

The Brazilian Response to AIDS from the 1980s to 2010: Civil Society Mobilization and AIDS Policy

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Brazil is renowned for its progressive and early response to the AIDS epidemic. Brazil was among the first countries to provide free and universal access to AIDS treatment. This article discusses Brazil's evolving civil society movement related to HIV/AIDS and explains its critical role in developing Brazil's HIV/AIDS policies and the country's National AIDS Program. This article examines these developments in historical context and argues that the Brazilian response to the HIV/AIDS epidemic was strongly influenced by the interaction of civil society institutions with nascent democratic institutions that stemmed from Brazil's two decade-long process of democratization. Brazil's domestic institutions, in turn, had lasting impacts on global health institutions.

INTRODUCTION

Civil society mobilization is widely recognized as a critical factor in responding to the HIV/AIDS pandemic and Brazil provides an excellent example. This paper explores the evolving role of civil society organizations (CSOs) in the Brazilian response to the AIDS epidemic. Specifically, we explore initial CSO activity at the onset of the epidemic; the role civil society played in shaping public policy during the late 1980s; and the evolving and increasing collaboration with the Brazilian National AIDS Program (NAP) in the 1990s. We then explore the important role of civil society networks in the late 1990s and in the new millennium, Brazil's role in shaping international AIDS policy and the engagement of CSOs in the issues of access to AIDS medicines and intellectual property rights. This article draws on technical documents, over 150 original interviews with policymakers, activists, researchers and dozens of other individuals engaged or knowledgeable about Brazil's civil society movement. These interviews were conducted over a 15-year time span. We also drew on publications from the governmental and non-governmental sectors, historical archives, and the direct programmatic experience of the authors. Numerous works published in English explain the development of Brazil's AIDS policies, but none provide a comprehensive historical examination of

Brazilian CSOs and the AIDS epidemic in the way presented in this article.^{1,4}

Brazil presents an excellent example of the connection of local and global activism and the involvement of CSOs in shaping the response of governments in the establishment of initiatives for AIDS prevention, as well as the involvement of CSOs, including people living with HIV/AIDS in regarding access to AIDS medicines.

Presenting the historical initiatives and evolution of CSOs dedicated to HIV/AIDS in Brazil the article offers a unique opportunity to understand the development, evolution and policy implications of one of the first and most powerful global AIDS movements. Brazil's AIDS movement has dramatically impacted local health policy as well as global AIDS policy, and the lessons learned from the Brazilian experience have important implications for other settings.

AIDS IN BRAZIL

Brazil is the largest country in area and population in Latin America and has 190,732,694 inhabitants.⁵ According to the Joint United Nations Programme on HIV/AIDS (UNAIDS), “about one third of all people living with HIV in Central and South America live in Brazil.”⁶ The cumulative number of AIDS cases (1980-June 2011) reported by the Brazilian Ministry of Health (BMoH) is 602,230, and the cumulative number of AIDS deaths is 241,469.⁷ Of these total cases, 397,662 are male and 210,538 female.⁷ National estimates of the number of people living with HIV/AIDS (PLWHA) range around 630,000.⁸

The Brazilian response to the HIV/AIDS epidemic presented here shows the importance of community mobilization to promote and maintain prevention policies, as well as to advocate for treatment. It is important to mention:

“[the] most notable characteristic of the Brazilian response to HIV/AIDS has been the integration of prevention, treatment, and defense of the rights of HIV-infected individuals. This model for fighting the epidemic challenged the false dilemma [of] “prevention versus treatment” that prevailed until the end of the 1990’s in the international scenario, of which one of the most incisive examples is the 1997 World Bank publication, *Confronting AIDS*.”³

As a result of this comprehensive policy, some previsions in the 1990s by the World Bank proved to be wrong; the World Bank “estimated that

Brazil would have more than a million people living with HIV/AIDS by the turn of the century”, but in 2006 the estimated number of people living with HIV/AIDS in the country was approximately 630,000.⁸

Brazil has been providing free and universal access to AIDS treatment since 1996 via the national public health system.^{4,9,10} In 1997, 35,900 patients were receiving antiretroviral treatment (ART), and by 2010 this number increased to approximately 200,000.^{11,12} This policy brought international recognition to the country as a model in the fight against the AIDS epidemic, as well as to the forefront of the international battle to insure access to treatment for people living with HIV/AIDS.^{10,13,14}

Between 1996 and 2002, the Brazilian public health system may have saved over USD 2 billion through its innovative AIDS treatment policies, and AIDS mortality rate, decreased by 70 percent in São Paulo and Rio de Janeiro.¹⁴ Analyses published in 2007, highlight that Brazil saved over USD1.2 billion by challenging multinational pharmaceutical companies about AIDS medicines and producing drugs locally.¹⁵

Civil Society Organizations and the Brazilian Response to the HIV/AIDS Epidemic

In 1981, when the Brazilian media began writing about the first cases of AIDS in the United States, Brazil was transitioning to democracy from a military dictatorship (1964-1985). At the time, AIDS was referred to as the “gay cancer.”^{16,17} The onset of the epidemic coincided with a social movement for health called the “Movement for Sanitary Reform” which fought for changes in the public health system.^{4,14,18,19} AIDS activists who were also members of the Sanitary Reform movement and participated in Brazil’s democratization movement launched new strategies to promote AIDS awareness that included AIDS education and defending the rights of PLWHA.^{4,17}

Brazil’s unusual political environment, of a country transitioning to democracy after two decades of military dictatorship, combined with the politicization of the public health field in the 1970s and 1980s throughout Latin America, and the return of political exiles, produced a new political strategy called ‘movement for democratization’ which sought to consolidate democracy and reconstruct the Brazilian society.^{4,20,21} These political elements are intrinsically connected in Brazil’s response to the AIDS epidemic and the national discourse of access to health as a human rights

issue and strongly influenced Brazil's civil society response to the AIDS epidemic.²

The civil society organizations with activities in HIV/AIDS form part of a wider complex of initiatives from Brazilian civil society.¹⁷ Some of these initiatives, related to 'popular education', were established in the 1960s.²² The first governmental AIDS program in Brazil was created in the State of São Paulo, in 1983, and the NAP, held within the Ministry of Health — was created in 1985. That same year, the first AIDS non-governmental organization (NGO), Supporting Group for AIDS Prevention (*Grupo de Apoio à Prevenção à AIDS*, GAPA), was founded.^{19,23}

In the trajectory of the Brazilian NAP it is important to emphasize the relative stability of its directors: between 1985 and 2010 the country had 15 Ministers of Health and seven Directors of the National AIDS Program. It is also important to mention that the National AIDS Program went under several designations, with the two most recent changes coming in 2009: in May, the Program was elevated to the administrative status of Department.⁸ In September of 2009, the Viral Hepatitis Program was integrated into the STD (Sexually Transmitted Diseases) and AIDS Department, which changed its name to STD, AIDS and Viral Hepatitis Department.⁸ In this article, we use the term National AIDS Program (NAP) to refer to Brazil's federal National AIDS Program, now called STD, AIDS and Viral Hepatitis Department.⁸

Pioneering Initiatives: 1980s

The place of CSOs in responding to the HIV/AIDS epidemic in Brazil has, in broad terms, followed a trajectory: the 1980s were marked by confrontation between activist organizations and the public sector, whose responses were deemed inadequate. As in many countries, the initial Brazilian response was denial of the impending threat of AIDS to public health.^{24,25} In the late 1980s and early 1990s increasing segments of civil society became mobilized against the epidemic. Later in the 1990's civil society and government began to work more in partnership as part of the national response. This early response to the epidemic provides important historical context for understanding Brazil's response to the AIDS epidemic.³

Gay Mobilization

Like their North-American and European counterparts, gay men in Brazil were the first to mobilize against the challenge posed by the emergent epidemic and to update and disseminate the preliminary information about how to protect themselves and their communities, and to promote a culture of non-discrimination towards those affected by the emerging disease. In Brazil as in most Western countries, the epidemic was then misnamed the “gay plague”, and gay men and/or people living with HIV/AIDS were discriminated. Civic activity related to HIV/AIDS commenced with gay men’s organizations in São Paulo, such as Outra Coisa (Something Else) and Somos (We are). Many times paving the way for top-down initiatives, implemented by health secretariats or the federal government, grassroots initiatives proved vital in the evolving response to the epidemic.

Grassroots Organizations related to HIV/AIDS

In 1985, dissatisfaction with the way AIDS patients were being treated contributed to the establishment of the GAPA in São Paulo. The State of São Paulo saw the first organization formed from civil society devoted specifically to address AIDS. As the Brazilian State with the highest number of officially notified cases of AIDS, São Paulo had an important history of government and civil society collaboration in the response to HIV/AIDS. Made up largely of volunteers, GAPA focused on HIV prevention and education and earned prominence for its militant non-discrimination campaigns.^{17, 27}

One of GAPA’s main contributions to AIDS activism was the installation of a legal-assistance service for PLWHA. For example, GAPA sued companies for discriminating against PLWHA and the local, state and federal governments for failure to provide medicines to treat HIV/AIDS, most of which culminated in positive outcomes.^{17, 27} These court decisions had long-term impacts on public policy by outlawing discrimination, and compelled governments to provide medicines to PLWHA, thereby normalizing AIDS treatment early in the epidemic.^{4, 28} Several GAPAs are still functioning in various regions of Brazil; each GAPA is independent, with distinct profile and activities.²⁷

Shelters lead the way in dealing with the impact of AIDS on individuals of low socioeconomic status

The founding of the Brenda Lee Shelter in São Paulo in 1985 initiated a new form of support to PLWHA in Brazil. As increasing numbers of individuals became ill, many poor or already marginalized from their families, the need for shelter and hospice care became acute.²⁹ Brenda Lee, a transvestite who had administered a combined boarding house and venue for transvestite shows, transformed her establishment into the first AIDS-related shelter in Brazil; initially it catered to HIV-positive transvestites, but with time it began to receive men who were not transvestites.³

Other forms of direct assistance to PLWHA also appeared in the mid-80s, especially in São Paulo and Rio de Janeiro. Many of these were linked to religious organizations associated with the Catholic Church or the Afro-Brazilian religion namely *Candomblé*.³⁰ Home care was introduced as a variation on shelter support. Different services were offered, from provision of groceries, to medical care, to transportation to and from hospitals. With the introduction of more potent medicines, and increase in life expectancy, the shelters and the home care underwent adaptations to new regimes of care. With the increasing number of poor people affected by the epidemic, shelter services have continued to be crucial in meeting the needs of PLWHA in Brazil.³¹

Democratization of Information

Founded in Rio de Janeiro in 1986, the Brazilian Interdisciplinary AIDS Association (*Associação Brasileira Interdisciplinar de AIDS/ABIA*) has been devoted to critical analysis of national and international health policies related to AIDS.³² ABIA was the first Brazilian AIDS organization to have a HIV-positive president who disclosed his status. Herbert de Souza — known popularly as *Betinho* — was a famous democratization activist, former political exile, and a director of the widely recognized Brazilian Institute of Social and Economic Analyses (*Instituto Brasileiro de Análises Sociais e Econômicas*, IBASE). Betinho's political and personal history greatly influenced the program to be implemented by ABIA; his militancy guaranteed that advocacy for the rights and needs of PLWHA would be accompanied with a critical analysis and activism regarding the political dimensions aggravating the epidemic. Betinho's leadership and vision was an important factor to the AIDS movement in Brazil providing legitimacy and paved the way for the widespread mobilization in the 1990s.³³

ABIA and Betinho also played key roles in improving the quality of the blood supply in Brazil, “even in large urban centers such as São Paulo

and Rio de Janeiro, unscreened blood products were frequently used. As a result, recipients of blood or blood products were at high risk for acquiring HIV, as well as viral hepatitis and Chagas disease. In 1988, ABIA launched the campaign “Save the Blood of the Brazilian People”. The campaign was instrumental in bringing pressure to Congress, which in 1988 determined, as part of a newly approved Constitution, that blood could no longer be used as a commodity, leading to substantial improvement in the quality of the blood supply in the country.”²

Betinho and *ABIA* had lasting impacts on civil society mobilization in Brazil. Betinho’s activism helped to mobilize critical public policy support for HIV/AIDS at a time when little public funds were dedicated to the epidemic.³³

Religious Institutions and HIV/AIDS

Religious organizations played an important role in the AIDS response in Brazil, providing shelters and other services that helped to increase awareness as well as the response from the public sector to the AIDS epidemic in Brazil.^{30, 34, 35} But also some religious organizations, especially the Catholic Church, were involved with disputes with the Brazilian NAP regarding the promotion of condom use and many times the official position and statements from representatives of the Catholic Church didn’t help the promotion and implementation of prevention policies.³⁶⁻³⁸

In 1987 the Institute of Religious Studies (*Instituto de Estudos da Religião*, ISER), a NGO based in Rio de Janeiro, created an AIDS project called “Religious Support against AIDS” (ARCA). This project aimed to sensitize the various religious traditions to the epidemic. But also religious groups, themselves, offered diverse responses to the epidemic.³⁰ One example is the *Projeto Esperança* (Hope Project), created by the Archdiocese of São Paulo in 1987, which emphasized AIDS support services. At present, the universe of religious organizations that offer AIDS services includes the most varied religious traditions such as Catholics, Evangelicals, and practitioners of the African-Brazilian religions, *Candomblé* and *Umbanda*.³⁹

Groups of People Living with HIV/AIDS

Since the end of the 1980s, following an international trend, Brazilians living with HIV and AIDS have created organizations and spaces that give voice to the demands and needs of HIV-positive individuals. In

1989 the first group of PLWHA was founded in Rio de Janeiro: *Pela VIDDA*, an acronym that means for the Valorization, Integration and Dignity of People with AIDS (*Pela Valorização, Integração e Dignidade do Doente de AIDS*). The introduction of *Pela VIDDA* on the national scene changed the quality of discourse presented by Brazilian CSOs working with HIV/AIDS. Herbert Daniel, founder and first President of the group denounced discrimination towards HIV positive individuals. He labeled discrimination and denial of human rights a "civil death."⁴⁰ Daniel died in 1992. At present there are others *Pela VIDDA* groups in the country. Like the GAPAs, the *Pela VIDDA* groups are autonomous in relation to one another, and engage in distinct projects. In 1990, another group of PLWHA — the *GIV* (Incentive to Life Group, *Grupo de Incentivo à Vida*) — was founded in São Paulo.

The National Meetings of CSOs and PLWHA

Through 1988, these somewhat disparate groups began coordinating efforts for the first time when the Brazilian Meeting of CSOs working with HIV/AIDS was held in Belo Horizonte (Minas Gerais State) in July 1989, and was attended by approximately thirty persons from 14 entities.⁴¹ The idea of this national meeting followed a discussion in Montreal in an encounter called *Opportunities for Solidarity* that preceded the VI International AIDS Conference, that took place in Montreal, Canada, in 1989.¹⁷

The second national meeting was held in Porto Alegre and documents previously drafted by the organizing committee were submitted and voted on during the event. The organizations attending the meeting approved a document called *Charter of Principles* plus the *Declaration of the Fundamental Rights of Persons Living with HIV*.⁴² This last document in particular was a landmark that defended the rights of PLWHA in Brazil.

The national AIDS NGO meeting is still happening; at the 1997 meeting in Brasília it was decided that the national meeting of AIDS NGO would happen every two years. At these meetings representatives are elected to serve in several commissions of representation at governmental and non-governmental forums. In addition to representatives from AIDS CSOs, a number of scholars, health professionals, and governmental officials participated.²⁶

Additionally, beginning in 1991, the group *Pela VIDDA* started promoting an annual national meeting called *Vivendo* (Living). The *Pela*

VIDDA meeting, together with the national meeting of AIDS CSOs, are important venues for articulating strategies, sharing experiences, and empowering people and organizations working with HIV/AIDS in Brazil. Representing the organized civil society movement they help to maintain and to expand the rights of PLWHA, as well as to guarantee the continuity of the Brazilian governmental response to the AIDS epidemic.

Foreign Aid

In Brazil, in the beginning of the AIDS epidemic, the funds come mainly from abroad. The funding for Brazilian AIDS NGOs involved private and religious-based agencies, governmental resources, and bilateral and multilateral cooperation agencies.⁴³ These agencies, through their priorities and lines of action, allocated differentiated amounts of funds to the activities that the NGOs developed in the HIV/AIDS area.^{4, 17}

Between 1985 and 1989, a number of different initiatives from civil society appeared in Brazil. Towards the end of this period, support from international agencies for HIV prevention programs being implemented by CSOs increased. In 1987, the Ford Foundation initiated its commitment to supporting AIDS prevention initiatives in Brazil.⁴⁴ Other organizations, especially religious-based agencies such as Catholic Fund for Overseas Development (CAFOD, England), Misereor (Germany), and Diakonia (Sweden) also provided financial resources for HIV programs. Subsequently other institutions, such as the United States Agency for International Development (USAID); the MacArthur Foundation, USA; and Save the Children similarly began to support CSOs working with AIDS in Brazil.¹⁷

The New Brazilian Constitution and Access to Health as a Right

Access to the public health system was established as a universal right of citizens and a responsibility of the State under the new Brazilian Constitution, which was adopted in 1988.⁴⁵ The 1988 Constitution created the Unified Health System, known as SUS (*Sistema Único de Saúde*), which aimed to guarantee free, comprehensive health care to the entire Brazilian population, regardless of whether an individual held other forms of health insurance.^{10, 46-48}

The Unified Health System was built with the participation of health experts and members of the health reform movement and was conceived as a regionalized and decentralized network of health services, with

community and civil society participation, offering health care free at the point of delivery to the entire Brazilian population.⁴⁶⁻⁴⁸ The core principles of the SUS — integrality (integrated prevention, treatment and care), equity, public accountability and funding — emerged out of a long period of advocacy for governmental responsibility for health promotion.⁴⁶⁻⁴⁸

Democratic Transition and Expansion of Social Mobilization: 1990s

Between 1990 and 1992, important social changes in Brazil also affected the country's responses to the AIDS epidemic.²⁴ The impeachment of President Collor in 1992 and financial scandals at the Ministry of Health contributed to major social upheaval in Brazil. In addition, several high-profile Brazilian activists died of AIDS — including Herbert Daniel, who died in 1992. But it was also a time when, many new AIDS-related CSOs were formed, including a broadening of the societal response to AIDS, with the participation of the women's movement, organized sex workers, the transvestites' movement, and the private sector. One point in common in the agenda of these movements was a growing understanding of health as a right, and as a dimension of citizenship.^{2, 26}

The HIV/AIDS epidemic had an important role in the foundation of the first Brazilian groups and associations of transvestite, transgender and transsexual individuals. Among these are the Association of Transvestites and the Liberated (*Associação de Travestis e Liberados, ASTRAL*), founded in 1992 in Rio de Janeiro, and the Association of Transvestites of Salvador (*Associação de Travestis de Salvador, ATRAS*) founded in Salvador, Bahia, in 1995. In 1995 it was founded the Brazilian Gay, Lesbian, Bisexual, Transvestite and Transsexual Association (*Associação Brasileira de Gays, Lésbicas, Bissexuais, Travestis e Transexuais, ABGLT*), based in the State of Curitiba, in the South Region.¹⁷

Beginning in 1990, groups of sex workers started to develop activities in HIV/AIDS. *GEMPAC* (Group of Women Prostitutes in the Downtown Area), located in Belém in the State of Pará, is one example. *GEMPAC* is representative of a response that began to gain force in the late 1980s and had expression in "national prostitutes' meetings" which began in this period [many groups in Brazil prefer to use the term "prostitute" and not "sex worker"]. *GEMPAC*, along with other groups such as *APROCE* (Association of Prostitutes of Ceará) and the Association of Prostitutes of

Rio de Janeiro, was part of a new wave of community organizations that began to work with AIDS.^{3, 17}

Feminist groups also began participating in civic activities related to HIV/AIDS in the early 1990s, including the National Feminist Network of Health and Reproductive Rights, and the Commission on Citizenship and Reproduction (CCR). Also in the 1990s, lesbian groups became involved in responding to AIDS in Brazil.^{3, 17}

Despite some progresses in terms of the mobilization of people who misuse substances, much has to be achieved in this field, which remains basically linked to the initiative of activists and policymakers working towards a more pragmatic and humane drug policy, such as those congregated at ABORDA (The National Association of People Working in Harm Reduction; see <http://www.abordabrasil.org/>), and more recently the virtual community *Psicotropicus* (<http://www.psicotropicus.org/english>). Notwithstanding, much has to be achieved in the sense of fully integrating people who live with HIV/AIDS and misuse substances into the broader movement of PLWHA and to better integrate the movements towards drug policy reform and AIDS activism.

A New Model to Address the Epidemic

In 1993 and 1994, a new era commenced when Brazil received a large loan from the World Bank to work on AIDS. Although the federal government had established a National AIDS Program in 1985 the agency was underfinanced until the mid 1990s, when the World Bank granted Brazil a loan for the “Project for the Control of AIDS and STDs,” known as *AIDS I*, which infused new financial resources into the federal agency.^{23,4, 17} *AIDS I* formally institutionalized collaborations between the Brazilian NAP and CSOs. These transformations, which were accelerated by the resources made available by *AIDS I*, reflected changing global strategies for confronting the epidemic, as well as the particular dynamics of the societal response to AIDS in Brazil.^{49,4, 17}

Between 1993 and 2003 Brazil received three loans from the World Bank to HIV/AIDS/STI. The components of these loans were basically: prevention, epidemiological surveillance, and institutional development; ARVs are not included in the commodities paid with the money from the World Bank. An important aspect of the World Bank loan was that it was joined by a significant increase in commitments of Brazilian resources to fighting AIDS (the national counterpart), demonstrating the priority the

Brazilian government gave to fighting the HIV/AIDS epidemic. The fourth loan, approved in 2010, was accompanied by local commitments that are substantially greater than the value of the loan from the World Bank. The first loan (*AIDS I*), initiated in 1993 and completed in 1998, at USD 160 million which included a national counterpart of 90 million dollars.¹³ The second loan (*AIDS II*), for the period from 1998 to 2003, was for USD 165 million, with a national contribution of USD 135 million.¹³ In 2003, a third loan of 100 million dollars, with a national counterpart of 100 million dollars, was approved.⁵⁰

A fourth loan — of USD 67 million, with a national counterpart of USD 133 million was approved in May 2010, and “the expecting closing date is December 31, 2014”.⁵¹

One of the principal results from these financial resources, as mentioned above, was the expansion of the partnership between the public health sector and CSOs, and the scaling up of prevention activities. According to the Brazilian NAP, between 1998 and 2001, a total of 1,681 projects were financed involving 686 CSOs, with a total spending of USD 30 million; and between 2003 and 2007, USD 107.3 million were invested in CSOs.^{52,11} However, some activists were nevertheless critical of the involvement of the World Bank with the Brazilian response.¹⁷ It is important to point out, as our article shows, that CSOs were very active in Brazil before the loans from the World Bank. Certainly the loans changed the way the Brazilian AIDS CSOs addressed the epidemic, but CSOs working with HIV/AIDS were important and relevant years before Brazil started receiving loans from the World Bank for its AIDS Program.

The Expansion of Networks

In the mid-1990s, the number of organizations working with HIV/AIDS in Brazil increased, as did the number of local and regional forums and networks. Establishing these forums and networks was important not only because of the greater influence the organizations could yield, but also for facilitating coordination and the sharing of experiences in AIDS-related initiatives. One of the highlights of this period was the National Network of HIV Positive Persons (RNP+) that started between 1994 and 1995. An association of individuals rather than of organizations, RNP+ is made up exclusively of PLWHA; in 1997, offices were set up all over the country.

Building on the NGO network infrastructure established in the late 1980s, networks of religious organizations working with AIDS also began to receive financial support from the Brazilian NAP. Some of the examples of this partnership are: the collaboration with the National Council of Christian Churches and with the AIDS Pastoral, from the Catholic Church.¹¹ Since 2006, “the Ministry of Health has been forming partnerships with afro-Brazilians religions through the National Network of Afro-Brazilian Religion and Health.”¹¹ In the case of Brazil, these networks and forums were fundamental in the struggle to promote access to medication and treatment, as a right.

Changes at Local and International Levels: 1996 and Beyond

Beginning in 1996, the AIDS community in Brazil began to experience a new era marked by the commitment of the Brazilian government to distribute, through the public health system, free of charge, medicines for PLWHA.^{4, 9, 14} The successful passing of this law in large measure reflected the efforts of community groups which had filed lawsuits, beginning in 1988, against state and local governments to secure assistance and treatment for individuals with AIDS.²⁸ This is a period of intense transformation presenting new challenges and opportunities for the Brazilian AIDS movement as well as for the Brazilian NAP. At around this same time, treatment regimens also began showing increased efficacy; this combination of improved technology and greater availability of treatments had a profound effect on the life prospects of PLWHA in Brazil. Simultaneously, the loans from the World Bank allowed for an expansion of AIDS prevention activities, especially by CSOs.^{4, 17}

Brazil’s policies of promoting free and universal access to AIDS medicines in the late 1990s created a budget challenge for the BMoH, which was obligated by law to provide medicines. Also at this time, Brazil’s civil society networks began collaborating with global networks that had rallied around a global social movement to promote more widespread access to AIDS treatment.⁵³

In 2001, Brazil publicly challenged pharmaceutical companies about the high costs of HIV drugs, and threatened to produce generic antiretroviral (ARV) locally if companies did not lower the prices of their AIDS medicines.^{10, 54, 55}

Brazil’s policies regarding to AIDS medicines culminated in deep price reductions for ARVs from multinational pharmaceutical companies

over the years, saving Brazil over USD1.2 billion in drug costs.^{15, 56, 57} Brazil's global efforts also culminated in sweeping changes related to access to essential medicines.^{15, 58}

The question of access to AIDS medicines, especially in regard to intellectual property rights and the discussion around patents it is now part of the agenda of the Brazilian Government as well as of CSOs.⁵⁹ In 2003, the Working Group on Intellectual Property of the Brazilian Network of the Integration of Peoples (*Grupo de Trabalho sobre Propriedade Intelectual/Rede Brasileira pela Integração dos Povos*, GTPI/REBRIP) was founded and the Brazilian Interdisciplinary AIDS Association (ABIA) is one of the main AIDS NGO involved with this new network.⁵⁹

Another important change in this period, starting in 2002, was the move from the central level to States and Municipalities of the support to CSOs.⁶⁰ With the growing number of CSOs involved with the implementation of HIV/AIDS activities in Brazil it makes sense to decentralize the CSOs component. But, at the same time, in doing this — as argued by some authors — the Brazilian NAP would have less authority in a crucial component of the Brazilian response to the AIDS epidemic, especially because, in some states, local politics guides the way that the money allocated for HIV will be spent.⁶¹

The Future of Civil Society Organizations and AIDS Activism in Brazil

Though our purpose in this article has been to provide an analysis and historical overview of the critical role of CSOs in the Brazilian response to HIV/AIDS, we wish to refer briefly here to the uncertain future of AIDS activism in Brazil, especially following the financial crisis that is affecting the majority of Brazilian CSOs, especially since 2011.

Problems with sustainability are not a new issue for Brazilian CSOs in general, and AIDS CSOs in particular. Most recently this issue is taking a sharp negative turn, and the future of Brazilian AIDS CSOs — so important in terms of setting the stage as well as being the driving force of the Brazilian response to the AIDS epidemic as demonstrated in our article — is more uncertain than ever. Several organizations already closed their doors in the last couple of years and others are on the verge of doing the same.

The factors behind this crisis are multiple and the situation deserves a more comprehensive analysis than we can offer here. Among the factors pointed out by representatives of CSOs are that many international donors

have ended their support to Brazilian AIDS CSOs, and local donations and domestic philanthropy remain weak. As Brazil's economy has grown, it has become ineligible for financial support from some international donors, and changes in the local funding from the government to AIDS CSOs are also causing a negative impact.

The difficulties that the Brazilian CSOs working with HIV/AIDS are facing in the last years are coming at a time when the role of Brazil in the international cooperation scenario (together with Russia, India, China and South Africa, or the BRICS) is increasing. While the need for strong civil society involvement in the AIDS epidemic in Brazil will continue, it is unclear at this point how such organizations will survive in the critical years ahead.

Final Comments

Brazil's civil society organizations had critical impacts on the initial and ongoing Brazilian prevention and treatment responses to the AIDS epidemic. Brazil's policy outcomes are grounded in almost three decades long social movement deeply embedded in Brazil's democratization movement.^{3, 4, 17, 26}

Brazil's response to the AIDS epidemic is grounded both in evidence-based medicine and a human rights based approach to policy.^{62, 63} The analysis presented here traces these processes and Brazil's demonstrable impacts on AIDS-related mortality and morbidity demonstrate that rights-based and evidence-based medicines are highly compatible.

Moreover, Brazil's partnership with other countries, especially in the Global South, ushered in dramatic changes in trade, and laws related to access to essential medicines.^{55, 58, 64, 65} The Brazilian experience in response to the AIDS epidemic also demonstrates how Brazil's foreign policy had dramatic impacts on its public health policies as well.^{66, 67} Understanding how civil society organizations originally organized, and how they transformed AIDS policy in Brazil is critical for understanding Brazil's response to the HIV/AIDS epidemic as well as Brazil's long-term impacts on global health policy.

Disclaimer

The content of this article is solely responsibility of the authors and does not represent the official views of Brown University, Oswaldo Cruz Foundation, or UNITAID/WHO.

Dedication

This article is dedicated to the memory of Ronaldo Mussauer de Lima.

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² Galvão J, *Brazil and Access to HIV/AIDS Drugs: a Question of Human Rights and Public Health*. American Journal of Public Health, 2005. 95(7): p. 1110-6.

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