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AIDS activists in São Paulo.

Brazil's Virtuous Alliance: How the Grassroots and the Government Joined Forces against AIDS

By John Garrison and Jessica Rich

In Brazil, epidemiology, politics and institutions converged to produce a grassroots movement and partnership with government that proved crucial to fighting AIDS. The Joint United Nations Programme on HIV/AIDS (UNAIDS) regularly identifies the Brazilian National AIDS Program as an example of “good practice” and points to the significance of its government–civil society collaboration (UNAIDS 2007). But even this distinction understates the multifaceted role of grassroots organizations as a driving force in

AIDS policy. Their representatives have participated actively on the nation’s policymaking commissions as well as in countless planning meetings with Brazilian government officials and politicians. They do not hesitate, however, to voice criticism publicly or, when the state falls short of their expectations, to advance policy through the courts. An unusual blend of grassroots activism and political pragmatism over a 30-year span led to this effective approach to the AIDS epidemic, an effort that the IAF actively supported.

Early, proactive responses

AIDS arrived in Brazil in the early 1980s. As in the United States and Western Europe, it initially devastated urban gay communities, compounding the stigma and discrimination that already plagued them (Daniel 1991; Parker and Daniel 1991: 17-18; Galvão 2000: 52-59, 173-174). But in contrast to the denial that greeted the appearance of AIDS elsewhere in Latin America, the civic response in Brazil was early and proactive. (See Galvão 2000, Parker 2003.) Brazilians diagnosed as HIV-positive, their families and their friends were the first who rallied to decry alarming death rates, denounce discrimination, educate the public about prevention and pressure the government for increased treatment. Other organizations quickly sprouted, often led by highly educated, well-connected professionals dedicated to working with the marginalized. Despite resistance from traditionalists, clergy in some of the largest dioceses helped HIV-positive Brazilians form support groups often allied with the Pastoral da Saúde, the healthcare arm of the Catholic Church. Also notable were the Grupos de Apoio à Prevenção à AIDS (GAPA) that spread from São Paulo to other state capitals, including Salvador, where, in 1994, the IAF funded GAPA-Bahia's preventive services. Brazilians at the helm of some of these pioneering efforts would eventually provide the leadership for the government's AIDS program.

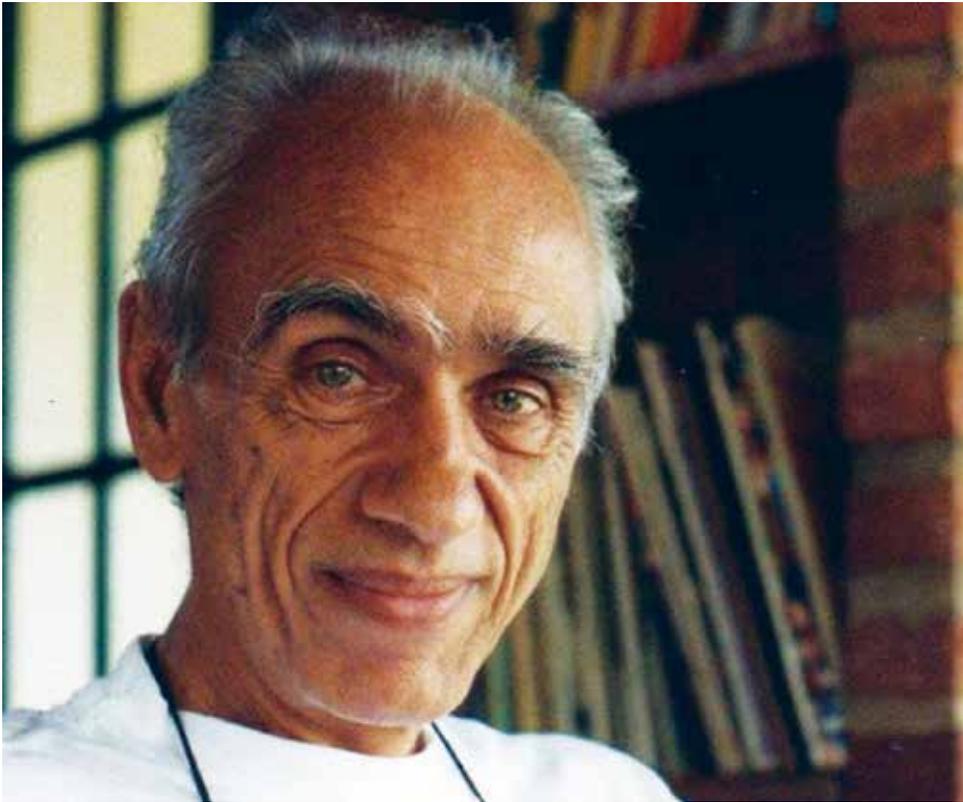
Perhaps the best-known of the advocacy groups is Associação Brasileira Interdisciplinar de AIDS (ABIA). Soon after its founding in 1986 by Herbert "Betinho" de Souza, ABIA became the first IAF grantee partner funded for the express purpose of producing and disseminating educational materials on AIDS. Betinho himself was an iconic social critic and activist who had spent the 1970s in exile, stripped of his citizenship by the military regime then in power. Upon his return to Brazil, thanks to new amnesty laws, he embarked on a career of grassroots organizing that extended through the early 1990s. Its legacy includes IAF grantee partner Instituto Brasileiro de Análises Sociais e Econômicas (IBASE), highly regarded for its socio-economic research and policy work and launched in 1981 with just three people and a computer. Betinho also led nationwide movements pressuring for agrarian reform and ethics in politics, and organized the massive Citizens' Campaign

against Hunger and Poverty and for Life, also supported by the IAF. (See *Grassroots Development* for 1995, vol. 19, no. 2.) The Citizens' Campaign would later influence the design of social programs instituted under President Luiz Inácio "Lula" da Silva, such as *Bolsa Família*, which has helped lift 28 million Brazilians out of extreme poverty.

Betinho reluctantly took on the challenging cause of AIDS in the 1980s, during the early days of the epidemic, when Brazil's blood banks functioned virtually unregulated. An estimated 80 percent of the hemophiliacs in Rio de Janeiro alone contracted HIV through transfusions. Among them were Betinho and his two brothers. Leveraging his national reputation, Betinho announced his diagnosis and put a human face on AIDS in Brazil, much like basketball superstar Magic Johnson did in the United States in 1991. Images of Betinho in a friendly hug, which flooded the media, convinced Brazilians that they could not contract HIV through such a casual social gesture.

He also used his access to the media and civil society partners to spur the government to expand its response. To clean up the blood supply, he helped launch a national campaign, Save the Blood of the Brazilian People, eventually winning support for legislation in 1988 that banned the private sale of blood (Galvão 2008). "Now, the fact that I am fighting back is a relief," Betinho said in an interview. "If you only concentrate on the personal dimension of the misfortune, you will sink with it." ABIA was instrumental in the passage of the 1996 law mandating free antiretroviral drugs for AIDS patients throughout the country. Brazilians receiving these drugs jumped from 35,900 in 1997 to more than 200,000 in 2007, while the number of reported deaths declined during the same period (Galvão 2008; World Bank 2005: 36).

Betinho's outreach included meetings with the CEOs of Xerox, Companhia Vale do Rio Doce, Petrobras and other corporate giants to encourage them to provide treatment to their HIV-positive employees, conduct prevention programs in the workplace and donate to grassroots educational efforts. Hesitant at first, executives soon discovered that exercising social responsibility by investing in measures to address the AIDS epidemic improved branding and in some cases the bottom line. Betinho



Herbert "Betinho" de Souza.

also worked to convince the World Bank that civil society should be an essential component of its AIDS project in Brazil. In 1997, he met with the Bank's president and invited the country director to his home to discuss ways to improve the impact and reach of the Bank's AIDS financing (Galvão 2008).

As it turned out, the expertise developed by ABIA and other civic organizations factored into the government's willingness to collaborate with civil society on policy guidelines. To this day ABIA is known as a leading source of information on AIDS in Brazil. Before agreeing to a second loan of \$165 million in 1999, for example, the World Bank asked the head of ABIA, Jane Galvão, to determine the social impact of its first loan earmarked to address AIDS.

In 1990, ABIA set aside its garage space and \$10,000 toward the founding of Grupo PelaVIDDA, an organization intended to complement ABIA's work with more aggressive positions and a greater focus on treatment. PelaVIDDA was headed by another returned exile, Herbert Daniel, openly gay and the AIDS movement's second most iconic figure. The two Herberts were near opposites in personality—Betinho

intellectual and reflective, Daniel passionate and expressive—and so were the organizations they led. ABIA's team of physicians, lawyers, sociologists and journalists provided the research and analysis required by the movement to inform legislation and monitor government programs. PelaVIDDA was combative and theatrical, staging protests in pursuit of cultural transformation and grabbing the headlines. Its very existence stemmed from a dramatic gesture: Its founders had all publicly announced their diagnosis without regard for the consequences—a radical

move at the time, given the prevailing stigma and ostracism. PelaVIDDA complemented ABIA's agenda by providing needed support for people living with HIV and AIDS, including psychological counseling. It developed the first AIDS hotline in Brazil, after Daniel discovered this tool during a trip to California. Herbert Daniel's groundbreaking work was recognized in *AIDS in the World*, the seminal book published in 1992, the year he succumbed to AIDS.

Eventually the clusters formed by these and other early grassroots AIDS groups evolved into local, regional and nationwide networks that exchanged information and began to influence public policy. Those located in state capitals—São Paulo, Rio de Janeiro, Porto Alegre, Salvador—became active and highly visible. One, Rede Nacional de Pessoas Vivendo com HIV/AIDS (RNP+), grew to include dozens of care and support organizations throughout Brazil. Several others joined forces in 1989 to organize the first National AIDS Conference that brought together hundreds of HIV-positive Brazilians, their family members and activists to discuss community responses (Galvão 2000).

Government support

By the 1990s, AIDS had spread to low-income heterosexual populations. New advocacy and prevention organizations emerged in favelas and in rural areas of the impoverished North and Northeast, reflecting the changing demographics. They included Brazilians of African and indigenous descent, sex workers, street children and Brazilians with disabilities.

A significant force behind this new phase of grassroots organizing was federal support. When the government developed its National AIDS Program in 1985, partly in response to relentless public pressure, its director was careful to integrate civil society into the policy process. The program offered civic organizations the means to improve their delivery of services, manage their finances and raise funds, and even organize meetings of advocacy networks. Between 1994 and 2010, the Brazilian government disbursed some \$145 million to more than 1,500 grassroots organizations undertaking some 3,500 projects in education, prevention or treatment. This sum included \$52 million or 12 percent of the World Bank's \$432 million loan to the Brazilian government to address the spread of HIV (Ministry of Health 2008, World Bank 2010). Channeling World Bank resources to civil society was unusual at the time, but the approach worked so well in Brazil that it was emulated in Africa where civil society organizations in 30 countries received \$1.8 billion, nearly half of the funding for the Bank's regional Multi-Country AIDS Program throughout the 2000s.

The investment enabled Brazilian organizations to analyze policy, continue their advocacy and offer services that ordinarily a government agency might provide: educational campaigns in communities and in public schools, the distribution of prophylactics and medications, patient care and counseling and family support. The National AIDS Program itself recruited representatives of civil society to serve on policymaking committees, manage its grant-making, advise grantees, monitor their progress, conduct demographic surveys and design community responses. Their grassroots groups used public funds to fight discrimination and develop young advocates and leaders. All this, along with access to information on the government's decision-making process, encouraged confidence on

the part of AIDS organizations as well as professional growth and greater responsibility for AIDS work.

The National AIDS Program pursued collaboration with civil society for several reasons, among them its need for their support. The mere mention of the epidemic and the preventive measures needed to address it was sufficient to galvanize the opposition of certain sectors. Civil society could mobilize grassroots constituencies to counter this pressure and monitor local implementation of federal AIDS policies in order to assure compliance with national guidelines. In addition, the social complexities of AIDS made officials view civil society's support as essential. Authorities with the National AIDS Program considered organizations working at the community level or with the marginalized better positioned to reach the populations most at risk and more apt to be realistic about how to modify behaviors. Their staff enjoyed the trust required to approach personal issues, such as sex practices and drug habits, and interact with Brazilians who might be suspicious of authority. And working through civil society could spare the government association with such politically sensitive topics as condom use or needle exchange.

The dynamic and effective grassroots response to the epidemic, which the government assisted, is supported by examples found throughout Brazil. In the Northeastern state of Sergipe, public funds awarded in 1993 financed a multifaceted program launched by the Associação Sergipana de Prostitutas. The goal was to train 400 health agents in preventive measures work now credited with substantially reducing the rate of HIV infection among the sex workers targeted. The government also channeled resources to the Associação Brasileira de Redutores de Danos (ABORDA) based in Rio Grande do Sul, whose capital, Porto Alegre, had reported in the 1990s the highest rates of infection due to intravenous drug use. The support allowed ABORDA's mostly volunteer staff to reach more than double the number of drug users envisioned as well as form effective working relationships with key care facilities and medical professionals, counsel children of users, and train university students and "neighborhood agents" to manage needle exchanges. Importantly, this work restored dignity and purpose to one of the most discriminated and vulnerable groups in society.

The Operations Evaluation Department of the World Bank, which analyzed the role of these organizations in the control of AIDS in Brazil, confirmed their benefit when it reported that they were “highly effective in reaching stigmatized and marginalized groups, making available to them both prevention and care services, for which they have a comparative advantage vis-à-vis public services” (World Bank 2004). What this report recognized was that the Brazilian government’s willingness to partner with civil society to expand and improve its own AIDS response efforts was key to its overall success.

Brazil has stood out as an international standard-bearer for AIDS policy development. Its guarantee of free access to life-saving antiretroviral drugs is a benefit lacking in many wealthier countries. Brazilians living with HIV/AIDS enjoy legal protection against discrimination. Prevention programs reduced the incidence of HIV to half the number of infections predicted for Brazil by the year 2000 (*The Economist* 2007). “Due to the efforts of civil society and Government,” the World Bank reported, “Brazil has been able to contain the epidemic at 0.6 percent of the adult population and has halved the number of AIDS-related deaths” (World Bank 2010). This led then-director general of UNESCO, Koichiro Matsuura, to comment: “[W]e must draw lessons from Brazil’s experience so that your example can save lives and help development elsewhere: in Latin America, in Asia, in Africa, in Europe. We must learn from Brazil. We must learn fast. And we must apply what we learn quickly and effectively” (Matsuura 2002).

The movement today

Government support has had two significant repercussions. First, Brazil’s AIDS movement has grown from a few dozen groups to more than 500 civic organizations officially registered with the Ministry of Health—the vast majority of which receive some form of government support. Second, activists use a broader repertoire of strategies to influence AIDS

policy. Grassroots associations still organize street protests, publicize their demands via the media and otherwise openly air their grievances. But negotiations that were once anchored in personal connections to insiders have given way to institutionalized relationships with all three branches of government. AIDS councils formed by governments at the national, state and municipal levels have become important venues where grassroots advocates work with executive agencies to shape policy. Attorneys with civil society organizations have become effective at litigation, often partnering with state and federal prosecutors to file class-action suits. And a congressional caucus builds the constituencies necessary to advance legislation.

At the same time, close ties between grassroots associations and the government have generated some controversy over the years. Activists and academics warned of the dangers of co-optation, whereby Brazil’s grassroots AIDS associations would temper their criticism for fear of biting the government hand that feeds them. But while the effects of official funding on grassroots advocacy continue to be debated, evidence indicates that the Brazilian government’s practice of awarding grants to civic groups has introduced significant opportunities for organization and mobilization. Funding from the National AIDS Program not only financed service projects but also advocacy campaigns and the growth of grassroots networks. Rather than silencing AIDS activists, federal support seems to have enabled them to voice their demands even louder.

Challenges ahead

Despite Brazil’s remarkable achievements, AIDS is still a problem that requires grassroots mobilization. Ironically, early achievements have given rise to new challenges. As more effective antiretroviral drugs are developed, for example, grassroots organizations must encourage the Brazilian government to pay for and distribute new and increasingly expensive medication.

*We must learn from Brazil.
We must learn fast.
And we must apply what we learn
quickly and effectively.*

—Koichiro Matsuura,
director general, UNESCO

They must also reach a new generation of Brazilians who might be lulled into complacency by the relatively wide availability of antiretrovirals and the success of these drug therapies (*O Globo* 2009).

But while the Brazilian AIDS movement is still strong, its future is uncertain. Grassroots organizations are experiencing budget shortfalls. Even the most prominent and professionalized have suspended prevention programs, and some have shut their doors. The movement can no longer depend on formerly reliable sources of funding. Reasoning that Brazil has “graduated” from the need for an emergency response to AIDS, international donors such as the World Bank have retreated over the last decade, shifting their support to poorer regions around the globe suffering from more widespread infection. In this context, government support has become even more important to the Brazilian movement’s survival, but it too is threatened.

Once protected from legislative meddling, funding for the National AIDS Program is now subject to congressional approval and, according to recent reports, could be susceptible to channeling to other public health purposes (Agência de Notícias da AIDS 2012).

The Brazilian experience has shown that it is possible for grassroots organizations to actively engage governments and rely on their funding, while still maintaining the independence to push for policy changes and better services. Key Brazilian authorities have appreciated the complementary role of civil society in the design and implementation of the Brazilian response to the HIV/AIDS epidemic and recognized pressure as legitimate even when it has targeted them. Grassroots groups, for their part, have shown commitment, resolve and patience as they have cooperated with different levels of bureaucracy, resorting to protest only after exhausting the



Courtesy Jessica Rich

Jessica Rich and grassroots activist Roberto Pereira, former president of the umbrella organization *Fórum de ONGs/AIDS do Estado do Rio de Janeiro*.



Decades of uninterrupted commitment: Betinho and John Garrison in 1994 at the Inter-American Dialogue in Washington, D.C.; grassroots activists in Rio calling attention to depleted antiretroviral stocks in 2010.



possibilities for dialogue. No one exemplified this process of effective and strategic evolution better than Betinho, who began his career as a vocal opponent of the Brazilian government and evolved into a civic leader who influenced both official policy and the practice of corporate social responsibility. While the historic convergence of an activist civil society and a proactive government bureaucracy to fight the AIDS epidemic was indeed “made in Brazil,” the

approaches and lessons of this virtuous circle are already being replicated in other parts of the world.

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