

ARTICLE

Braiding Public Health and Human Rights: AIDS, Activism, and International Agencies in Brazil, 1987–1996

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Abstract

This article examines the emergence of a synergy that allowed the early development of what was once considered the best anti-AIDS program in the developing world. Initial responses to AIDS in Brazil during the 1980s and early 1990s were marked by a confrontation between activists concerned with human rights, and a government focusing on biomedical management of the epidemic. After 1992, activists, medical researchers, government officials, international donors like the Ford Foundation, health officers, and multilateral agencies like the World Bank were galvanized to cooperate. This was a complex process of braiding knowledge and practices related to activism, science, public health, governance and philanthropy in which each constituency maintained its independence. The result was a complex, holistic, and nuanced AIDS program. The process helped bridge the gap between knowledge and advocacy, generated public awareness, and was instrumental to reducing AIDS mortality developing local human resources and comprehensive policies.

Keywords: AIDS; Brazil; Ford Foundation; World Bank

Resumo

Este artigo analisa a emergência de uma sinergia que permitiu o desenvolvimento inicial do que já foi considerado o melhor programa contra a AIDS no mundo em desenvolvimento. As respostas iniciais à AIDS no Brasil durante as décadas de 1980 e 1990 foram marcadas por um confronto entre ativistas, preocupados com os direitos humanos e governos, orientados para uma gestão biomédica da epidemia. Depois de 1992, a colaboração de ativistas, pesquisadores em medicina, doadores internacionais como a Fundação Ford, autoridades de saúde, e agências multilaterais como o Banco Mundial foi galvanizada. Foi um processo complexo de entrelaçamento de conhecimentos e práticas de ativismo, ciência, saúde pública, governança e filantropia, em que cada setor manteve sua independência. O resultado foi um programa de AIDS complexo, holístico e distinto. O processo ajudou a preencher a lacuna entre conhecimento e advocacia, gerou conscientização pública e foi fundamental para diminuir a mortalidade por AIDS e construir recursos humanos locais e políticas abrangentes.

Palavras-chave: AIDS; Brasil; Fundação Ford; Banco Mundial

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Between the mid-1980s, when the first responses to AIDS appeared, and 1996, when antiretroviral drugs transformed what had been a death sentence into a manageable illness, experts, donors, government officials, and laypeople in Brazil learned to work together. Initially, it was a learning process marked by confrontations between Brazilian activists and the government, but by 1993 a coalition emerged. The process redefined the focus, identity, and links between academic knowledge, activism, governance, and philanthropy. It humanized public health, made activism more scientific and governance more horizontal, and sensitized international philanthropy. It was a complex process of braiding rather than merging, in which each constituency maintained independence.

This article examines the synergy between the Ford Foundation (FF), the World Bank, and Brazilian organizations and government entities. We argue that this interaction was key to incorporating a human rights dimension into public health interventions and led to the elimination of the traditional—and usually counterproductive—segregation of the sick during epidemics (Engel 2006). Our analysis is based on the little-used papers of the FF office in Brazil (stored at the Rockefeller Archive Center in New York); the AIDS Collection at Yale University's Manuscript and Archives repository, which consists of reports, newsletters and pamphlets produced in different countries around the world; and the collection of papers of the Centro de Documentação (CEDOC) of the Associação Brasileira Interdisciplinar de AIDS, donated to Biomanguinhos, the main library of Fiocruz, in Rio de Janeiro. Our analysis aims to enrich the valuable body of studies on AIDS in Brazil produced by historians of medicine, public health scholars, and medical anthropologists (Nunn 2009; Parker 2009; Galvão 1997a, 1997b; Grangeiro, Silva, and Teixeira 2009; Fontes 1999).

The Ford Foundation and Brazil

During the 1970s and 1980s, the international work of the FF—created in 1936—abandoned its neo-Malthusian assumption that population control was the solution to poverty (Sutton 1987). FF's family-planning interventions declined after a decrease in fertility rates in many developing countries and criticism of family planning for enforcing abortion and sterilization, having no regard for the consent of women in reproductive matters, and ignoring overall socioeconomic development. At the same time, the foundation supported civil rights and became the United States' wealthiest foundation in 1980. Over the course of the 1980s and early 1990s, the FF underwent a process of self-criticism regarding population control and began to focus on sexually transmitted diseases. It decided to work with NGOs, arguing they promoted pluralism, helped deliver public services, and were agents of social change—a departure from other philanthropic institutions, like the Rockefeller Foundation, that worked with governments (Brier 2009).

A meeting of the FF trustees in December 1987 examined commissioned materials on AIDS. The first, sent by Lincoln C. Chen, a professor at Harvard University's School of Public Health, warned that the AIDS mortality rate in Africa was about to explode, disease awareness was low everywhere, and science was years away from controlling the disease (contrary to the belief of some politicians who thought the epidemic might disappear soon).¹ Chen claimed that the solution was to contain the disease through education and behavioral change and "interdependent" national and international responses. Emphasis on education was key because adequate preventive strategies did not exist. Another report, signed by a panel of experts who interviewed people in the United States, Europe, and Africa, portrayed AIDS not only as a medical problem but also as linked to "essential"

¹ Lincoln C. Chen to Oscar Harkavy, March 3, 1987, Reports 012371, "Implications of AIDS for Ford Foundation Programming," Box 610, Reports 11775-13948, FA 739E, Ford Foundation records, Rockefeller Archive Papers (hereafter cited as RAC).

human rights.² It criticized mandatory screening, quarantine of HIV-positive individuals, restrictions on the travel of gay people, and violence against gays. Other themes dealt with in the report were the critical situations in developing countries without tests, blood supplies, or free distribution of condoms and with unreliable epidemiological data. Some trustees had been in touch with the World Health Organization (WHO) Special Program on AIDS (later the Global Program on AIDS, or GPA), directed by the American Jonathan Mann, who was beginning to shape human-rights-inspired notions for AIDS prevention (Fee and Parry 2008). Mann believed that the FF had to work on the social dimension of AIDS because no other international organization was doing so. The FF supported Mann and decided to develop its own programs. Initially it was not clear how to proceed. A FF field officer who worked in Rio de Janeiro remembers trying to convince the trustees to work on AIDS in several nations, but always receiving a negative response until in the late 1980s, when she passionately argued in a meeting to think about their accountability in twenty years (Forman 2011). The call had an impact. At another meeting of the FF trustees, in 1988, they formed the US National-Community AIDS Partnership to collaborate with other philanthropic organizations and over four hundred American civil-society organizations, hoping to encourage other organizations that had shied away from supporting AIDS work (Telsch 1988).

Nevertheless, not all was clear for the FF trustees. One question was whether the FF should finance first-world institutions to work in developing countries or concentrate on building up human resources within the developing countries. There was also a fear of "parachuting" in foreign experts who stayed for a short period of time in these countries, dictating what should be done but not grasping the local dynamics. Another concern was how to work with foreign NGOs that criticized their own governments (US regulations prohibited American philanthropies from intervening in politics). Another source of uncertainty for the trustees was how to work in a new research area: social studies on sexuality. Despite these uncertainties, the FF moved forward. When the trustee meeting took place in 1988, the foundation had already provided AIDS grants in the US (over USD 25.8 million), to developing countries (over USD 18.6 million), and to multilateral agencies (over USD 2.2 million).³ The trustees felt that the FF's offices in Nairobi and Rio de Janeiro were critical for their international outreach, since they operated where AIDS was having a "high impact" and might serve as a model for other locations. Brazil, with a significant number of people with AIDS, provided opportunities for private philanthropy. USAID terminated its operations in Brazil in 1979 and the Peace Corps followed suit in 1980. Since the military regime, which had begun in 1964, was being pressured to hold general elections and stop political persecution and torture, human rights—supported by the FF—was an excellent theme. This cause was reinforced in the early 1990s by a "Ford Foundation Initiative on the Politics of Inclusion" that emphasized human rights and the reproductive rights of women, and a series of UN conferences like the one held in Vienna in 1993 that led to the creation of the post of High Commissioner for Human Rights by the UN General Assembly.

Since the early 1980s, the FF office in Rio de Janeiro—created in the early 1960s—had been supporting studies to reduce social disparities and promote democracy. The political context helped the FF. The Brazilian military government was forced to allow a congressional election to choose a civilian president. The winner was Tancredo Neves, who defeated the military's nominee. However, Neves died suddenly before being inaugurated. His vice presidential candidate, José Sarney, a less-respected politician because he had

² "The AIDS Challenge: A Ford Foundation Response," 1987, Box 11, Series 11, AIDS Background files FA717, Office Files of Shepard Forman, Ford Foundation records, RAC.

³ Marjorie Muecke, "Memo: What We've Been Doing about HIV/AIDS for the Past Decade," 1997, Reports 015017, Box 752, Catalogued reports 13949-17726, FA739F, Ford Foundation records, RAC.

worked with the military, became president in 1985. He was seen with distrust by the National Congress and by the Left, coalesced around the Workers Party (PT) founded in 1980. To gain legitimacy, Sarney recast himself as a left-of-center politician backing social programs. At the same time, an emergent *sanitarista* movement—a loose alliance of health workers, physicians, scientists, and health activists that organized the landmark Eighth National Health Conference in 1986, which promoted public health as a duty of the state and a right of citizens—fought to displace privately administered health care and promote a more democratized, decentralized, and universal health care system (Borzutzky 2021)

When FF grants related to AIDS in Brazil were about to begin, epidemiological information revealed that the disease—as well as stigma and panic—had been spreading since it was first identified in 1982. According to a newspaper article from 1985, a "collective neurosis" followed the news of 425 cases and 201 fatalities (Riding 1985). In the same year, an evangelical pastor insisted that AIDS was a punishment sent by God to homosexuals, and a Catholic archbishop stated that AIDS was a result of a violation of nature (*Jornal do Brasil* 1985). In March 1987, over 4,400 reported cases and over 2,400 deaths occurred in a country of 145 million people. Thus Brazil had the highest rate in Latin America, surpassing France and Haiti and ranking second only to the United States in number of cases outside Africa.⁴

AIDS and NGOs in Brazil

Peter Fry—an anthropologist born and trained in the UK who had lived in Brazil since 1970 and had worked on gay rights—was head of Brazil's FF office between October 1986 and December 1988 and was a key intermediary between the FF and Brazilian NGOs (Carrara and Aguião 2011, 14). Fry knew that the government program created in 1986 was inadequate. He was also concerned about the lack of public awareness about AIDS and was convinced that NGOs should lead the battle against the disease. Fry established priorities for supporting NGOs in Brazil: concentrate on a few NGOs, investigate the social dimensions of AIDS, and bridge the gap between global knowledge and local advocacy. Thanks to Fry and other officers, the FF became a flexible group where debate and the use of knowledge on community health practices in preventing and controlling AIDS were simultaneously local and global. Emphasizing studies on sexuality was then a necessary correction to the initial overemphasis on the biomedical aspect of AIDS. Fry was also aware of the need to understand Brazilian health and gay-related NGOs and their links to the sanitaristas, who envisioned the comprehensive national health system that was enshrined in the new 1988 Constitution and led to the Sistema Único de Saúde (SUS).

Of the approximately forty Brazilian NGOs working on AIDS during the second half of the 1980s and early 1990s, three were important: Grupo de Apoio à Prevenção da Aids (GAPA), Grupo Pela VIDDA, and Associação Brasileira Interdisciplinar de AIDS (ABIA).⁵ Although they were independent and there was some duplication in their work, they had common features. They were formed by gay volunteers who came from urban, middle-class families; joined forces to hold street demonstrations; deemed government responses too slow, inadequate, or poor; and participated in international AIDS conferences. Many of the founders who had not died of the disease became leaders within NGO networks, schools of public health, and local and federal programs on AIDS (and eventually were hired by international agencies). They also had some differences. For example,

⁴ "Intervention of Dr. Santos (Brazil) Fortieth World Health Assembly," May 5, 1987, https://apps.who.int/iris/bitstream/handle/10665/164150/WHA40_VR-4_eng.pdf?sequence=1&isAllowed=y (accessed September 18, 2020)

⁵ Other smaller NGOs received aid from the Ford Foundation and other US and European philanthropies (Valle 2018).

initially their work overlapped; they competed for grants from the same donors, and some favored assistance for the sick whereas others concentrated on research and public health politics.

GAPA was the first Brazilian NGO explicitly created to address AIDS. It appeared in 1985 in the city of São Paulo and thrived until the early 1990s. GAPA held its first meetings at the Hospital das Clínicas and at the offices of the Division of Leprosy and Dermatological Health of the São Paulo State Health Secretariat. The division head was Paulo Roberto Teixeira, who created the first official AIDS program in Brazil in 1984 under the progressive state government of Franco Montoro. Based on Teixeira's experience with people living with Hansen's disease (referred to with the discriminatory name leprosos), he distributed condoms, educated gay people, dispelled conspiracy theories that HIV was created in a laboratory, and identified unused beds in hospitals that could be allocated to people with AIDS (França 2008; Teixeira 1997). GAPA founders included physicians, health workers, federal employees, and university professors and became a network of organizations using the acronym GAPA plus the initial letters of the state or city (for example GAPA-SP was for the city of São Paulo). By 1988, there were GAPA branches in the states of Rio de Janeiro, Minas Gerais, Pernambuco, Bahia, Pará, and Santa Catarina, and the state of São Paulo had three branches. One of its leaders, prominent in newspapers, was clinical technician Paulo Cesar Bonfim (president of GAPA from 1986 to 1989) who worked with about forty volunteers and became municipal AIDS coordinator in São Paulo in 1989. He defended safe sex, a principle of gay movements, in simple terms: "You don't ban driving because cars can kill. You tell people to wear seat belts and drive slowly We're saying you should wear condoms and have fewer partners."6 The idea inspired the first poster produced by GAPA with the slogan "Transe numa boa," which presented information on condoms and a hotline. GAPA's distinctive feature was assistance for people living with AIDS and helping people with HIV who did not require immediate hospitalization. These tasks were important because the sick frequently faced unprepared, understaffed hospitals. GAPA created the first legal unit to help people with AIDS who had been dismissed from work or denied medical care. This activity was key because favorable court decisions made clear that the citizen's rights envisioned in an article of the Constitution lobbied for by sanitaristas could be enforced (Galvão, Bastos, and Nunn 2021).

Another problem faced by GAPA was that some sick individuals rejected the help of gay volunteers because they did not consider themselves homosexual, which led to the recruitment of psychologists and the preparation of volunteers to be hospital companions. In addition, they confronted the segregation of the sick (a common practice in epidemics). A GAPA member recalled how sick people were isolated in hospitals and "talked to their families through a glass window . . . at least when the patient could get up and communicate" (Contrera 2000, 43, 44). Segregation was linked to stigma and was fought by GAPA-Rio de Janeiro (GAPA-RJ), created in 1987. Two of its leaders, Artur do Amaral Gurgel and Paulo Fatal—the latter a respected gay leader—opposed a stigmatizing Portuguese term used by journalists, physicians, and even public health workers at the beginning of the epidemic: aidético (a negative word for an HIV-positive person similar to those used in previous epidemics like *leproso*, or *pestoso* for people suffering from bubonic plague). They preferred "people living with HIV/AIDS," which was common in international agencies.

ABIA was created in Rio de Janeiro in December 1986 by twenty-eight physicians, lawyers, artists, community leaders, and a Catholic priest. Some were leftist Catholics of the Pastoral da Saúde, the health care arm of the Church, who envisioned an active role for the Church among the poor. ABIA's name included the word *interdisciplinary* because it was influenced by the recently created International Interdisciplinary AIDS Foundation, based in London, and was not limited to medical care. ABIA focused on research and policy

⁶ Cited in Riding 1986.

proposals and participated in public demonstrations, whereas GAPA's focus was providing services. Initially, ABIA operated with a full-time staff of six people, part-time volunteers and a connection with IBASE, a social science center that had opposed the military. The link between the organizations came through the sociologist Herbert "Betinho" de Souza (1935-1997), who returned from exile when democracy was about to be restored, was infected during a transfusion to treat hemophilia, and was elected ABIA president (although he was never in charge of the day-to-day activities) (Rodrigues 2007). He was well-known for his activism with the Catholic Church in fighting inequality and hunger. Betinho made a connection between AIDS and human rights similar to Mann's ideas at the same time. Shortly after resigning his WHO position in 1990 because of conflicts with Director General Nakajima, Mann founded the NGO HealthRight and joined Harvard University, first as professor at the School of Public Health and later as director of the Harvard Francois-Xavier Bagnoud Center of Health and Human Rights. He polished his thinking on health and human rights in meetings like the 1992 International Conference on AIDS, in Amsterdam, and a trip to Brazil the same year to advise the John D. and Catherine T. MacArthur Foundation (hereafter the MacArthur Foundation) on AIDS projects, where he met with Brazilian activists as well as FF staff.

By mid-1988 ABIA gained independence from IBASE when it moved to the Jardin Botánico neighborhood and when the gay writer and former guerilla fighter Herbert Daniel (1946–1992) became an iconic AIDS figure (Green 2018). Betinho and Daniel worked together in an informal division of labor. Betinho oversaw political issues and contacts with the media and Daniel helped with activism and the daily operations of the NGO. ABIA aimed from its beginning to have a national scope and influence newspapers and TV (unlike GAPA, which was interested in direct communication with affected people). Nevertheless, one of the first successful anti-AIDS campaigns, on blood safety, was organized by GAPA and ABIA and led by Betinho. He denounced the network of illegal blood banks that supplied hospitals in Brazil. It was estimated that only about 10 percent of blood used in hospitals—for leukemia, hepatitis A, hemophilia, and other conditions—was distributed by government sources. Furthermore, the equipment for testing blood was scarce and primitive, and about half of the country's 5,500 hemophiliacs contracted HIV through transfusions (Wendel et al. 1985; Santos, Moraes, and Coelho 1991; Kirp 1999). ABIA and GAPA worked with groups interested in blood control, such as organizations of people with hemophilia, thalassemia, and chronic kidney disease, demanding greater state control over private interests in medical services. Thanks to GAPA and ABIA, as well as their strong partnership with the sanitaristas, who promoted safe blood in medical services, commercialization of blood was prohibited in a 1988 law that established mandatory testing for hepatitis B, syphilis, Chagas disease, malaria, and AIDS in hospitals (called the Betinho Law to honor the ABIA president). Later, blood screening was included in the 1988 Constitution. The campaign was important because it was a victory of an emergent alliance and because it demonstrated the importance of a disease that many lay people mistakenly thought was restricted to gays.

The Grupo Pela VIDDA (Pela Valorização, Integração e Dignidade do Doente de AIDS, hereafter GPV), created in May 1989 in Rio de Janeiro, grew out of ABIA. It was a product of Herbert Daniel's conviction regarding the need for a political organization for people living with AIDS. In contrast to ABIA, GPV was combative, staging dramatic protests to capture the attention of the public. Like GAPA, the new NGO also organized legal aid to help defend the rights of people with AIDS (Rich 2020). Besides Daniel, other ABIA members also worked with GPV. In fact, for some years both organizations shared the same office. Eventually, GPV followed GAPA's lead and created NGOs in Niteroi, São Paulo, Curitiba, and Vitória. Daniel became a powerful thinker on AIDS. His main ideas, instrumental in dismissing stigma, are encapsulated in the notion of "civil death," explained in his book *Life before Death*. The book energetically challenges a new form of prejudice; one

that no longer treated homosexuality as an illness, but medicalized and blamed gay lifestyles as the source of AIDS (Daniel 1989). His ideas on discrimination were expanded in a book coauthored with Richard Parker that examined the relationship between AIDS, concealment of sexual identity, and the fear the sick bore that they might never enter into a new emotional relationship again (Daniel and Parker 1991). Daniel demanded not only safe conditions for sufferers of AIDS but also the creation of better conditions for those living with HIV, because an infected person was not moribund, nor an invalid, but someone that needed care, love, and work. According to *Life before Death*, the real sickness in Brazil was not AIDS but an "ideological virus" that created panic, prejudice, segregation, and immobility. Combating the disease publicly was a means not only to confront the virus but also to mold full citizenship in a society plagued by inequalities. Moreover, Daniel considered solidarity a vaccine against stigma. In these writings Daniel repeated the motto: "Viva a Vida!" A global echo of the motto was heard at a plenary session of the 1992 Eighth International AIDS Conference in Amsterdam, which read his message: "AIDS has not defeated me . . . Viva a Vida!"

Ford Foundation grants in Brazil

In mid-1987 Fry had a conversation with Betinho. According to the FF officer, "ABIA was perfect" for a grant because it already had a reputation and was not solely identified with gays (at a time when journalists portrayed the disease as a "gay plague"). In an email to the FF's New York office, Fry called ABIA the intellectual "center of gravity" for critical thinking on AIDS in Brazil.8 In October 1987, ABIA received a seven-month grant of USD 50,000 for a project entitled "The Social Impact of AIDS," which included a study of the social background of the sick and the publication of a bulletin (later, a supplementary grant was awarded for its Centro de Documentação, CEDOC). To receive these grants, ABIA obtained legal status as a nonprofit organization, which was mandatory to receive FF donations, and learned to write a sound proposal, prepare reports, and, later, to lobby congresspeople. At stake was a bill to limit the entry of HIV-positive foreigners, granting people living with AIDS the same rights as those guaranteed to workers with incapacitating illnesses, and the creation of an advisory National AIDS Commission in the Ministry of Health. Thanks to the grant, and IBASE's help, ABIA modernized its computer resources, and CEDOC became a clearinghouse for statistics, DVDs, and international journal articles —when most were not in an open access system. It became a resource not only for the public but also for newspapers.

However, there was no designated funding line for AIDS at the FF in 1987. While the FF grant benefited ABIA, in 1988 the trustees of the foundation asked Richard Parker to write a report identifying opportunities for its work in Brazil. He was a young anthropologist who had been doing field work in Rio de Janeiro since 1982 for his doctoral dissertation on sexuality and Carnaval (Parker 1988). In February 1989, Parker submitted a report with three main themes: the need for social studies on AIDS, the conflict between NGOs and the Ministry of Health, and the FF's need to get involved in AIDS work. According to his reasoning, the themes were related: despite alarming statistics, the disease received little attention in Brazil, little was known about the social dimension of AIDS, and the government was reluctant to share information. (Parker described a troublesome meeting with

 $^{^7}$ The message was read at the Eighth International Conference on AIDS, Third STD World Congress in Amsterdam, July 19–24, 1992.

 $^{^8}$ Ford Foundation interoffice memorandum, Peter Fry to William D. Carmichael, October 19, 1987, FA 739E, Ford Foundation records, RAC.

⁹ Richard Parker, "The Social Dimensions of AIDS," enclosed in a Ford Foundation inter-office memorandum from Joan Dassin to Richard Horovitz, February 27, 1989, FA 739E, Ford Foundation records, RAC.

Lair Guerra de Macedo, director of the AIDS Program from 1985 to 1990. According to Parker, she did not understand how social science could help her.) Another reason for Macedo's resistance was the influence of the Pan American Health Organization (PAHO) in Brazil. PAHO's director, Carlyle Guerra de Macedo, was Lair's brother, and the Washington DC-based agency had little interest in the social dimensions of AIDS (De Barros and da Silva 2016).

Parker's report excoriated the government's aversion to sharing data and its decision to not include university researchers in delegations sent to international AIDS conferences (nevertheless, they had been traveling with funds provided by the FF and other philanthropic organizations). He found that university researchers in São Paulo believed that they "could do better" on their own rather than working "in concert" with the federal government. In Belo Horizonte, he found a project on HIV and street children working as sex workers that subtly bypassed the ministry. It was carried out by the Federal University of Minas Gerais (UFMG) and Johns Hopkins University. Local researchers sent some information to the ministry, to avoid explicit opposition, but did not discuss their results with the ministry. He also found that local researchers felt that the division of labor with the American researchers was unclear and that they were induced to collect data with little control over analysis of the results. For Parker, the experience suggested that NGOs should keep some control of their relationship with the government and demand full participation in international projects. Parker's report celebrated the FF's support of ABIA's study because he believed it was a pioneering study of a key cultural dimension of the disease. He underlined the existence of fluid gender roles, in which many men who engaged in homosexual practices did not identify themselves as gay, and transgender people identified themselves as part of a third gender. Thus Parker challenged the rigid "risk groups," such as homosexuals, that informed the first responses to AIDS, and suggested anyone was vulnerable (Parker 1985, 156; Parker 2009, 187). Later, Parker's idea was instrumental to supporting AIDS work as relevant to all. In Parker's view, the FF should support research on sexuality because Brazil had a pool of highly talented social scientists interested in AIDS but who worked on "shoe-string budgets" and needed to overcome a tradition of fragmented investigations. The report recommended supporting policy-oriented research projects, increasing collaboration among researchers, improving dissemination of information on legal and ethical issues, and changing the deferential relationships of NGOs with respect to the government and to international partners. Shortly after Parker's report was read by the FF officers, a 1989 internal report by the foundation used new concepts that would resonate with Brazilian NGOs: "gender equity" and "reproductive health." They were part of a field under construction that replaced family planning in the 1990s, known as Sexual and Reproductive Health (Brooke and Witoshynsky 2002).

FF grants helped NGOs underwrite the salaries of administrators and secretaries, pay rents, purchase equipment, and fund meals for volunteers (Smallman 2007, 82, 92). From 1989 until the early 1990s, Brazilian NGOs received donations and help from the InterAmerican Foundation (IAF), Oxfam, the Catholic Fund for Overseas Development, Misereor of Germany, Diakonia—a Swedish faith-based development organization, the International Center for Research on Women (ICRW), USAID, the Save the Children Fund, the Scottish Catholic International Aid Fund (SCIAF), and other organizations from industrialized countries. Also during the 1990s, Family Health International, a nonprofit organization based in North Carolina that led an AIDS Control and Prevention Project (AIDSCAP), worked with Brazilian NGOs and the government (Fernandez, D'Angelo, and Vieira 1999). These grants came when AIDS infections appeared to be slowing in industrialized countries but were increasing in developing countries (Bastos 1991). Initially, there was no "overhead" item in proposal budgets, but toward the mid-1990s this category appeared, suggesting a professionalization of the administrative staff at NGOs. Preparing adequate reports for American philanthropic organizations became a challenge.

A case in point occurred in 1992 with a USD 44,000 FF grant received by GAPA-Rio Grande do Sul, based in Porto Alegre. The report was returned by the foundation office due to missing receipts. The directors of the NGO retorted they were new, and no full records could be found.¹⁰ This occurrence revealed a common problem of NGOs: frequent turnover in leadership because many volunteers died or became too sick to continue contributing.

FF awarded a sizeable grant to ABIA in 1988: USD 267,000 to be used over the following two years to support research, enhance CEDOC, and network with other NGOs. With this support, ABIA continued its campaign for safe blood, published its bulletin, and launched a call for small proposals from emergent grassroots organizations to implement their own projects (ABIA 1990a). In 1990, FF grants benefited GAPA-SP (USD 70,980) for advocacy on behalf of people with AIDS, and the smaller NGO Atoba Gay Liberation Movement Group, created in 1985 (USD 41,700 for a year), to support prevention. Early in 1991, another FF grant was made to ABIA (USD 125,000) to produce materials for the education of women, adolescent males, and poor urban families. Thanks to these grants, members of NGOs were also able to travel to the Seventh International AIDS Conference in Florence in 1991, where Daniel and Parker helped organize the Social and Behavioral Science Track, These meetings were learning experiences for Brazilian NGO representatives, who established a dialogue with other scientists and health activists and even used those spaces to confront their own government. An activist recalled that, at the 1989 Fifth International AIDS Conference in Montreal, Brazilian activists and members of the international NGO AIDS Coalition to Unleash Power (ACT UP) "went after Lair Guerra ... to get Brazil to take a more progressive position in its AIDS response" (Souza 2011).

Brazilian activists were impressed by American activists from ACT UP and found that differences between their work and that of activists in industrialized nations was a matter of degree, not kind. Both had to do advocacy, pool resources, be informed of the best science to follow or challenge governments, coordinate international campaigns, and shape a human-rights-based perspective (Follér 2001). At the Montreal meeting the activists promoted the first international network of organizations working on AIDS—which came to be known as the International Council of AIDS Service Organizations (ICASO)—that included ABIA as the point of reference for Latin America. Brazilians returned from Montreal with the idea of creating a national network, something tried by GAPA in 1987. ABIA, GAPA, GPV, and other NGOs organized a meeting in July 1989 in Belo Horizonte, attended by fourteen NGOs working on AIDS. Little was decided, and another meeting occurred in October 1989 in Porto Alegre, with thirty-eight civil society organizations. Then they created the Brazilian Solidarity Network and approved a Declaration of Rights of People Living with HIV, which was instrumental in the subsequent creation of a National Network. These meetings revealed that the relationship between NGOs was not free from tension. In the third meeting of NGOs working on AIDS in April 1990, in Santos, a debate emerged on whether the priority of activists should be assistance or politics (ABIA was accused of the latter). Those that emphasized assistance, like GAPA, believed that an emphasis on politics alienated authorities. Another accusation against NGOs receiving funds from abroad, like ABIA, was that they had too much power, were unaccountable, and their agenda was dictated by foreign donors. ABIA leaders believed that an approach limited to care diverted attention from the human rights issues that were a driver of AIDS. An indication of the disagreement among activists working on AIDS was the 1995 decision by GPV to move out of the office it shared with ABIA. After the death of Daniel, in 1992, cordial ties between the two organizations dissolved and each took different paths; ABIA consolidated its position as a policy-oriented organization, and GPV became a political leader for people living with HIV/AIDS. Eventually, the

¹⁰ Adelmo Turra [President, GAPA-RS] to Sonia Boechar Mattos [Administrator, Ford Foundation, Rio de Janeiro office], June 15, 1993, microfilm 925-1106, FA 739E, Ford Foundation records, RAC.

Solidarity Network fell apart, and in the early 1990s a broader network—not specifically focused on AIDS—appeared: the Brazilian Association of Nongovernmental Organizations (ABONG). This experience indicates that the braiding process involved not only learning to cooperate between different historical actors (activists, officers of international philanthropic organizations and the government) but also to work inside each constituency.

This learning process took place at the same time that NGOs developed projects with the Ministry of Health. A more flexible Guerra de Macedo attended the Fifth International Conference on AIDS in Montreal (1989) and learned that activists were crucial to her work. The fact that NGOs were receiving significant grants in US dollars was important, since the dollar was strong compared to the local currency and the economy had been sliding into recession and inflation since 1987. The election of a free-market conservative in 1990, Fernando Collor de Mello, did not solve the crisis. Within two years of his election, Collor faced impeachment for corruption, and in December 1992 he resigned, shortly ahead of a decision in Congress. NGOs working on AIDS during Collor's term became sources of resistance because the new minister of health—conservative politician Alceni Guerra—agreed with the budget cuts guided by Collor's neoliberal logic, dismissed Guerra de Macedo (provoking the resignation of most program officials), and was unable to maintain regular epidemiological statistics (Laurindo-Teodorescu and Teixeira 2015, 430) To make matters worse, the ministry isolated the program from international science by rejecting WHO's offer to conduct an HIV vaccine trial, using the argument that Brazilians were not "guinea pigs" (De Barros 2018, 125). Despite these problems, not all was adrift during the Collor years. A law prohibited HIV testing of new government workers as a requirement for contracts, private hospitals were reimbursed for AIDS treatment, hospitals had to reserve beds for people with AIDS, and prisoners were tested for HIV. Beginning in 1991, the health system distributed the first antiretroviral (ARV) drug to treat the disease, AZT, and later offered medication for opportunistic infections linked to AIDS (Nunn 2009, 49). Then, in late 1992, the National AIDS Program was revived when Guerra de Macedo was reappointed and the new minister of health Adib Jatene established sanctions against fraud and corruption in medical centers (Rassi 2015).

The development of studies on drugs like AZT to treat the disease had an impact on the branding process described in this article. Upon learning that new drugs could be used by those who could not tolerate AZT, Brazilian activists demanded their distribution through the public health system. Initially, they included Ganciclovir, Pentamidine, and other expensive drugs like dideoxyinosine, also known as ddI, manufactured by Bristol-Myers Squibb; dideoxycytidine or 3TC, produced by the Canadian company Biochem International (related to Glaxo); and dideoxycytidine, or ddC, patented by Hoffmann-La Roche. Activists demanded access to these drugs since the ministry was not clear regarding whether or not it intended to buy them. Sometimes the authorities' excuse for not buying these drugs was that they required strong discipline, or adherence; namely, they had to be taken several times a day to be effective (a similar argument would be used by some international agencies). Eventually, the government agree to these demands.

ABIA's problems and solutions

In 1991, ABIA experienced a crisis that reflected the financial and administrative problems faced by other NGOs. Although ABIA hired Cesar Behs as administrative director, his recommendation—to fully professionalize the staff—encountered resistance. A partial solution came from Betinho, who recruited companies to fund ABIA's "Solidarity" project to cover treatment for their HIV-positive employees and to conduct prevention programs in the workplace (ABIA 1990b). Toward the end of 1991, Betinho invited Parker and João Guerra to renew ABIA (Guerra was a member of IBASE). From September 1991 to May

1992, Parker, Guerra, and Behs tried to get the house in order, and ABIA was restructured. Betinho remained president, while Guerra, Parker, and Behs worked together in ABIA administration. In addition, a Board of Directors and a General Assembly helped create transparency. An important addition was the anthropologist Jane Galvão, to reinforce the research capacities of the organization. With the resignation of Behs in 1993, Galvão assumed administrative responsibilities and became well known at home and abroad. Thanks to Parker, ABIA obtained new contributions. An important one came from the MacArthur Foundation, which provided USD 169,000 to support ABIA's staff and create a homepage on the Internet (a novelty at the time) (MacArthur Foundation 2003). The aid from this foundation increased in the following years and a total of USD 1,068,000 was donated to ABIA between 1992 and 1998. The MacArthur Foundation also supported GPV (USD 230,000 between 1996 and 1998) and GAPA (USD 250,000 between 1994 and 1999). 11

NGOs working on AIDS refocused the work of charities. For example, the Interchurch Organization for Development and Cooperation, a global NGO, and the Canadian Conference of Catholic Bishops' agency, Développement et Paix, began to work on AIDS after contacts with Brazilian NGOs. Thanks to these grants, NGOs consolidated their partnerships with academics, such as the association between ABIA and the Institute of Social Medicine at Rio de Janeiro State University (UERJ), launching a book series that helped transform doctoral dissertations into books and translate key books on AIDS into Portuguese (Mann, Tarantola, and Netter 1993). In these publications, dramatic figures appeared. As many as 420,000 people between the ages of fifteen and forty-five were infected; hospital costs for an AIDS patient in Brazil were USD 17,000, eight times more than the average cost in Latin America; the length of stay in a hospital was twenty-three days, twice that in the US; and a Brazilian with AIDS lived, on average, 5.1 months (in Europe and the United States, survival was 12 months).

In 1992, ABIA was engaged in the FF-funded project "Reproductive Health in the Times of AIDS," which involved production of state-of-the-art papers by working groups of national and international experts. GPV also received important FF grants for education and legal assistance for people with HIV/AIDS. Beginning in 1993, GPV-RJ, GPV-SP, and ABIA jointly organized the ambitious project "Men Who Have Sex with Men" with the help of AIDSCAP and the Ministry of Health. Beginning in the mid-1990s, ABIA and other NGOS suffered a reduction in funding for long-term projects and greater dependence on smaller grants from fewer donors (mainly the MacArthur Foundation; the Protestant Association for Cooperation in Development, or EZE in German; and the FF). Only then did ABIA decide to follow the advice to professionalize the organization and refurbish its Board of Directors, which was modified to include eighteen distinguished members from different Brazilian institutions. In 1995, Parker became secretary general of the board and three years later was elected ABIA's president. ABIA recovered from its problems and by the end of the 1990s participated on the boards of regional organizations such as the Latin American and Caribbean Council of AIDS Service Organizations (LACCASO). The reorganization came with a new theme that reflected the increased pauperization of the epidemic. ABIA developed the concept of "vulnerability"—opposed to "risk"—that denounced unjust economic structures that made poor people susceptible to the epidemic (Parker 2000). However, ABIA's recovery was not free of problems. In April 1994, the press reported that it had received USD 40,000 in the past from mobsters who run an illegal gambling game known as jogo do bicho. After Betinho accepted that it had been a mistake to accept a donation from mobsters the scandal began to quiet down (Escóssia 1994).

¹¹ MacArthur Foundation, "Grant Search: Associação Brasileira Interdisciplinar de AIDS, https://www.macfound.org/grantees/4983/ (accessed January 14, 2021).

NGOS, a new government, and the World Bank

Toward the mid-1990s, the Brazilian economic and political situation stabilized and NGOs consolidated. In late December 1992, Itamar Franco (Collor's running mate) legally replaced Collor as president and, after a few months, tamed hyperinflation thanks to his finance minister, Fernando Henrique Cardoso (Flynn 1996). The success of the economic policies led to Cardoso becoming a presidential candidate. In 1994 Cardoso was elected president with 54 percent of the vote, more than twice that of his nearest opponent, the PT leader Luiz Inácio Lula da Silva. As described by Power (2010), Brazilian democracy became more stable after the underperforming period of 1985 to 1993. The new president had to solve a difficult problem. Brazil was the largest bank debtor among the Latin American countries and was being pressured by the International Monetary Fund (IMF) to reach an agreement with its creditors that included a neoliberal structural adjustment, a smaller role for the state, and privatization of government-controlled services. Although Cardoso embraced neoliberalism, his government supported some social programs like those for AIDS and recognized the need for NGOs (Riley and Cason 2009). In this context, Jatene—who was again minister of health—opposed the privatization of public medical services, reinforced the AIDS Program, ensured a minimum wage for people affected by AIDS who were unable to work, and recruited celebrities such as Pelé to promote condoms. Officials of the Ministry of Health were willing to braid their work with NGOs. At the Ninth International AIDS Conference, which took place in Berlin in 1993, Guerra de Macedo led a group of Brazilian activists through the booths of pharmaceutical companies, chanting "lower prices!" and later published catalogues of NGOs working on AIDS (Ministério da Saúde, Brasil 1997). The program reconnected with international science by participating in a global vaccine trial and promoted the local production of generic drugs.

In March 1994, when the WHO reported twelve thousand AIDS cases in Brazil and over seventy Brazilian NGOs were estimated to be working on AIDS, Brazil signed a three-year loan agreement for USD 250 million with the World Bank (USD 160 provided by the Bank and 90 million by the Brazilian government), making Brazilian AIDS program resources among the largest of developing countries (Ministério de Saúde, Brasil 1994). The loan occurred when the WHO was losing its prominence and the World Bank's Department of Health and Population was becoming the international health leader (Cueto, Brown, and Fee 2019). An important difference from the FF was that the bank relied on loans and required governmental matching funds and alliances between NGOs and the government, in contrast to FF's modus operandi (Faria and da Costa 2006). As a result, these loans became instrumental in leveraging political power on the part of civil society organizations.

The previous relationship between Brazil and the World Bank (WB) made an agreement improbable. Until the 1980s, the WB's aid was for energy, transport, and industry, and only a few social infrastructure nutrition and population-control projects were supported (World Bank 1989a). Most of these loans were considered unsuccessful because of poor local management and delays in the necessary counterpart financing. Because of these experiences, Collor informed the WB that Brazil would no longer request help for its social programs. However, after Brazil gained international attention with the UN Earth Summit, held in Rio de Janeiro in June 1992, and with a meeting between WB officials and the Brazilian government, the possibility of financing AIDS activities emerged. Senior economists at the WB were hesitant—not only because of Brazil's bad reputation as a receiver, but also because they did not consider AIDS work to be a productive investment. But not all officials shared this belief. Since the late 1980s, the WB had been discussing its mandate, resulting in a famous 1993 report entitled *Investing in Health*, which would influence the future relationship between the WB and developing countries (World Bank 1993). The

report argued that sound health programs helped economic growth, measured the cost of disease in productivity and premature mortality, and urged governments of these countries to select several cost-effective public health interventions such as immunizations, AIDS prevention, and essential clinical services (Pereira 2012). It was also important that, after 1989, the World Bank decided to include environmental groups and NGOs in its work—not only governments.

The negotiation of the loan involved a wide range of institutions, including the Ministry of Finance, local governments, and members of NGOs. The initial goals were to strengthen surveillance, prevention, and biosecurity. Another area of negotiation was the role to be played by NGOs. An independent team—parallel to the Ministry of Health but responsible to the minister—was to run the program. About half of the approximately two hundred staff members formerly worked in AIDS-related NGOs. The WB—more than the Brazilian government—wanted a competitive system of grants, with NGO proposals with a maximum budget of USD 100,000 per year (an amount higher than most of the grants provided from philanthropies from abroad). The government, which had little experience working with NGOs, agreed because it believed that the 15 percent earmarked to NGOs would not make a significant difference. The objectives of the loan were to reinforce prevention, train a cadre of health professionals, modernize epidemiological surveillance, and secure support from states and municipalities.

NGOs relied on their experience with the FF and other philanthropic organizations to improve their managerial capacities, streamline administrative work, train personnel, write consistent budgets, and offer mechanisms for monitoring their performance. New NGOs were formed, and existing ones devoted to other themes, like women's rights, began to work on AIDS (by 2000, about five hundred AIDS-related NGOs existed in Brazil). In 1993, the AIDS Program in Brasília established a formal NGO liaison unit that formalized relationships between the Ministry of Health and civil-society organizations and advised them on how to prepare one-year proposals with quarterly progress reports on topics like education, psychological and legal assistance, condom distribution, and training of lay health personnel. An external selection committee, appointed by the Ministry of Health, decided which NGO proposals would be supported, and the program could directly contract with those NGOs. Something different compared with the grants from the FF was that the contracts did not cover NGO overhead costs and strict controls prevented them from spending funds differently than budgeted. These contracts frequently bypassed conservative local governments unwilling to collaborate on preventive interventions perceived as controversial because they involved gays and sex workers, needle exchanges for drug users, and condom distribution. The relationship between NGOs and the AIDS program of the ministry was also instrumental in establishing networks between civil-society organizations and nonconservative local authorities who had paid little attention to AIDS control (Arnquist, Ellner, and Weintraub 2011).

Municipalities and states pursuing funds had to create or reinforce specialized units on AIDS and establish long-term plans with measurable targets and timing for prevention, epidemiological surveillance, treatment, and human rights activities. They received funds according to the coherence of these plans, the prevalence of AIDS, or the concentration of high-risk populations in their locations and their commitment to providing local matching funds (that were usually less than the funds provided from the federal government). As a result, every state in the country and the cities with the highest concentration of AIDS cases had units by the end of the 1990s. The federal government supplied ARVs to the local governments, while the latter had to purchase drugs for opportunistic infections.

The WB agreement highlighted the relationship between prevention and treatment—a crucial theme in Brazil and in international health. The WB intended to limit the work to prevention. The bank argued that, up until 1993, prevention was not actively pursued outside major cities, and it feared the escalating costs of the drugs used for treatment (Beyrer,

Gauri, and Vaillancourt 2005, 13). After some discussion with Brazilians and experts from the Centers for Disease Control (CDC), who sided with the Brazilians, the WB was persuaded to include testing and counseling in the project but "agreed to disagree" with regards to Brazil's free treatment policies (the latter was especially important after 1996 when a Brazilian law established the provision of free ARVs to all people in need through the SUS). Brazilian negotiators made clear that they would not request financing for drugs, but they emphasized that to develop broad prevention efforts, they needed a high-quality laboratory network, which became the Voluntary Counseling and Testing (VCT) centers (eventually they were used not only for testing but also for delivery of ARVs paid for with Brazilian resources) (Brooke 1993). By the late 1990s, there were 247 VCT centers and 480 dispensing units connected through a computerized system to supervise regimes (before the bank's loan, Brazil had only seven clinics where people could be tested for HIV). In annual tenders, locally produced generics were favored because of their low prices.

The WB's loan lent legitimacy to work with gays and sex workers, conveying the idea that work on AIDS was a concern not only of the Left but also of center-right parties and international agencies (Ugalde and Jackson 1995). Another outcome of the loan was that Brazilians who supported the program became politically strong and successfully negotiated with the WB a second (1999–2002) and a third agreement (2003–2006). However, these loans, called AIDS II and AIDS III (the first one was known as AIDS I), still did not cover treatment, which was the responsibility of the government, and the WB became blunter in its criticism of Brazil's comprehensive health care system by arguing that SUS was financially unsustainable (World Bank 1989b). Most activists were aware that part of the motivation of the World Bank was to mitigate criticism of its previous development policies, and they believed that the braiding between the Brazilian government and activists was strong and could resist the World Banks's pressure to downsize the SUS (Mattos, Terto Júnior, and Parker 2001).

Final reflections

In 2006, Jacob A. Gayle, the deputy vice president for HIV/AIDS at the FF, reflected on the foundation's work on AIDS, celebrating Brazil along with India. For Gayle, the joint work of philanthropic and grassroots organizations encouraged policymakers to design comprehensive responses that combined science and human rights. His account summarized the braiding process in Brazil, where progressive NGOs, empowered by democratization, demanded a national program based on human rights and science, and agencies abroad seconded this demand. This braiding was the basis for the "activist state" described by Biehl (2004) as a mark of a holistic Brazilian response to the epidemic. For the World Bank, working with Brazilian NGOs was a learning experience and was instrumental to more ambitious anti-AIDS programs launched in Africa in 2000.

In the years following 1996, the braiding of anti-AIDS Brazilian work was successful. However, by the early twenty-first century, it was clear that not all official public health policies were based on partnerships among governments, donors, and NGOs. As a result, the Brazilian AIDS program was an island of modernity in a country where conservatives had retreated, but not disappeared, and were ready to attack progressive forces that supported the work on AIDS. At the same time, there were no major grants after 2006 because international agencies began to lose interest in AIDS. Eventually, the isolation of the program negatively affected the political and economic sustainability of the complex process

¹² Jacob A. Gayle, "Early Thought about the Ford Foundation and the Global Response to HIV/AIDS," January 25–26, 2006, Reports 016850, Box 867, Catalogued reports 13949-17726, FA 739E, Ford Foundation records, RAC.

in which activists, public health workers, and international organizations had learned to overcome differences and work together (Cueto and Lopes 2021, 2022).

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