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# Brazilian leadership in the context of the UNGASS Declaration of Commitment in HIV/AIDS

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## ABSTRACT

The present article focuses on the subject of leadership in the United Nations Declaration of Commitment in HIV/AIDS, discussing the advancements, challenges, and limitations to the action of major social forces acting to control the HIV/AIDS epidemic in Brazil. The national policy on AIDS was characterized by the illustrative Brazilian experience in summoning multiple government, civil society, and private sector initiatives to fight the HIV/AIDS epidemic. The synergy between different partners needs to be enhanced and efforts in the field of scientific and technological development must be articulated in order to minimize the effects of technological dependence. These actions are aimed at the sustainable production of drugs and other products, with the perspective of improving the fulfillment of the constitutional precept of health as a universal right.

**KEYWORDS:** Acquired immunodeficiency syndrome, prevention & control. Social control policies. Social control, formal. Social control, informal. Program development. Non-governmental organizations. Human rights. Leadership. Brazil.

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## INTRODUCTION

The present text proposes a reflection on a potential link between the unfolding of the AIDS epidemic in Brazil and the establishment and activity of leaderships in the Brazilian context. These leaderships, be they personal or institutional; governmental, or emanating from civil society, devise and organize measures aiming at the control of AIDS/HIV in Brazil. For this purpose, we shall first present the concept of leadership set forth in the Declaration of Commitment of the United Nations General Assembly on AIDS Special Session (UNGASS). Next, we shall present a “critical dialogue,” where the concept of leadership from the perspective of different authors is presented. The scenario for this discussion is the body of knowledge generated by the Brazilian experience in the fight against AIDS. The “critical dialogue” was organized along two basic lines. The first of these offers a perspective on issues involving the achievement of the UNGASS leadership targets according to the governmental action – in the case of Brazil – of civil society and the private sector. Major issues and lacunae deemed relevant by the authors were identified. The second line, critical-propositional in character, considers the directions and major challenges to be addressed in order to advance in the achievement of UNGASS targets, considering not only Brazil, but other realities and scenarios as well.

## LEADERSHIP, AIDS, AND SOCIAL MOVEMENTS

The UNGASS Declaration of Commitment begins with a statement of the commitment of heads of State and Government to combat the HIV/AIDS epidemic in “all its aspects” and summons leaderships worldwide to employ their powers in “securing global commitment” to the control of the epidemic.<sup>15</sup> The declaration is based on the following precepts:

- To secure the commitment of world leaderships as a catalyst of action;
- To establish that strategies developed for combating the epidemic should build on the experience gained in the last 20 years;
- To reiterate the need for working in partnership with all actors and identifying vulnerable groups;
- To acknowledge the diversity of social, political, and cultural realities against which the epidemic is set throughout the world;
- To implement programs of prevention, reduction of stigmatization, construction of infrastructure, and securing of treatment, care, and respect for persons living with AIDS/HIV.

The targets listed in the Declaration redefine tradi-

tional views of the social responsibility of world leadership in face of the impact of the pandemic. The role of leaderships may be viewed in this context as an effort to produce cooperative social measures<sup>1</sup> aimed at reducing the impact of HIV/AIDS. In spite of relevant advances, the control of AIDS worldwide remains an important challenge, which demands the renewal of commitments and the review of personal, collective, and institutional responsibilities. Official numbers, which estimate about 4.9 new infections in 2004, indicate the continuous growth of the epidemic.<sup>14</sup>

The targets defined at UNGASS aim to create social conditions that favor the effective reduction of the social and political vulnerabilities that promote the expansion of the epidemic, which is becoming increasingly associated with the social inequities present in many societies, including Brazil. Ultimately, the commitment expressed in the Declaration implies the acknowledgement of the importance of not delaying the political responsibility of making the right decisions when dealing with issues with direct impact on the life and dignity of the approximately 40 million people living with HIV/AIDS worldwide.<sup>13</sup>

Regarding leadership specifically, the UNGASS Declaration recommends measures for the elaboration, at the national level, of strategic plans of action with political support, aimed at fostering the development of preventive and care-related measures; securing respect to the human rights of persons living with AIDS/HIV; stimulating the development of civil society; and implementing monitoring and evaluation strategies.

The targets defined by UNGASS include the acknowledgement of the fundamental role of leadership as a mobilizing agent in the battle against AIDS, given their role as levers for achieving the effects desired. These effects imply the participation of some sort of power,<sup>2</sup> be it from governments or non-governmental organizations (ONG), from the private sector, from workers unions, religious institutions, and community groups, or also from the media, the academic community, and other social forces, both at the regional and international levels. The UNGASS Declaration strategically summons the entire capacity accumulated by nations in order to decelerate the increase in the number of new infections and to ensure efficient access to currently available technological resources, especially to populations living in situations of poverty, risk, and marginalization.

The concept of leadership expressed in the document is apparently novel. Considering the need for mobilization generated by HIV, it will not be enough to rethink leadership only from the traditional perspective,

based on the authority held by certain individuals in which power is invested, or on the classical appeal to the charisma of leaders. Instead, it is based on the systematic promotion of possibilities to strengthen organization and articulation capacity and on the creation of new relationships between social actors. Thus seen, leaderships should engage in the construction of a new ethics in the use of power, giving new meaning to individual and collective dimensions in the commitment to control the epidemic. The Declaration highlights the need for grounding the practice of leadership on new values. Structural elements in the materialization of this new conception include the acquired knowledge and abilities and the legitimation of the other party in the division of social responsibilities. Built upon values such as solidarity, tolerance, and visibility of excluded and socially invisible social subjects, its practice influences social transformation and the more clearly conscious involvement of different social actors as catalysts in the battle against the pandemic. The Declaration may be said to express a relationship between the concepts of power and right,<sup>2</sup> the building of which, in many contemporary societies, is still an ongoing process.

From different standpoints, authors such as Pollack<sup>11</sup> already argued, at the very beginning of the epidemic, that AIDS was imposing on societies a “socialization of seropositivity.” This led to what the author termed “associative mobilization,” assuming AIDS as a disease that imposes extreme experiences. Some of the early leaders of the social movement connected to AIDS emerged from the personal experience of the disease, which granted specificity on the fight against AIDS in Brazil as well as in other countries. There was an important connection between social movements and the construction of leadership, which will be further discussed below, in the context of the Brazilian response to AIDS. It is in the scope of UNGASS that AIDS is reaffirmed as an issue of Public Health, conceived of as a commitment with human wellbeing as a social and political realm of contemporary societies. Dazon & Fassin<sup>3</sup> consider public health as “a state of mind,” to which AIDS has brought a body of new meanings and actors. We highlight the process of construction of leaderships that attributed new meanings to the understanding of relationships between health, disease, and society, precious examples of which are provided by the NGO social movement in Brazil.

If, on one hand, there is a propositional dimension to the definition of leadership adopted in the UNGASS document, on the other hand, the document abounds in normative language, characterized by expressions such as “intensifying responses,” “enhancing coor-

dination,” and “increasing ongoing actions.” When evaluating the document, we find little reference to the possibility of changing the course of action. The document also contains references to the “acceleration of the implementation of measures,” and the verb “to strengthen” is employed on countless occasions. Beyond the subject of leadership, there is a profusion of terms such as “to complement,” “to supplement,” “to decisively support,” “to increase,” among others. Or also, when discussing scenarios aggravated by the impact of AIDS, verbs appear such as “to attenuate,” “to reduce,” and “to cease,” always referring to a mechanism that is already ongoing, and which seems to require only simple modifications in the intensity of its action. Therefore, there seems to be little room for a leadership that disagrees with, or wishes to change the course of, what is traditionally being done in terms of prevention and treatment of AIDS. The room left for innovation is thus compromised by the general language of the document. However, this does not eliminate the possibility of a propositional role – which is what is expected from leaderships, be they personal or institutional – a desire expressed by the UNGASS document.

Focusing on social mobilization, the commitments and actions in the fight against AIDS must constantly be concatenated and reconsidered in order for new agreements to enhance synergy in fighting the epidemic. Other international documents, such as the Regional HIV/AIDS plan, which is to be fulfilled by Latin-American and Caribbean countries, are important to reinforce the political dimension of the State.<sup>9</sup> The inter-sector dialogue is an essential requisite for the action of the State towards the establishment of alliances, which are vital tools for meeting the principles of universality and equity that should govern interventions in the field of health.

As a whole, the Brazilian responsibility towards the commitments made at UNGASS cannot be understood unless two major actors, essential to the fight against the epidemic, are considered concomitantly: government and organized civil society. These two forces have different processes of construction of leadership and different modes of action. There is also an important transit of leaderships, not only from NGOs to government, but also in the opposite direction, which shall be discussed below. It is well-known that one of the major characteristics that support the Brazilian response to AIDS is the articulation between government and large social sectors in the management of initiatives aimed at reducing the incidence of infection and dealing with the major problems faced by the affected population. From the very beginning of the epidemic, as indicated by the documentation regis-

tered in different studies,<sup>4,8,10</sup> the articulation between these two actors was essential aimed at shaping the Brazilian response to the epidemic. Paradoxically, this peculiar trait of the Brazilian response to AIDS, which we consider as illustrative to other contexts, poses to Brazil an increased challenge in terms of improving this partnership and discerning novel courses of action in the battle against the epidemic. If some countries still need to be convinced of the importance of such articulation, in Brazil it will be strategic to devise other possibilities of development for an already fully consolidated relationship, which needs to demarcate new territory and engage in the fulfillment of ever more complex agendas.

### MONITORING OF LEADERSHIP-RELATED COMMITMENTS IN THE CASE OF BRAZIL

From the governmental perspective, the initiative of monitoring the advancement of UNGASS targets and of strengthening managerial and technical capabilities that favor their achievement must be acknowledged. The monitoring of activities provides evidence of the action of leaderships. Regarding the National Program for STD/AIDS (*Programa Nacional de DST e AIDS* - PN-DST/AIDS), for instance, there have been important advances in the quality of antenatal and maternity care, with an increase in the coverage of women diagnosed as HIV-positive, especially among expectant mothers, and reduction in mother-to-child transmission rates. Another important factor is the articulation between several areas of the Ministry of Health – Woman's Health, Family Health, Child Health and Nutrition – to establish directives for reducing mother-to-child transmission. All these actions are marked by the pressure and activity of leaderships from the feminist movement and women's organizations. These range from leaderships restricted to neighborhoods or specific regions to instances of nationwide articulation, such as feminist councils and NGOs with deep penetration into the media and strong influence over the executive and legislative branches of power. This is complemented by the possibility of using the quick test for diagnosing HIV in populations exposed to greater risk or to whom access is difficult, regulated by a ministerial decree, as a strategy for increasing access to diagnosis.\* This achievement was characterized by the activity of leaderships from the homosexual and sex workers movements and from NGOs providing aid to drug users.

Leaderships from civil society, especially NGOs, act mainly through projects that are usually financed by government or international funds. The quest for sustainability in NGO activities, and consequently, for

the activity of the leaderships within these organizations, has led to the creation of novel logistics for the transfer of financial resources. Worthy of note in this scenario is the decentralized character of resource transfer which increases the possibility of synergy between government and different civil society groups, whose major achievements are analyzed below.

Civil society's initiative to become involved in the monitoring of UNGASS targets represents a more elaborate level of activity funding, and is a reference point for understanding the innovative role of Brazilian activists. The involvement of civil society grants greater power to the mobilization policy and social participation that are characteristic of NGOs in the exercise of the social control predicted by the Unified Healthcare System (*Sistema Único de Saúde* – SUS). Brazilian NGOs also spoke up, and became part of the official Brazilian delegation at the UNGASS meeting.<sup>7</sup> What was seen was that the leaderships of Brazilian NGOs were not restricted to the role of executors or critics of the Brazilian AIDS program, but instead, are going through a process of appropriation of the concepts of evaluation and monitoring, and of occupation of niches at this level. This has also allowed these leaderships to represent Brazil at the United Nations, especially in decision-making forums, such as the 2001 UNGASS, illustrating the process of production of Brazilian leaderships recognized at international level within the context of the AIDS epidemic.

There is no doubt that the role of NGOs remains fundamental to work with populations of difficult access and with marginalized sectors. The repeated struggle for the fulfillment of the guarantee of universal access to antiretroviral drugs is at the front of the actions of organized civil society. In 2005, a number of scenarios marked by the scarcity or lack of medication have required firm positions from civil society in defense of rights established in the Brazilian Constitution. Requests have been diverse in nature, including the holding of public acts of disapproval, the filing of petitions, and even public proposals to the Ministry of Health for the breach of the patents of certain antiretroviral drugs, which consume a substantial portion of the national budget for HIV/AIDS care.

The leadership of NGOs could be felt also within another important decision-making organ, the National AIDS Committee (*Comissão Nacional de AIDS*), which works as an assessor in the elaboration and implementation of the Brazilian HIV/AIDS policy. This committee incorporates a variety of social actors, from both government and civil society, closely involved

\*Brasil. Ministério da Saúde. Secretaria de Vigilância em Saúde Portaria nº 34. Brasília (DF): Diário da União. Edição 145 de 29/7/2005.

with the course of the epidemic. It is also a forum for the resolution of problematic issues, such as the compulsory licensing of medication, pharmaceutical technological development, the fight for the human rights of persons living with HIV/AIDS, the battle against discrimination and stigmatization, and the acknowledgement of the diversity of sexual orientation, among other subjects.<sup>6</sup>

Within the realm of Brazilian civil society, the generation of leaderships connected to religious institutions is also worthy of note. In spite of their peculiar view of the epidemic, these institutions promote actions for the prevention of HIV/AIDS. The *Pastoral da AIDS* considers the epidemic as a problem of society as a whole, and its activities reach beyond the Brazilian border, including exchanges with other countries. The Lutheran church promotes mobilization campaigns in media networks, promoting solidarity, the revival of ethical values, and the need to respect persons living with HIV/AIDS.

#### ADVANCES, CHALLENGES, AND PROBLEMS REGARDING THE LEADERSHIP TARGETS

A common characteristic of the various responses to the UNGASS Commitment in Brazil, with respect to the leadership phenomenon, is the presence of concrete facts that show that the Commitment is being undertaken to an expressive degree by government and civil society alike. Both sectors are engaging efforts in maintaining high mobilization, and show synchrony in the execution of more inclusive social policies and in the planning of socially relevant strategies of action. However, certain fragilities and differences in pace reveal the need for a fine tuning of the capacity of articulation between these two actors and for the inclusion of new players in the battle against the epidemic, thus enhancing cooperation and filling the remaining gaps.

Present results in terms of large-scale policies allow us a certain degree of optimism. Arduously earned achievements are at the root of Brazil's worldwide leadership and the effectiveness in the execution of a national response which articulates comprehensive actions of prevention, care, treatment, and human rights, with significant results.<sup>8</sup> The activity of leaderships from civil society, government, and private enterprise have turned Brazil into a worldwide leader in the fight against AIDS. However, results in terms of small-scale policies vary in a country with geographic, social, economic, and sanitary conditions of continental breadth. At this level, some major fragilities, pertaining to the action of leaderships both from civil society and government, become apparent.

The current scenario varies greatly in terms of region and of the working methodology employed within different civil society organizations. A number of NGOs rest on the certainty of government-funded projects and do not fully explore the possibilities of expanding their funding sources through professional fund-raising activity. Lacking means for self-sustainability, these organizations remain at risk of becoming hostages of the funding organs, thus limiting the full extent of their most genuine capabilities and their scope for critical reflection.

An important issue regarding the Brazilian experience is the continuous consumption of leaderships from NGOs by the government, especially by the National Program and by state and municipal organs, in a process that occurs throughout the country. While an evaluation encompassing the whole range of peculiarities of the national scenario is still lacking, an assessment of the country's major states and municipalities shows that the migration of leaderships from NGOs to government leaves a void in civil society, which is often filled by individuals of lesser theoretical and political caliber and weaker understanding of the epidemic.

The evaluation indicates that the production of leaderships by NGOs and other civil society instances is perhaps not occurring at the pace or level necessary to keep up with the enormous diversification of issues currently brought up by the fight against AIDS. We find that the social AIDS movement in Brazil either does not have leaders for a series of areas of activity, or these leaders are insufficient in number. This is evident in the issue of drugs and patents, in the cooperation between countries in the South-South context, and in the presence and activity in the networks built by civil society across Latin-America and throughout the world. Brazil is clearly underrepresented at these levels. We also lack leaderships able to dialogue with and infiltrate the more general issue of SUS and public health, which assumes an understanding of its history, dynamics, and current processes.

Similarly to what is seen in NGOs, the government itself rests on the symbolic capital of being acknowledged as running a program of excellence, thus postponing incisive responses to fundamental problems such as the complete fulfillment of drug and anti-retroviral therapy distribution programs. Decentralization was an advancement in the consolidation of SUS and an acknowledgement of civil society organizations as partners in the fight against AIDS. However, it has also led to new modes of public administration which are still being constructed and assimilated, slowly and at different rates, by the state and

municipal levels of government. Delays and the non-fulfillment of planned activities for the management of the epidemic are still common in certain states and municipalities. All these issues indicate a process of bureaucratization and a relative “settling” of leaderships formed in the governmental sphere, who manage the epidemic with little attention to the substantial changes occurred in recent years, such as the appearance of new actors, the aggravation of old problems, and the emergence of new scenarios.

There are still problems with access to diagnosis. As to prevention, although government distribution of condoms is increasing year after year, there are few projects for the social marketing of condom use, and the cost to the consumer is still high. Other fragilities are observed in the care and health promotion for AIDS orphans, estimates of which are not a consensus. Reaching the population of users of injectable drugs is also a challenge to the improvement of hazard-reduction policies.

Countless forums and seminars have led to the conclusion that the role played by NGOs was much more propositional in character during the designing of the Brazilian experience at the beginning of the epidemic, and that now this process is losing in importance. The technicalization and bureaucratization that is currently affecting NGOs have helped reduce this possibility. As an example, we may cite the projects proposed by NGOs in the last five years in the state of Rio Grande do Sul, Southern Brazil. The proposals included in these projects show strict adherence to what is prescribed in the application forms or calls for projects, showing little innovation. Why not propose a program of prevention for the deaf communities of large cities, or a household visit campaign for housewives? Or also, why not focus on a specific population, such as young members of traditional cultural centers in Southern Brazil or in other regions? NGOs, organized in forums and other instances, collaborate in the definition of themes and in the elaboration of calls for projects published by state AIDS coordinations. However, this process still seems to be oriented by a strong epidemiological logic, which relegates issues of political nature, in which NGOs tread, to a secondary status.

There is also little participation of traditional NGOs from other areas in the calls for projects for AIDS interventions. Unions of populations of workers defined as epidemiologically vulnerable according to official documents (such as truck drivers and miners, among others) also fail to elaborate projects in response to the calls made by PN-DST/AIDS. Furthermore, partnership with these unions is rarely sought

by NGOs traditionally dealing with the AIDS problem, as evidenced by the list of projects approved in recent years, published at the PN-DST/AIDS website.

A complex issue is that of the construction of the institutional leadership of an NGO within a specific population. For example, the leadership constructed by certain NGOs among sex workers all around the country seems occasionally to be converted into a process of tutoring for this population. There is a tendency to situate NGOs halfway between the specific population and the State apparatus, especially healthcare services and police instances. NGOs play the intermediate in a series of problems, “making life easier” life for both healthcare and police agents and the target population. The institutional leadership of the NGO thus seems to lean upon an eternal role of “representing” the population, hindering the construction of autonomy of popular representation by leaderships emerging from within the population itself.

Another relevant issue, related to the already mentioned subject of Brazil’s continental dimensions, are the enormous problems faced by the country’s NGOs due to the disparity between these organizations. The NGOs from the South and Southeast Regions often carry out projects in partnership with others from the Northeast, North, or Center-West Regions. The idea that the “enlightened” will share their knowledge with the “unenlightened” is scandalously evident, with severe effects on the idea of respecting the local production of knowledge. The tendency to convert constructed experience into a formula for export to other areas of the world hampers the formation of national leaderships to act at global level. Furthermore, it impoverishes and reduces the Brazilian experience in fighting AIDS to a few elements. How much more enriching wouldn’t it be to show an experience involving urban and rural populations, from the coast, the jungle, and the inlands, from the outskirts of large cities and from small and medium-sized cities; experience in working with the Amerindian, European, and African populations; with different genders, age groups, religions, professional groups, sexual orientations, and the entire range of differences with which the human experience manifests itself. In short, enriching the Brazilian experience means making it the size of Brazil, and forming leaderships that share this view.

A positive aspect of the UNGASS document is the presence of many elements that constitute an essential part of the Brazilian response to AIDS. Among these, we highlight the respect to human rights and fundamental liberties; the inseparability of treatment and prevention; the right to access to medication; confidentiality; work in partnership with civil soci-

ety and with persons living with HIV/AIDS; and the acknowledgement of the role of leadership as a mobilizing element in favor of the fight against AIDS. This leads us to the belief that Brazil may constitute a potential source of leaderships in the field of AIDS, a leadership constructed upon the relationship with the abilities accumulated by other countries. The concept of leadership in the UNGASS document is articulated with the ideas of commitment and action, and points towards a new ethics in the exercise of power. This construction of a new ethics is dependent on the ability of the leadership to produce concepts. Both leaderships from the social movement and those from the government sector may be regarded as producers of concepts, which are tools that are brought to the world, and which also imply novel ways of looking at things. In Brazil, this is seen in the concepts of solidarity, life before death, person living with AIDS, and in the importation and local adaptation of concepts such as safe sex, among many others. The issue now is whether the current conceptual production of Brazilian leaderships is in tune with the political needs of the battle against AIDS. From this perspective, one may ask the following questions: has Brazil generated African leaderships that are engaged in the fight against AIDS? Are there any workers unions involved in it? Are there leaderships engaged in combating AIDS within the army? Have leaderships emerged from the homeless and landless move-

ments which include the AIDS issue in their agendas? Have leaderships been created among the caretakers of orphaned children? In other words, has the focus of Brazil's traditional leaderships in the field of AIDS been broadened to include the whole range of social forces acting in the country? The production of leaderships that act in the field of AIDS cannot rely only on persons coming from the anti-AIDS movements. It needs to be broadened, to include leaders coming from all social sectors. It is indispensable, for instance, that public school teachers include leaderships authorized to deal with the subject of AIDS and which are recognized within that milieu. The growth of the AIDS epidemic among the elderly leads to the question of whether leaderships in the field of AIDS exist among the Brazilian retired.

It is a consensus that "a global crisis such as AIDS will require global solutions,"<sup>12</sup> and that this implies the formation of leaderships. These leaderships, arising from concrete and successful experiences from the political and technical points of view, as is the case with the Brazilian experience, may be able to devise solutions that are viable in ever increasing areas of the world, respecting the countless local peculiarities. However, it is also pertinent to point out that the world, in spite of its great differences, has also enormous homogeneities, which cross the different faces assumed by the pandemic worldwide.

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