

Non-governmental organizations and access to anti-retroviral treatments in Brazil

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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 11th 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.¹

At the 11th 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 52nd 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 13th 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

¹ 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 5th, 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 4th 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 4th 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 1st), 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.² 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 5th, 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.

² 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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