

Universal access to AIDS medicines: the Brazilian experience¹

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INTRODUCTION

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

Some historical references are mentioned in order to provide a better understanding of the principles underlying the Brazilian policy, which primarily result from the inevitable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

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

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

UNIVERSAL ACCESS TO AIDS MEDICINES: THE BRAZILIAN EXPERIENCE

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

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

lic health services, and participation by civil society.

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

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

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

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

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

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

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

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

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

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

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

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

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

Everything happened at break-neck speed. The Group to Support AIDS Prevention (GAPA) was set up in São Paulo in 1984 and officially founded in 1985.¹ The basis for this

¹ GAPA was the first CSO created in Brazil in response to the AIDS epidemic.

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

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

ACTIVISM AND SOCIAL CONTROL

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

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

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

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

THE INTERNATIONAL SCENARIO

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

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

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

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

nology developed by Brazil to deal with the epidemic.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

THE GLOBAL FUND TO FIGHT AIDS, TUBERCULOSIS, AND MALARIA

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

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

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

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

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

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

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

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

IN SHORT...

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

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

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

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INTRODUCTION

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

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

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

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

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

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

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

Human rights and politicized quality of life definitions

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

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

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

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

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

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

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

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

The *continuum* between prevention and care

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

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

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

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

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

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

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

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

policies, enactment of human rights and patent laws.

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

Many challenges in this area remain quite urgent.

- better multi sector integration, “transprogramming”⁶;

- expanding the underlying concept of prevention that AIDS affects all people, “all people”, actually meaning “HIV negative people”.

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

- Reproductive rights and health care for people living

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

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

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

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

with HIV have not been protected and promoted.

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

The simplistic result of this approach has been that programs and research, mass “interventions” or small face-to-face groups have ended up effectively treating its target public as “HIV-negative” (synonymous to “all”). They should protect themselves from possible “HIV-positive” people. We talk about the obstacles preventing “HIV-negative” individuals to accept or even consider others to possibly be “HIV-positive”, but the difficulties faced by people living with HIV to perform the appropriate tests, to reconstruct a new life for themselves, protecting themselves and others from re-infection, is rarely openly discussed⁷. It was as if such people were not part of the country, but belonged elsewhere. Their reproductive rights, particularly, are still marked by silence

or restricted to behind-the-scenes controversies⁸.

Reproductive health care, component of the Women’s Health Programs, rarely encourages “wives and mothers” to undergo anti-HIV testing in the gynecological and pre-natal services (spaces for “all”, where HIV is not even thought about). Moreover, people living with HIV have no space where they can reflect upon or discuss their reproductive intentions (as they are treated in spaces which is not used by “all”, but which is specialized in HIV/AIDS). Such topics constantly emerge as one of the key demands made in the support groups for female and men who have sex with HIV+ women. One of the few occasions on which the sexuality of people living with HIV is actually discussed is during the compulsory counseling session following an HIV test, and access to counseling sessions of this type has not increased⁹. The focus of such sessions is usually on the need for using a condom or at the very least, modeling and conducting ‘behavior prescription’. There is no consideration given to the contextual dimensions of sexuality, and certainly no discussion of what his or her reproductive intentions might be.

Brazilian sexes and genders

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

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

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

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

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

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

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

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

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

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

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

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

These subsystems mingle in very singular ways.

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

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

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

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

although over a third of sexually active women living with HIV in this country still do not use condoms consistently¹².

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

Again, many challenges in this area remain quite urgent.

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

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

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

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

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

While concern with gender relations and respect for sexual diversity have indeed been incorporated into many prevention activities since the beginning of 90s¹³, the needs of women living with HIV regarding their responsibilities for their families and children have in effect not been taken properly into account in the course of the organization of their care. Their more frequent demands are: nowhere to leave their children while attending the relevant care service and low attention has been

paid to the issue of access to reproductive care¹⁴. A further point is that ‘gender’ continues to be thought of in the singular, as being synonymous with female oppression. There has been little attempt to look more deeply into prevention activities or to deal with the impact of gender culture and relations regarding the increased vulnerability of *males*. ‘Men’ receive almost no guidance as to how to deal with their reproductive dilemmas (also virtually non-existent as far as women’s health programs are concerned).

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

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

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

¹² Enhancing care initiative website (op.cit).

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

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

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

adheres (not complies) to health care guidelines¹⁵.

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

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

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

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

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

which will best sell this idea, product or behavior.

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

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

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

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

¹⁶ Definition by “Aurélio”, our best selling dictionary.

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

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

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

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

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

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

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

PSYCHOSOCIAL EMANCIPATION

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

¹⁷ AYRES, J. R., 2000. ECI working group meeting. São Paulo.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

IS OUR BRAZILIAN RESPONSE TRANSFERABLE?

If we have gotten our point across we understand that every place needs an exercise of politicizing its process, negotiating and finding its "best processes and practices". Not from any universal and all transferable guideline or "best practice". We may 'inspire' other context-based initiatives, we may share common values and an idea of human rights – necessarily individual and socio-economic human rights. Taking into account what Boaventura Santos¹⁸ has stated: within the constant tensions that justify the search for a progressive policy and politics of global human rights

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

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

END NOTE: ABOUT PEDAGOGY
OF OPPRESSED

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

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

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

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

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

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

where they are denied the right of simply being different.

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