praised the importance of the involvement of the gay community in the fight against AIDS.

[8] Deserving a separate analytical treatment that is not in the scope of this work, the pervasive form of local racism is nevertheless relevant in several ways. Not only does it provide a paradigm to better understand the local sexual ways but it also has a subtle impact on topics that appear without reference to race, and where it is yet present, like the "pauperization" of the epidemic, or the "Africanization" of Brazilian AIDS. Fort a wider discussion see Bastide and Fernandes 1951, Burdick 1995, Fernandes 1979, Fry 1982, 1989, Skidmore 1992, Sheriff 1995, Twine 1995, and the later Twine 1997.

detailed ethnographic descriptions of clandestine urban gay life (Guimarães 1977, Terto 1988), historical interpretations of same-sex interactions in past centuries and cultural interpretations of sexual meanings (Fry 1982, Parker 1991a).

In spite of the diversity of interpretations about the characteristics of Brazilian sexual culture, in the context of the *Abertura* (literally, "Opening," the movement of democratization within the military dictatorship that characterized the late 1970s) there was a rising gay movement, corresponding mainly to *SomoS* and *Lampião,* but it did not last long (McRae 1990). At the beginning of the epidemic in Brazil only a few of those groups remained. Even though they addressed the problem and developed AIDS-related work, like *Atobá* in Rio de Janeiro and the *Grupo Gay da Bahia* (GGB) in the city of Salvador, state of Bahia, these groups did not provide the leadership in the fight against AIDS. It was not in the context of gay organizations that the majority structured responses to AIDS were developed; rather, it was under the banner of human rights, and with the particular format of NGO (non-governmental organizations).

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ONG, for *Organização Não-Governamental*, which literally translates as NGO, Non-Governmental Organization, became the most popular acronym for the community-based organizations involved in the fight against AIDS in Brazil. Rather than supported by local gay organizations, Brazilian AIDS activism was largely connected to the international mobilization against the epidemic. The crystallization of the organizational form ONG, NGO, symptomizes at some level its international support and external aid; the link between this acronym and

WHO-sponsored forums would only increase in the following years and expand to other fields.[9]

As other community organizations throughout the world (Altman 1995, Arno 1989, Nelkin et al. 1991, Pollak 1994, Van Vugt 1994, Watney 1994, Wolfe 1994), NGOs were central players in the social movement responding to AIDS in Brazil in the decade 1985-1995. In this chapter I will discuss their role in the production of knowledge on the epidemic, examine their morphology and dynamics, their networking efforts, and their relationship with other intervening social actors such as international agencies, the Brazilian government, and the medical establishment. Unlike the community organizations in the United States discussed in chapter 2, Brazilian NGOs are defined not only in relationship to other local social forces, like the government or the medical establishment, or structured by the local dynamics of people with AIDS; both the existence and form of those groups is deeply intertwined with external and international social forces, both through funding and through the sharing of knowledge.

The year of 1985 may be described as the first moment of international awareness on AIDS. It was the year of the First International Conference on AIDS, and of the launching of WHO special programme. It was also the year of Rock Hudson's death and its scrutiny by the media. Public awareness also started at that time in Brazil. *Cadernos ISER*, the journal of the large organization ISER, [10] dedicated its seventeenth issue to AIDS and counted with the contribution of several scholars and political activists (ISER 1985). A group of São Paulo's citizens, including health professionals and social activists with or without

[9] The environmental Earth Summit in Rio 1992 and the Conference on Women in Beijing 1995, for example, would both have their separate NGO forums.
[10] The *Instituto Superior de Estudos de Religião*, Institute for the Study of Religion, is another umbrella NGO whose scope goes much beyond its title and promotes different social intervention programs as well as research. It is basically funded by religiously inspired donor agencies from Northern European countries like Holland, Sweden, and the U.K.

experience in the gay movements within *Abertura*, created the first and forever largest *GAPA*, *Grupo de Apoio à Prevenção à AIDS* (AIDS Prevention Action Group). The following year gave birth to the largest Brazilian AIDS agency, the *Associação Brasileira Interdisciplinar de AIDS* (Brazilian Interdisciplinary AIDS Association), or *ABIA*, in Rio de Janeiro. *ABIA*'s founders included medical and social scientists, physicians, social activists and a number of citizens concerned with the little response of the Brazilian government to the epidemic.

During the following decade, a number of similar but smaller organizations multiplied throughout the country, associating this particular organizational form to the social response to AIDS. In 1989 there were 51 AIDS-NGOs, counting both the ones that added AIDS to their concerns and those who were created specifically to fight AIDS (rede Brasileira 1989a:4); one year later there were 60 (Valinotto 1990:6-7), and 87 were reported in 1992 (Solano 1992:8); finally, the 1994 catalogue published by the government counted 140 (Ministério da Saúde 1994a:91). Retrospectively, 22 organizations claimed to be working with AIDS as early as 1986; eleven had initiated their work in 1987, eight in 1988, and the number increased the following years. Twenty organizations started with AIDS work in 1989, eighteen in the following year, and again eighteen in 1991; in 1992, twenty five initiated activities, and seventeen were counted in 1993 (Ministério da Saúde 1994a:92).

"ONG" was an uncommon term that gained popularity in the 1980s (Landim 1988:24) until near exhaustion by the 1990s in several fields of social intervention in Brazil, in Latin America (Reily 1995), and worldwide. Regarded as an "imported" term, "coined in the Northern countries," (Landim 1988:25) "adopted for convenience" (Fernandes 1988:8) from the jargon of international aid agencies, and consolidated during the time of *Abertura*, the term became

irreplaceable in the Brazilian repertory of social institutions. Its "myth of origin" refers to the 1950s and to religious activism (Fernandes 1988:9, Fernandes and Carneiro 1995:72). Indeed, the Catholic grass-roots movement which had its most visible expression in *CEBs* (base ecclesiastic communities) provided an important background experience for many of the NGOs that bloomed later, including those with AIDS support services. Left-wing politics were another source of organizing ((Fernandes 1988:9, Fernandes and Carneiro 1995); it was in the late 1960s, when the dictatorship was particularly harsh, that this organizational format matured, often as the possible legal face for political action(landim 1988:31). A third source for the NGOs derives from universities. Non-profit agencies act like magnets for "organic intellectuals:" they are appealing work sites for those who want to avoid the sterility of ivory towers, the slow bureaucracy of public service, or the stress and materialism of corporate business; in NGOs, university graduates can fulfill their social commitment agendas by providing "intellectual support for the popular movements," (Fernandes and Carneiro 1995:75) whether they do it full or part-time, out of strong political faith or just as a job in the market.

The social response to AIDS in Brazil coincided with the period of expansion and consolidation for NGOs. In the late 1980s, the acronym ONG occupied the symbolic spot where there had been *movimentos* (movements), *associações* (associations), and *grupos* (groups), for the field of AIDS as well as for other spheres of social intervention. Also, the term *ativista*, tailored after the international icon "AIDS activist," replaced the older term *militante*, seasoned in the local political left wing. A new social vocabulary had emerged in response to AIDS.

AIDS-NGOs, like NGOs in general, varied greatly in form and function. They might resemble business offices housed in mansions with several full-time employees, high-tech equipment, a number of on-going projects, multiple international connections, and renewable generous grants; or they operated out of someone's back room, gathered volunteers, and lived off raffles, button sales, small donations and volunteer work. They could be committed to political intervention or devoted to assistance work. They could act as monitors or critical partners of the government, or merely take a day-by-day perception of their area of action. They implemented research projects, organized conferences, and published competitive pieces of work; or they engaged directly in social intervention without ideological, political or scientific guidance. Such diversity is sociologically recurrent: "If heterogeneity is the rule within and among Latin American countries, it is gospel among NGOs and social movements" (Reily 1995:22).

In the social profile of Brazilian AIDS NGOs in 1992 drawn by Nelson Solano from GAPA-São Paulo, they are presented as a diverse group that shares common goals. His survey included 87 organizations, of which 51 were considered autonomous; 19 had religious affiliations, and 11 were linked to sexual emancipation groups. They were seen as a new and spontaneous social phenomenon, considered by the analyst as mostly autonomous, except for the religious-affiliated groups (Solano 1992:9). The author's formalist reading fails to account for the driving force of funding that helped create, sustain, and sometimes define the work of these organizations. As NGO analysts Ruben César Fernandes and Leilah Landim had commented, NGOs do not like to refer to their sources of funding and take it quite matter-of-factly (Landim 1988:47-48).

Solano contrasts AIDS-NGOs to previous Brazilian social movements, who pretended to represent the "popular classes;" the new movement did not have that pretension, nor did it necessarily oppose the government, but rather its health policies. The AIDS-NGOs seemed related to the urban centers with a relevant epidemiology or the presence of clearly defined homosexual or religious communities, which are implicitly acknowledged as the other driving force for this social movement. The author blames amateurism, absence of reflection, and excess of pragmatism, with the corresponding absence of political, educational, and social goals, as well as an absence of articulations with other sectors of society, for the identity crisis and difficulties experienced by the movement (Solano 1992:9-10).

Several attempts to organize and articulate the Brazilian AIDS-NGOs under a common structure took place, often inspired or supported by international networks. Among the many GAPAs that were created in the meantime in the different Brazilian cities, to a total of 18 in 1992 (Galvão 1992b:7), there were a few channels of communication and cooperation, such as the exchange and borrowing of materials, ideas, styles, and the sharing of experiences. Between 1987 and 1989 alone there were five nation-wide inter-GAPAs meetings (Solano 1992:12).

Even though much of the constituency of AIDS-NGOs was gay, it did not follow a pattern of gay-based AIDS-activism from the Northern hemisphere; rather, it went together with the global efforts promoted by international funding agencies. The AIDS-NGOs movements in Brazil had experienced a turning point with the official acknowledgement of their role in the global fight against AIDS by the World Health Assembly in May 1989 (WHO 1989c). This acknowledgement followed the attempts of the Global Programme on AIDS to

formally include the Community Based Organizations in the fight against the epidemic (WHO 1989c). This move helped empower, strengthen and fund local groups throughout the entire world.

The highest moment of exaltation in this collective movement was probably the Forum "Opportunities for Solidarity," sponsored by the World Health Organization in June 1989 in Montreal, prior to the Fifth International Conference on AIDS. Coming from everywhere, more than three hundred organizations and six hundred activists participated and exulted with the acknowledgement of their transformative power. Some were already incorporated into the inner planing and executive core; ABIA, from Brazil, participated in the organization of the meeting (ABIA 1989b:12).

The language of networking was a key in the Montreal meetings. ICASO, the International Council of AIDS Service Organizations, and the future Latin American Network of Solidarity were given as examples of integrating structures for local action. The forum "inspired the Brazilian NGOs who participated to seek regional and global forms of participation and response" (Galvão 1992b:10). Such forms were to be found, at least partially, by means of "the articulation through national networks, as a first step to the formation of regional and international networks, interconnected through ICASO" (Galvão 1992b:10).

NGOs lived then and there intense moments of empowerment and stood out among the other social actors involved in fighting AIDS, such as medicine, science, and the public administration. Several Brazilian organizations were present in Montreal. From Rio de Janeiro alone, there were ABIA, GAPA-RJ, the gay group *Atobá*, *Prostituição e Direitos Civis* (Prostitution and Civil Rights), and *ARCA* (Ação Religiosa Contra a AIDS), these last two linked to *ISER* (the High Institute for the Study of Religion, a large umbrella-NGO with many different

social research and intervention programs); the *GAPAs* of São Paulo and Bahia, *GETAIDS*, from Brasília, and the Pernambucan gay group *Movimento Antônio Peixoto* (Rede… 1989a:3). They returned home with the enthusiasm to create a national network and execute common projects.

Shortly after, the first meetings of the AIDS/NGOs Brazilian Network of Solidarity were held in Belo Horizonte, Minas Gerais (June 14-16), gathering fourteen organizations: the *GAPAs* from São Paulo, Rio de Janeiro, Bahia, Belo Horizonte, Pernambuco, Rio Grande do Sul, Santa Catarina; *ABIA*, *ARCA/ISER*, *Prostituição e Direitos Civis/ISER*; the recently formed group *Pela VIDDA* (an association of people living with AIDS, their families and friends, inspired by Herbert Daniel); the Group Solidariedade, from Belo Horizonte; the Lambda support center, from São Paulo: and the young national "names"/quilt project, Projeto Nomes.

A committee named at those meetings, including Nelson Solano (GAPA-SP), Jane Galvão (ARCA/ISER), Ranulfo Cardoso (ABIA), and J. Eduardo Gonçalves (GAPA-RS), was given the role of expanding the network and raising funds for the next meetings. Their survey counted 51 NGOs and obtained international funds from the British agencies CAFOD (Catholic Fund for Overseas Development) and the Save the Children Fund; from the US-based Ford Foundation, and national donations from a local industry and a private donor (Rede 1989a:5). Thirty-eight NGOs participated at the meetings held in Porte Alegre. There were already thirteen *GAPAs*: adding to those present in the previous meetings there were also the *GAPAs* of Baixada Santista, Ribeirão Preto, São José dos Campos and Taubaté (all in the state of São Paulo), plus Belém (Pará) and Fortaleza (Ceará); there were groups with similar names, like *GEAPA*, *GETAIDS*, and *GEPASO*; there were now three *Pela Vida* groups (Rio de Janeiro,

São Paulo, and Rio Grande do Sul); four delegations of the *Nomes* project (the national coordination, and the delegations from Florianópolis, Salvador, and Santos); there was *ARCA/ISER* and ABIA, from Rio, and the smaller *ALIA*, from Londrina, Paraná; there were several gay-denomination groups (*Atobá* and *Turma OK* from Rio, and the *Grupo Gay da Bahia*); volunteer and support groups such as those linked to the Hospital Emílio Ribas (SP), *Solidariedade (MG)*, *Solidariedade (SP)*, *Esperança*, *PRAIDS*, *MAPA*.

The enthusiasm of the participants in hat meeting reached its highest moment with the reading of the letter of support to the Brazilian Network personally signed by the director of WHO's Global Programme on AIDS, Jonathan Mann (1990). There was the presentation and discussion of several important documents: the proposal for a chart of principles for the network was presented and discussed (ABIA 1989d, Rede… 1989b), the declaration of rights of the person living with AIDS, which the Pela VIDDA group had developed as their centerpiece (Rede… 1990); and a document with the statement of principles for the network was approved (Galvão 1992b:11).

There was a third series of meetings in April 1990 in Santos, where some "traumatic" (Galvão 1992b:11) moments brought unsurmountable differences to the surface. A major conflict split the participating organizations and "postponed the dream of the creation of a Brazilian Network of AIDS-NGOs that included everyone, from Oiapoque to Chuí" (Galvão 1992b:11).

Social commentators relate the schism to the contradiction between two styles of organization. One the hand, there were the organizations whose constituencies pre-existed the AIDS crisis (like gay or prostitute groups) which, having suffered repression under the previous regime, were now willing to work

with policy makers towards AIDS prevention.[11] On the other hand, there were the AIDS-NGOs that integrated anti-dictatorship activists and would not consider negotiating with authorities that continued the structures of the authoritarian regime which they had fought and did not trust (Valinotto 1990, 1991; Parker 1994a:40). There were a number of other issues at stake, such as class, regional tensions, and the permanently underlying race and gender tensions. But, no matter how critical they might have become, they were not what counted the most at that moment.

My argument, from the analysis of the worldwide processes, is that the critical reason for the breakdown of the movement did not rely as much on its internal characteristics, but rather on its background international context. In spite of its inconsistency, looseness and contradictory nature, the movement might have continued if there had been funding, leadership and support for it. However, the period of revolutionary transformations was over, and there was not a full perception of that fact at a local level, at least for the majority of social actors involved. Institutional attempts to create organized international networks like ICASO (International Council of AIDS Service Organizations) and the Latin American Network of AIDS/NGOs equally failed, an issue that Brazilian analysts attributed to conflicts regarding representation of groups and countries, allocation of resources, power competition, and bureaucratic obstacles (Solano 1992:19).

The problems were of a wider scope, though. A larger shortage of funding and support was taking place everywhere and anywhere. In New York City, CRIs

[11] Often, government officers commented that it was easier to work with this type of groups with the self-assigned AIDS/NGOs. I could observe that the groups Atobá in Rio or GGB in Bahia, both of gay affiliation, were more willing to work with the board of health or the medical institutions than, for instance, ABIA, whose critical stance often prevented them from cooperating with government- or medical-sponsored pragmatical programs. Prostitute groups, also, cooperated with the government for joint programs, like the ISER affilieted group "*Prostituição e Direitos Civis*" (prostitution and civil rights), that produced a number of leaflets (e.g. ISER 1990) under the program "*Previna*" (see Braiterman 1991a, 1991b).

were about to lose funding. The Global Programme on AIDS had changed leadership, and the world seemed shifting into another direction. It might be that the "utopic moment" of transformative action was over, ceding pace to more institutional, bureaucratic and medicalized approaches.

Yet, the epidemic progressed with growing evidence that technical responses were not sufficient to stop its spread; and the more the social intervention was needed, the less it was proportionally supported. Already in 1990, the expectations for the Sixth International Conference on AIDS (San Francisco) had turned into frustration. NGOs boycotted the conference due to the U.S. restrictions on the entry of HIV-positive travelers, which prevented people with AIDS from participating and from giving their irreplaceable contribution to the global efforts (AHRTAG 1990a). It contradicted the entire rhetoric of WHO and AIDS action. The boycott of the San Francisco conference was closely followed and respected by Brazilian NGOs (ABIA 1990a, 1990b).

The second international meetings of AIDS-NGOs, held in Paris in November of that year (AHRTAG 1990b:1, 11), did not raise new strength for the movement either. Instead, for many activists those meetings marked the end of a dream of equality and ability to introduce change in a frustrating reality. According to a delegate from São Paulo, the differences that in Montreal had been seen as the ferment for the multiplication of exchanges had now transformed into insurmountable barriers (Bouchara 1991:9). One of the things that shocked Brazilian activists the most was the type of exclusionary identity politics adopted in the fight against AIDS. Two of the delegates from Brazil to the Paris meetings, untested for HIV antibodies by their own choice, were not allowed to a meeting supposed to be exclusively for HIV-positive people. At the

time, Brazilian groups fought hard for inclusive politics, using the line that "we all live with AIDS," a *motto* of the *Pela VIDDA* group.

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The short one and a half years between the NGO meetings in Montreal (June 1989) and in Paris (November 1990) were the peak of exacerbation for this social movement. There was a shared belief that something completely new was going on. Jonathan Mann had referred to it as a Health Revolution: for the first time, the affected communities were heard, fought for their rights, and challenged their own governments about health policies. People with AIDS had taken into their own hands the responsibilities of organizing, demanding, showing directions for research and assessing the needs for treatments. They had turned upside down some of the old assumptions of the medical practice, where patients were voiceless bodies in which symptoms were inscribed to be read and acted upon the sole mighty power of medical doctors. Now, "patients" were (impatient) persons who had voice, awareness, knowledge, and ability to act.

The changes brought by AIDS could have transformed the entire field of health in the world; there was now an officially endorsed and globally disseminated awareness that in order to address some medical problems one had to address questions of poverty, social development, and human rights. The flame faded quickly, though; as in so many other social upheavals, the goal of equity was undermined by the inequities of real life, and the differences within the social movement crystallized into antagonisms and inability to cooperate. International funding ceased to promote vaguely defined social goals that could

be locally interpreted at will, and instead directed quite closely the projects that were chosen for funding. After 1991, the belief in radical transformation gave place to more limited ambitions, short-term goals, and to more pragmatic as well as more fundable proposals.

Internationally and locally, AIDS had became more "domesticated" towards the side of the medical establishment; there were more drugs and therapeutical approaches, less fear and panic, and more experience on the part of the health professionals and the pharmaceutical industry. The radical activist energy was drained by losses, burnout, and diminishing international funding. Pragmatic alliances appeared as a possibility: with the government, with the medical sector, with the scientists or the local corporations. After 1992, the institutionalization of a new National AIDS Program in Brazil with a number of social interfaces, and a significant amount of funding from the World Bank, helped redefining much of the landscape for local activism.

From the activists' perspective, a strategy which defined a successful platform for expanded cooperation started in 1991 with the People Living With AIDS Meetings held by the Pela VIDDA group, Rio de Janeiro. Pela VIDDA had been created one year earlier due to the impulse of Herbert Daniel, a Brazilian PWA and writer who had perhaps the strongest single-handed influence in the local movement of response to AIDS. Daniel had been a radical revolutionary with periods of exile in Europe. On his return to Brazil at the time of Abertura he had integrated a political campaign as a gay candidate in a small ecological party. A brilliant speaker and inspired writer, Daniel could cheer an audience as well as persuade a funding agency. His influence touched mainstream international agencies, and the Global Coalition's *AIDS in the World* (Mann et al 1992) is dedicated to his memory. His fight against the inevitability of death by declaring

a commitment to life and solidarity as a Person with AIDS made him a role model for younger PWAs and brought much energy into the Brazilian NGOs as well as to international AIDS settings. One of Daniel's biggest legacies was the creation of the Pela VIDDA group in 1990, while he was a staff member and on the board of ABIA. "Pela VIDDA" simultaneously means "for life" and is an acronym of "for the Valorization, Integrity, and Dignity of AIDS Patient."[12] The group's headquarters were literally in ABIA's backyard; then, ABIA's headquarters were a mansion in Jardim Botânico, and there was space enough to accommodate the "offspring" organization with which a symbiotic connection was kept alive for years.

The PWA meetings format responded to pragmatic needs and helped organizing further actions and projects. A number of factors may have contributed to the success of the new effort: organizations had matured in the meantime and benefited from earlier experiences; the epidemic had expanded and gained visibility; other social forces were more prepared to articulate and interact with NGOs; people with AIDS, rather than self-assigned experts, took the responsibility of defining the priorities and directions for action.

The formula of the *Pela VIDDA* meetings remained consistent throughout the following years in creating a national space for discussing the social issues of the epidemic in Brazil. Plus it provided a platform for collective debate on the most important questions: how to live with AIDS, how to implement education and prevention, how to negotiate health policies with the federal and local governments, how to handle the loans from the World Bank and the WHO- or NIH-sponsored projects for local participation in HIV vaccine development.

[12] With the increasing use of *Pessoa vivendo com AIDS* (PWA), the term *Doente de AIDS* (AIDS patient) was abandoned.

Simultaneously, in August 1991, GAPA São Paulo coordinated a successful inter-NGOs meeting, gathering over 70 organizations (Parker 1994a:42). Rather than to repeat the failed attempts to institutionalize consensus, the aim of the meetings was limited to the discussion of specific issues like vaccine trials, and to help organizing action for the purpose.

This type of forum gathered more interest and success than the previous ones. From then on, Pela VIDDA-RJ organized yearly the "National Meetings of People Living With AIDS," which gathered delegates from the entire country, plus scholars involved with AIDS research (microbiologists, clinicians, social scientists, or epidemiologists), as well as international activists, government, WHO officers or delegates from the Global AIDS Policies Coalition.

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As a whole, the social response to AIDS in Brazil was largely articulated to the international movement; the synchrony between global sponsorship and the expansion/contraction of local activism is documented above in this chapter. The international synchronization, however, was not felt evenly in Brazil. Its reverse side was internal differentiation. Rather than leveling, external aid induced a differentiating process among the local social forces. Some NGOs were, or become in the process, more cosmopolitan than others; while the former held to international links, the latter were either their subsidiary or struggle in isolation, backwardness, and limited action. In the field of AIDS in Brazil, as the international flows were fast, intense, vital in access to information, and involving large amounts of funding, the differentiation process among locals was enhanced. Cosmopolitan NGOs could better benefit from the international

activism energy, know-how, expertise, educational materials, vocabulary, graphic styles, and funding. The ones able to participate in international forums thereby improved their own networks, expanded their knowledge, visibility, ability to develop projects, to maintain funding and to remain active. With more funding they could recruit more qualified and high paid staff and reproduce their economic status quo through grant writing and international networking.

Some local organizations excelled at being cosmopolitan: ABIA, from Rio, maintained a constant exchange with major international NGOs, with the WHO Global Programme on AIDS, with USAID's agency AIDSCOM (later merged with AIDSTECH, forming AIDSCAP), and with major foundations like Ford and McArthur. ABIA stood out in several international settings: it was central in ICASO and in the Latin American Network of AIDS/NGOs; it had a partnership with AHRTAG (Appropriate Health Resources and Technologies Action Group) in the publication of Ação Anti-AIDS, the Brazilian version of AIDS Action; and it was represented at a higher level in the Global AIDS Policies Coalition. Frequently accused of elitism by other Brazilian NGOs (and dramatically so in the 1991 meetings in Santos), ABIA would not adopt a populist attitude nor lower its standards. Instead, this organization kept giving priority to research and reflection with international standards. They combined research with the task of sharing their expert knowledge, mostly through the publication of a nation-wide newsletter, Boletim Abia (which documents most of the AIDS social movement), plus a number of target-group publications, videos, media appearances, and conferences.

ABIA's unique style resulted from a rare combination of circumstances. Its first major funding, by the Ford Foundation, launched an early international career from 1986 on. That funding supported an academic-style type of research

on the "Social Impact of AIDS in Brazil," which brought together anthropologists Carmen Dora Guimarães and Jane Galvão and the activist/writer Herbert Daniel. Their work produced a critical examination of the narrowness and cultural inadequacy of the epidemiological models used by the government and local health authorities to define the terms of AIDS reporting (Guimarães et al 1988).

The explicit purpose of the new agency was to "develop a multidisciplinary approach to the issues raised by AIDS" (ABIA 1988a), and attempt "to set forth adequate prevention, education and information policies to face the overall impact of AIDS" (ABIA 1988a). It was part of ABIA's early doctrine that AIDS was a major health challenge with a severe social impact, in the need of a multidisciplinary, engaged response. It became apparent from ABIA's statement that, in the context of AIDS, epidemiological knowledge could not exist separated from social action and intervention:

> *only global prevention action will be able to check the progress of this virus against which no cure or vaccine is yet available. Such an action, however, will only be effective if it manages to avoid the harm caused by fear and prejudice for which only solidarity can provide treatment methods.*
>
> *The AIDS virus knows no boundaries, nor country of class or social group. The ways by which it is transmitted, through sex and blood, involve complex social practices often surrounded by taboos. This turns the epidemic into both a severe medical and epidemiological threat and a huge historical challenge, raising cultural, political, economic, ethical and legal issues.*
>
> *There are many facets of social life in every country which are brought to bear on the epidemiological profile of the disease. To know precisely what are the multiple aspects is the fundamental topic of prevention activities. (ABIA 1988a)*
>
> *For that purpose ABIA gathered members from all areas of knowledge -- medical and social scientists, media and education professionals, lawyers, politicians, artists, church and community representatives. The NGO stated goals were, in the first place, "to follow and assess AIDS-related government policies and initiatives in Brazil"; as it was made clear, due to the historic public neglect of public health in Brazil, "only through permanent surveillance and joint pressure" would society be able "to claim its right to health, forcing the state to take on responsibility in this area." The second set of goals, "to produce and disseminate updated, accurate and reliable information on HIV-infection prevention and control," was to be achieved mostly through work on information and knowledge: critique on available*

> *information, avoidance of "misinformation," fight against partial and incomplete information, namely what might produce panic and prejudice; create the means to have direct access to updated data on the epidemic in Brazil and throughout the world; "prepare written and audiovisual aids holding clear and reliable information" directed at various audiences, reached by joint work of ABIA and other agencies; to research on the local social impact of the epidemic in order to "establish the epidemiological, social and cultural profile of AIDS" in Brazil; and to provide consultancy and advisory services to the media and any public demand on the epidemic (ABIA 1988a).*

Counting on the executive skills of Silvia Ramos and Walter Almeida, having the nationally known PWA and sociologist Herbert de Souza (Betinho) for president, and with the collaboration of many prestigious founders, volunteer associates and full-time coordinators, ABIA's staff developed early on a number of international connections that enabled the organization to grow and hold a leading role within the international networks of AIDS. What seemed to the smaller NGOs as lavish expenses in airplane travels, computer and modern communications equipment, full-time social researchers, and a number of glossy color publications, was regular business for ABIA, which never planed to be a community-rooted organization but rather a fast-acting agency oriented to work with information, knowledge, and a critical monitoring of the epidemic.

This orientation characterized ABIA's first period, lasting roughly from 1987 to 1991. It was focused on a broad intervention in the sector of information coupled with the production of original texts of analysis and reflection, mostly by political writers Herbert Daniel and Silvia Ramos, and combined with international networking, mostly conducted by medical doctor Walter Almeida.

Throughout the time, internal changes in ABIA led to variations within this orientation. A second moment in the life of ABIA (1992-1994) was characterized by the formalization of multiple partnerships and social intervention in different fields, like work places (ABIA 1991d, Solano 1993), low-income communities

(Fernandes 1994), and schools (Monteiro et al 1994). Herbert de Souza (Betinho) remained as president, while the former staff was lost either to AIDS, burnout, or incompatibilities; the new direction included Jane Galvão, from ARCA/ISER, João Guerra, from NGO community intervention, and as main coordinator Richard Parker, from the State University of Rio de Janeiro, and also a skilled international fund-raiser that brought to the agency a wave of new funds, that in 1994 reached the level of one million U.S. dollars a year. The staff was expanded and included Veriano Terto, Nelson Solano, José Stalin, Christina Valinotto, Simone Monteiro, Jacques Schwarzstein, Cristina Castelo Branco, and others. In 1992, the headquarters moved from the elitist neighborhood of Jardim Botânico to a downtown office building. This act was both symbolic and budget minded, since that year bankruptcy had been eminent. The Pela VIDDA group moved with ABIA to the new and more accessible downtown location, where there was also ABIA's open resource center with documentation, videos, and books.

In a third phase, starting in 1994, ABIA's profile changed again. Remaining in the downtown headquarters, the staff was dramatically reduced, and the projects of intervention and partnership with communities and corporations were reduced in size and number. The agency focused again on a more academic style of research, as well as on the organization of seminars and the production of social knowledge on AIDS, with partnerships with the university, particularly with the Social Medicine Institute of the State University of Rio de Janeiro (Parekr and Galvão 1994, Parker, bastos, galvão and Pedrosa 1994). One particular project that combined research and intervention became central to ABIA's activities: the project "homossexualidades," targeting gay men, executed in partnership with Pela VIDDA-Rio, and sponsored by AIDSCAP/USAID, the McArthur Foundation, and the Ministry of Health (Terto 1993, ABIA 1994,

Quemmel 1994, Parker, Mota and Rodrigues 1994). After many years of conceptual elaboration and public education against the link of prejudice about AIDS and homosexuality, ABIA was now ready, with the support of international funding agencies and the government itself, to address the population that kept standing out in the statistics of illness and risk.

Only a few other NGOs succeeded in establishing their international networks and developing their local action accordingly -- benefiting from funding or privileged knowledge. A successful example is the joint publication, by Pela VIDDA-SP and GAPA-Bahia, of the Cadernos Pela VIDDA, a newsletter on treatment news and a glossary of AIDS-related terms where most articles were translated from international treatment activism newsletters. This publication brought innovation and filled an empty space, spreading and sharing a type of knowledge that had been available only to the few English readers with access to international newsletters or conferences (see Gaspar 1992).

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The consistent opposition to governmental policies regarding AIDS (or, in activists words, the lack of those policies) was a central element in the first period of social organizing against AIDS in Brazil. Earlier in the epidemic, public officials had referred to AIDS as an international and foreign issue with little local relevance, especially when compared to the traditional endemic plagues. Public dismissal and governmental unwillingness to act upon AIDS, until at least 1986, fueled NGOs criticisms; this partially explains why their early efforts were concentrated on persuading the public that AIDS was locally relevant, that adequate measures should be implemented, and that awareness had to be raised.

NGOs' assumed that the government would never meet their requests, nor people's needs in general.

The governmental program on AIDS was legally created in 1985, taking effect in 1986; during the following years the program, headed by Lair Rodrigues,[13] gathered and published epidemiological data and a few manuals for AIDS care that were sent to the health services (Ministério da Saúde 1987, 1988a, 1988b), as well as lobbied for international support and scientific attention to AIDS. Working through a loosely organized action program, and within a decadent health system in the aftermath of a long dictatorship, governmental action upon AIDS had severe discontinuities. Public awareness campaigns might have had good intentions but were criticized by most vocal activists (see ABIA 1988c:2, Mott 1988c:6). Targets for criticism were the government's choice of communication styles, words, priorities, and the slowness or absence of intervention in critical sectors like blood contamination (ABIA 1988d, 1988e, 1988h, 1988i, 1988j, Ramos 1988:6; Tema/Radis 1988). In spite of the shared goal of intervening and containing the AIDS epidemic in Brazil, the governmental and non-governmental sectors had then a quite difficult interaction. While the government had a narrowed medical perception of the epidemic, NGOs, backed by international organizations and by their own political and social science knowledge, insisted on the wider social dimensions of AIDS and on the need to address them as a central strategy for action.

[13] Lair Guerra de Macedo Rodrigues headed the first National Program on AIDS and STDs (1986-1990), was replaced during Fernando Collor's presidency, and returned when this president replaced corrupt Minister of Health Alceni Guerra by INCOR's surgeon Adib Jatene in 1992. Previously a biomedical sciences professor at the University of Brasília, Lair Macedo was personally connected to international bureaucracies of PAHO and WHO and her vitae included a period at the CDCs in the United States. As a woman, a Northeasterner and a Baptist, she challenged at every instance the usual profile of power (male, Southeasterner, catholic or laïc) with an unusual political savvy. Her career was tragically interrupted by a car accident in 1996, during a work trip.

NGOs developed their own expert knowledge about AIDS in Brazil, often rejecting the knowledge used and disseminated by the government, even what we might think of as "technical knowledge." Figures were challenged as under-representing the epidemic (ABIA 1988c:2, 1988f, 1989a); from an assertion of a level of 30% under-reporting, ABIA estimated later a level of 50% under-reporting, supposed to be even worse in the state of Rio de Janeiro, where the 800 reported cases in 1989 might correspond to over 2,000 actual cases (ABIA 1989a, Guedes 1989). Epidemiological concepts, including the "risk groups," were challenged as culturally inadequate, discriminatory, prejudiced, and misleading (ABIA 1988f, 1989c; Guimarães et al. 1988:4-5; Ramos 1989:9; Parker 1989a:10); in this area alone, a vast subfield of research on local sexual cultures, drawing from the constructivist view on the local sexual ways (Fry 1982; Fry and McRae 1985; McRae 1990, Perlongher 1987, 1992; Parker 1987), and developed into an international model by anthropologist Richard Parker (1987, 1988, 1989b, 1991a, 1992) inspired the rejection of the narrower medical models upon which the epidemiology of AIDS was based. Media campaigns were rejected as either offensive, ineffective, scarce, or using incorrect imagery (ABIA 1988d; 1988e; 1988j; Ramos 1988:6); publications were criticized as too few or too many. A harsh criticism of the government preceded a more "objective" analysis of the contents of governmental efforts and the possibility of working cooperatively towards containing the epidemic. The knowledge and world views from where activists and public officers stood seemed then to belong to different galaxies.

There were historical reasons for the opposition: governments had been headed since 1964 by military dictators, and NGO personnel had politically matured while fighting them: as for the generic NGO activist, "the state was an obstacle, rather than an actor for cooperation"(Landim 1988:45). Even after

military resignation to and the advent of civilian rule in 1985, there was no evidence of a substantial change in the administration.

The 1990 presidential elections brought a promise of change, with labor movement candidate Lula and the anti-corruption candidate Collor. They were won by the latter, who proceeded with frantic reforms in the monetary system and multiple efforts to modernize the international image for Brazil. He did not, however, change much in the health structure except to allow the slow and insidious dismantling of the public health care system, with the diminished role of the state and government in public health. The decline on the population's quality of life was quite visible during the time of my fieldwork. Ironically, this president was impeached two and a half years after election on grounds of corruption. His minister of health, Alceni Guerra, was dismissed earlier for proven corruption when allocating funds of the 1991 anti-cholera campaign for his own electoral benefit and overpayment of "emergency" purchases, often defined by the interests and profit of his political supporters.

During Alceni Guerra's mandate (1990-1991), the little that the government had previously done to fight AIDS was replaced by fewer and constantly postponed actions. AIDS officer Eduardo Côrtes, who at the time of appointment (1990) was better praised than previous officer Lair Rodrigues, promised fast action and an "aggressive" media campaign. The campaign came to light a few months later, funded by a consortium of corporations. Its tagline *Se você não se cuidar, a AIDS vai te pegar* ("if you don't watch out, AIDS is gonna get you"), combined with naked silhouettes of a woman and a man with targets on their genitals, was seen as of bad taste and inefficient. Yet it was bland when compared to the TV-spots of the same campaign. On those, a succession of different people with illnesses like cancer and tuberculosis announced to the

cameras that they had been ill but had been cured. In the end, the screen brought in the face of a young man that announced he had AIDS and had no cure. Stating the opposite of what the social movement of PWA dignity had been fighting for, the campaign was declared altogether a disaster by the NGOs, which were backed by letters and comments from the public (ABIA 1991b, 1991c), and by many of the health professionals I interviewed. The relationship between government and non-government continued to sour. The years of 1990-91 were also some of the economically most afflicted times ever experienced by the Brazilian population; and those were the years when the AIDS crisis and its problems became more evident and demanded more action. By 1991, opposition between NGOs and the government had reached its most difficult levels.

It took time, changes in the Ministry of Health, international pressure, mounting evidence of the gravity of AIDS in Brazil, and its characteristics of medical and social emergency, for some convergence between the governmental and non-governmental sector to occur. Towards the end of 1992 there were increasing levels of interaction between the two sectors in practical matters (Schwarzstein 1992:3-4). The government had created an interface to negotiate with NGOs, and regularly called in consultants and experts from the NGO world. New concepts and strategies used by the government showed evidence of NGO influence: communication styles, publications, and interest in community-based organizations. Also, NGOs agreed to negotiate with the government about specific issues, some of them as critical as the support for vaccine development projects, or the allocation of World Bank special funds for AIDS prevention and care in Brazil.

Even though they did not converge in symbiotic harmony, the boundaries between the spheres of action of NGOs and of the government views became

occasionally blurred. Many activists complained about confused identities when they started being funded by the World Bank via the government, and to see their organizations listed in government-published catalogues (Ministério da Saúde 1994a), or still to hear their own words of action borrowed by governmental-sponsored campaigns.[14] As some organizations became locked into a survival strategy that brought them under governmental supervision, others moved into other sectors of intervention, such as applied, or academic type social research on AIDS-related subjects -- sexuality, drug use, social meanings, and coping strategies. International commentators observed, catching a trend, that in the Tenth International Conference on AIDS, held in Yokohama, 1994, where Brazil had a strong visibility in many different sectors (MInistério da Saúde 1994b), the governmental booth looked like that of a NGO, whereas the booth of ABIA, the largest Brazilian AIDS-NGO, looked like an academic publishing house.[15]

At that moment, the government had taken over much of the role of defining the world of NGOs -- a role that is not unrelated to the general movement towards emptying the state of its social functions by relying on their fulfillment by civil organizations, whether or not funded for that purpose. Handling in 1993 a U.S. $125 million World Bank loan to fight AIDS in Brazil, matched by an equal amount from their own treasury, sometimes described as a total of 300 million (Schwarzstein 1993a, ABIA 1993b), the government passed funds to different NGOs through cooperation projects. Many NGOs felt co-opted

[14] The campaign that launched in early 1994, Você precisa aprender a transar com a existência da AIDS, was welcome by NGOs and the public. It included sketches with young people addressing candidly and in attractive ways the issues of safe sex and needle use.

[15] This observation was made by some of the international delegates to the conference and the view that "ABIA turned into a publishing house", instead of promoting the development of new AIDS therapies, was a remark made by ex-coordinator Walter Almeida, M.D., to Jornal do Brasil, March 18, 1995, in a interview about the potential of passive immunotherapy (based on the infusion of the plasma of long-term asymptomatic HIV positive people).

and tied up, limited to work on the one project for which they wrote the grant proposal, in a radical shift from their earlier partisan, community-serving, and alternative style in which international funds were allocated for loosely defined social goals. Like many others in Latin America, the AIDS NGOs in Brazil were in "their journey from protest to proposal" (Reily 1995:24), and did not feel completely at ease in their new social persona.

Calling in the Pela VIDDA and ABIA coordinator Stalin Pedrosa to head the interface with the NGOs, the government took the role of surveying, counting and mapping the world of AIDS-NGOs in Brazil. In 1994, 140 NGOs serving AIDS were counted, 69 of them specifically defined around AIDS and/or human rights; among the others, 26 had religious denomination, 14 were women organizations, nine had gay denomination, four were from social movements, and the other four from health professionals movements (Ministério da Saúde 1994a:83). In 1993, 55 of those NGOs had joint projects with the government, ranging from U.S. $6,000 to $100,000. In 1994, there were 24 NGOs with new projects funded and 34 waiting for approval.

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If one of the strongest components of the AIDS social movement in the U.S. was its interaction with the medical establishment and the ability to intervene in the previously inaccessible world of biomedical research, in Brazil things were different: that component was a let comer in the social movement. Before 1991, when both "Cadernos Pela VIDDA" were first published and public discussions on the local participation in HIV vaccine development were initiated, there were no traces of local "treatment activism." The changes this disease had

brought into the doctor-patient interaction were restricted to a niche of educated, personally empowered middle class patients with access to information. Even if not exclusively, this was the bulk from where the new social character grew: the person with AIDS, fighting for his or her life and anxiously following the latest scientific news, transforming a "death-sentence" into a chronic condition and a demonstration of life; this had a special impact on a medical culture like the specialty of infectious disease, with its proverbial almighty aloofness and distance from the patient.[16]

However, the intimacy with which North American activists worked through partnership-based innovation in science (chapter 2) was quite removed from Brazilian reality. The very relationship between a Brazilian PWA and a medical drug was mediated by a number of institutions, like laboratories, corporations, agencies, research centers, or information centers, that were located somewhere else and above, physically and politically, in the First World. People involved with AIDS in Brazil were by definition in a peripheral setting: they were in the Third World, removed from the centers of decision, doubly removed from the possibility of lobbying them directly. The ability to interfere in the core of the medical and scientific process was submerged in an ocean of basic and urgent difficulties. Long-approved drugs were still out of reach, too expensive or unavailable locally; there were not enough hospitals and hospital beds; many doctors and health professionals still refused to treat AIDS; families rejected people with AIDS, and an intense fear and prejudice dominated the society as a whole.

[16] The typical and poverty-related parasitic and infectious diseases required a brief treatment, for the patient either died quickly or got fully cured with no sequels. Doctors from that specialty often mentioned that they did not use to have any personal tie with the patients umtil they treated AIDS.

In this context, and according to their specific historical background, NGOs were oriented towards wider, more general questions. Like the agencies that supported them, Brazilian NGOs were concerned with the potential annihilation of human rights brought about by the prejudice that loaded the popular perception of AIDS, that symbolically placed in the death row the people diagnosed with HIV antibodies, stripped them of their rights; as a response, community organizations fought for solidarity, defined as the "social vaccine against AIDS" (Daniel 1989).

For a number of years, no actual bridges or compatible knowledge between NGOs and the medical establishment were consistently pursued: NGOs worked on the area of human rights and general social issues, while the medical establishment produced and used its own knowledge. The "blood fight," which epitomizes an early interaction NGOs/government around a medical question, was conducted under such assumptions: having medical knowledge as a background, activists demanded action from the government to fulfill their right to have an uninfected blood supply.

As for other topics, there was no consensus among NGOs: for some, it was irrelevant to demand medical "quick-fix" solutions in such a devastated field of health; they preferred to work in the social and political sphere, demanding from the government a stronger and more effective intervention, involving the complete restructuring of the health care system. Other groups were oriented to work within the existing gaps, for example, to help people with AIDS find medication when the bureaucracy of public services delayed their treatment (Gurgel 1988; GAPA-RJ 1989). Until the question of the free distribution of AZT launched a public discussion in 1991, leading subsequently to the publication of

Cadernos Pela VIDDA (Gaspar 1992:2), there was not much room to question and interact with the medical establishment.

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A turning point for the local increase in interaction between activists and the medical sphere coincided with the discussions of vaccine development, from 1991 on (See Beloqui 1994, Grupo Pela VIDDA et al. 1992, ONGS/AIDS do Brasil 1991, Schwarzstein 1993b, Sutmoller et al. 1994). The need for a community partnership for HIV vaccine development brought about a new style of action both to the medical establishment and to the activists. Unprepared for the social negotiation of their protocols, the medical researchers had now to face community representatives or NGOs; and NGOs had to learn the scientific details of the protocols they were involved in negotiating, which led to further mechanisms of differentiation. Turned into "experts" on the issue, some community leaders became invested with additional symbolic power.

The vaccine discussions brought together all different social aspects of AIDS: the tensions between government and NGOs, among NGOs, between educational and vaccine prevention, between spending quotas, between First and Third World, private industry and public cause.

The first public proposal to integrate Brazil into the global efforts to develop a HIV vaccine had been raised by WHO in 1991. Brazil combined an adequate epidemiological profile with the existence of a local scientific community able to contribute, and benefit from, the development of an AIDS vaccine. This suggestion, based on technical criteria, met the momentary situation

in Brazil in the worst terms. The Minister of Health (Alceni Guerra, see above) and his AIDS office appointee, Eduardo Côrtes, were at the time severely criticized by the NGOs: the governmental AIDS budget had shrunk, the national program offices in Brasília were empty and unproductive, the "aggressive" educational campaign was considered faulty (ABIA 1991a, 1991b).

Also, a history of abusive medical experiments in the Third World, combined with a sophisticated anti-imperialist rhetoric, inflamed anger about the possibility of using Brazilian bodies as "guinea pigs" for international experiments (ONGs/AIDS do Brasil 1991, Schwarzstein 1993b). There was no local history of treatment activism nor experience with volunteer participation in clinical trials. While U.S. activists fought for the possibility of being included in drug trials, often with dangerously toxic substances, Brazilian activists rejected the entire concept and mistrusted the system.

Moreover, the choice for prevention through education, rather than through vaccines, remained in the air waves from the exalted moments of the "health revolution." The idea that "the vaccine already existed, and it was called solidarity" (Daniel 1989) had been broadcast throughout the activist networks. To go for a laboratory vaccine was somehow equivalent to acknowledging a defeat in the social fight against AIDS and the final acceptance of its medicalization.

Some of the points raised by vaccine development, such as the basic requirements for fair trials, as well as the production of community documents, launched awareness and interest in the community (ONGs/AIDS 1991). This generated the comment that Brazilian "treatment activism" took its actual first steps around the question of vaccines (Grupo Pela VIDDA et al. 1992), following its incipient start around AZT.

The issue got full attention in 1992, after the new Health Minister Adib Jatene redesigned the public priorities for health in a way in which AIDS was given full attention. Lair Rodrigues was re-invested in the AIDS/STD office, now with a multidisciplinary staff and an interface with NGOs, anticipating the international mega-loan from the World Bank. The participation in vaccine trials was given a high priority, and was the subject of a number of documents and seminars (Grupo Pela VIDDA et al. 1992). This might have been the moment of a major transformation but, both at a local and at an international level, history proved that it was not (yet?) the case.

The integration of different specialties, from virology to clinical medicine, immunology, epidemiology, statistics, behavioral sciences, and the diverse world of community representatives, was a difficult (and still on-going) component of the implementation of the steps necessary for the development of vaccine products. To add complexity there was competition between the different academic institutions in charge of the process, exacerbated by the promise of benefits like transference of technology, funds, and international connections brought by vaccine trials in a situation of scarce resources (see Marques 1993).

The combination of these multiple tensions characterizes the field of vaccine development at this moment in Brazil, where both WHO sponsored and NIH sponsored projects compete for cohort studies among similar populations, actually overlapping in cities like Rio. In the meantime, in the United States, in spite of better interactions between the different social actors involved, attempts for vaccine development experienced difficulties that led to the suspension of the "phase three" efficacy trials in 1994 (See Green 1995). This suspension directly affected the Brazilian situation; when developing countries are encouraged to test products rejected in the developed countries for reasons of potential danger and

lack of safety, the spector of using third-world populations as "guinea pigs" rises naturally. The Fourth national meetings of people living with AIDS, held in Rio in 1994, were largely focused on this problem. It included guests from the relevant international and national institutions: WHO, Ministry of Health, Federal University of Rio de Janeiro, Federal University of Minas Gerais, University of São Paulo, FIOCRUZ, ACT UP-New York, ARCA-SIDA, as well as most Brazilian NGOs. No consensus is yet in sight, as there is none at the international level. The most noticeable trait of this process is its openness to public scrutiny.

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To summarize, the social response to AIDS in Brazil should be analyzed both in terms of its sociological background (political, religious and academic) and its relationship to international responses to AIDS. These two elements, rather than the actual details of the medical and epidemiological problem, help us understand the particular forms and dynamics of AIDS organizations and AIDS action in Brazil.

As for the actual historical context, the coincidence between the early development of the epidemic and the generalized economic depression and institutional dismantlement following the dictatorship made AIDS in Brazil seem "The Worst AIDS on Earth," or made so, by the government's ineptitude (Ramos 1989). NGOs demanded the most and the government responded the least. Inspired by the international movement and supported by international institutions, NGOs aspired to general health reform, if not a health revolution; the government could not but give scattered and short-term responses. After a period of difficult and feisty interaction, opponents became closer and better able to

negotiate with one another around pragmatic issues, such as the management of the World Bank loan to fight AIDS in Brazil and the participation in the international vaccine trials. Many people and ideals were left out of the process: people who lost their lives to AIDS, who left disagreeing with the changing terms of action; ideals that were too broad to be met by the practicalities of human interaction and institutional competition, and which more easily turned into disenchantment. The history of social response to AIDS in Brazil, as in the world at large, is at once one of achievement, empowerment, learning and teaching, fund-raising, research, publishing, media visibility, cosmopolitan links, rushing and anxiety, and one of losses, grief, and endless sorrows.

The declining charisma, the multiple losses, the bureaucratization, and the routinization of action and research could not find a better match than the triple cocktail therapy, announced as a possible cure for AIDS in 1996. At that moment, conflicts had given place to cooperation, and efforts were most of all focused on making the new treatments available to the population. Government and activists had finally agreed in a subject.