The Brazilian AIDS Program combines prevention with free distribution of antiretroviral therapies and is widely touted as a model for stemming the AIDS crisis in the developing world. In the face of the devastation brought on by AIDS, the unlikely availability of a vaccine in the near future, and the relatively few interventions that seem replicable, this is a most welcome success story. It emerges not out of utopian principles or privileged contexts but out of a desperate reality and redirection of what seemed inflexible, commercial, scientific, and state logic toward equitable outcomes.

In 1992 the World Bank and the Brazilian government approved an unprecedented $250 million aid package for the creation of a new National AIDS Program whose aim was to reverse what international experts were calling the “Africanization” of AIDS in Brazil. AIDS activists, politicians, economists, and scientists organized an impressive governmental and nongovernmental administrative apparatus that is believed to have contained the epidemic’s growth through massive and community-mediated prevention projects, with a focus on condom distribution, HIV testing, and behavioral change among the so-called high-risk groups. In 1996, for the first time, national data showed a decrease in the epidemic’s growth rate. The National AIDS Program and the World Bank now report that half of the projected 1.2 million HIV cases have been averted.

In 1997 the Brazilian government began to provide free antiretroviral drugs to all of the country’s registered AIDS cases. There are some 135,000 patients taking antiretrovirals today. The availability of the cocktail and lab testing, funded by the Brazilian government at an annual cost of approximately $2,000 per patient, is said to have reduced AIDS mortality and the demand for hospital services by more than 50 percent in São Paulo and Rio de Janeiro, the areas most affected. HIV transmission from mother to child is said to have been reduced by two-thirds. This policy of biotechnology for the people is being hailed as “proof that poor nations can do it” and “a model for treating AIDS worldwide.” The Brazil story is now an important component of international medical activism.
More than 40 million people are living with HIV worldwide, 95 percent of them in the developing world, and more than 44 million people in thirty-four of these poor countries, mostly in sub-Saharan Africa, will have lost one or both parents to AIDS by 2010. The Brazilian response to AIDS challenges the perception that it is impossible economically to even consider intervening in the pandemic’s course in low-income countries and calls our attention to the possible ways in which biotechnology can be integrated into public policy and can contribute to political and human advancement in developing contexts, even in the absence of an optimal health infrastructure. Affirming the need to combine daring prevention policies with treatment, this policy opens the political and moral debate on the role of industry, medical science, government, and philanthropy in providing medications to poor countries and on the immediate and long-term implications of doing so.

In this article, I explore the role played by science and technology in the constitution of the Brazilian control of AIDS and assess the social reach and the political and medical impact of this intervention, particularly among the urban poor. After examining how this model policy came into existence through an assemblage of international financial institutions, commercial science, a reforming state, and nongovernmental mobilization—all in a context of deeply entrenched inequality—I consider how its developments dovetail with former president Fernando Henrique Cardoso’s efforts to internationalize Brazil’s market. I argue that the following elements and practices were key to the success of this pharmaceutical form of control: a centralized and business-like management of an AIDS epistemic community; regional AIDS programs and epidemiological monitoring making some AIDS populations legible; activism within the state; a revitalized state-run pharmaceutical sector that was in ruins; a decentralized universal care system facilitating drug distribution; international partnerships and global visibility. Through the AIDS policy, I show that economic globalization does not necessarily limit states. Rather, it opens up new prospects for states and allows them to experiment with new forms of regulating markets for lifesaving treatments. Grassroots activities as well those of public opinion combined to maximize social equity in the face of the market’s “inevitable” agency in resource allocation or denial. I then examine concrete situations in which this policy is involved and how it affects local trajectories of the epidemic both institutionally and in lived experience, particularly among the urban poor where AIDS is spreading the most.

This is not an ethnography of marginality per se or an evaluation of the capacity of state policies to reach marginal groups but a critical analysis of the interactions among governmental, nongovernmental, and marginal
groups and individuals over medical claims. I am concerned with the new fields of exchange and possibility generated as state actors and institutions reach out and so-called marginals leave (some successfully, some not) their predetermined place and face AIDS and its technical and political apparatuses. What social capacities and institutions are instantiated? What destinies do urban marginals embrace as they are slated for intervention? More broadly, how are disease, misery, and marginality governed through the AIDS response? Overall, I am concerned with assessing the larger political, economic, medical, and social implications of a shift that the Brazilian AIDS program represents: from a crumbling welfare state to an activist state, from international and public health understood as prevention and clinical care to access to medication; and from political to biological rights.

**AIDS and Democratization**

AIDS emerged in Brazil in the early 1980s, concurrently with the demise of a military state. The growth of the disease coincided with the country’s democratization amid a ruined economic and social welfare system. First reports showed that AIDS was most prevalent in urban centers, among men who had sex with men—but this epidemiological profile would rapidly and dramatically change. In 1985, 79 percent of the reported AIDS cases were individuals who had either finished high school or had a college education. Ten years later, 78 percent of the reported AIDS cases were illiterate or had finished only elementary school. In 1983 there were forty men for every woman with AIDS; in 1990, the ratio was six to one; in 1996, the ratio was already three to one; now, it is almost one to one. Amid panic, fear, and discrimination, the government’s refusal to seriously address AIDS would play a determinantal role in the unfettered course of the epidemic nationwide.

In those early years of AIDS and in the absence of international and national support, the response to the epidemic sprang from grassroots movements, most notably from gay activists who pressured local municipal and regional health services for information and treatment, and carried out prevention campaigns. In São Paulo, for example, such a mobilization led to the creation in 1983 of a statewide public health AIDS program, the first of its kind in Latin America (under the supervision of Dr. Paulo Teixeira, who would later bring this know-how to the National AIDS Program). Here, grassroots and regional state interventions were not antithetical to each other. They shared a progressive political commitment and understood the need to integrate information and care, and...
pragmatically established alliances with health technicians and philanthropic institutions. The AIDS epidemic also occasioned the creation of several new nongovernmental organizations throughout the country. These new social movements galvanized actions aimed at securing civil and human rights mandated by the new progressive constitution of 1988, which made health everyone’s right and the state’s duty. This universal right would have to find ways to be realized amid the country’s wholesale neoliberalization and state restructuring. AIDS activists representing socially vulnerable groups such as homosexuals and sex workers developed a strong public voice in the dispute over access to ever-more scarce public and medical resources. While the underfunded and understaffed state public health services were increasingly paralyzed in their capacity to address the growing complexities of AIDS, grassroots spaces of health care emerged and bore the medical and social burden of the AIDS crisis among the poorest.

With AIDS increasingly viewed as a development problem and with international funds available, AIDS activists left behind antagonism to the state and together with health technicians, epidemiologists, medical and social scientists, economists, and psychologists constituted a new epistemic community within the state. The work and infrastructures previously developed by local programs and NGOs became a key asset in the development of a centralized, efficient, and transparent HIV/AIDS management mediating international monitoring and regional demands for intervention. According to the World Bank, the Brazilian AIDS epidemic was neither “nascent” (as in Chile and Morocco) nor “generalized” (as in sub-Saharan Africa and Haiti). It was “concentrated” (meaning that HIV infection was found among more than 5 percent of the risk groups and in less than 5 percent of all women undergoing prenatal care) and was thus amenable to technical improvement.

The Brazilian AIDS epidemic has served as a test case for the Bank’s new development policies. The majority of international and national funds were allocated to AIDS prevention, mostly through NGOs (which grew from about 120 in 1993 to about 480 in 1999) and to the institutional development of regional and municipal AIDS programs that operated like NGOs. There was now an impressive prevention apparatus at work. As of 1996–97, the year I did my long-term ethnographic fieldwork, the main prevention activities fostered by the National AIDS Program were mass media interventions aimed at consciousness raising over risk and attitudes and values related to self-esteem; educational campaigns and advertisement strategies to stimulate the use of condoms; support to projects addressing behavioral change toward safe sex; support to community associations and nongovernmental and governmental organizations
developing programs to reduce vulnerability and risk of HIV infection; and education of human resources as STD/HIV/AIDS prevention disseminators. In my work in several regions of Brazil, I documented how the local implementation of HIV/AIDS prevention projects corroborated at least three cultural processes: (1) the individualized ingraining of a health-based concept of citizenship mediated by risk and vulnerability assessments; (2) the management of the subjective in public health sites through testing technologies; (3) the shaping of an ideal form of humanitarian sociality. Social ties were being recast in nongovernmental sites, anonymous epidemiological clinics, and in short-term lived community initiatives. At any rate, at this moment in the model’s life course, afflicted populations were represented by NGOs within the state, and at a local level, NGOs were ruled by what the anthropologist Jane Galvão calls “the dictatorship of projects.” Also at local levels, religious and philanthropic institutions triaged AIDS patients’ access to welfare and medical goods, a phenomenon that I called the pastoralization of the social domain.

After the combined antiretroviral therapies (ARVs—also referred to as the AIDS cocktail) were presented at the Eleventh International AIDS Conference in 1996, AIDS activists and patients, together with politically progressive technical specialists working within the National AIDS Program, were able to mobilize public opinion and to garner the support of various political parties in guaranteeing the right to these new technologies. In November 1996 President Cardoso signed a law that made AIDS medication universally available to all registered HIV/AIDS cases. Proposed by the conservative senator and former president José Sarney, the law obliged the public health system to freely dispense these drugs (from 1992 to 1995, treatment for people infected by HIV was limited and irregular). Technical specialists, at national and regional levels, generated criteria for identifying AIDS patients and for implementing this intervention through the ailing universal health care system. Doctors were required to report cases to the Health Ministry in order for patients to be able to obtain the medication from their local public health services. All this should have led to “a greater notification of cases.”

The epidemic was finally becoming legible, albeit in retrospect. In December 1996, a consortium of epidemiologists and social scientists prepared an official evaluation of the state of the epidemic. I participated in the final workshop in Salvador, Bahia. After several days of intense discussions over the validity of risk categories and of biostatistical modeling and over epidemiological surveillance failures and unaccounted-for cases, among other things, a representative of the National AIDS Program came into the final plenary session and asked the participants: “Which version of the epidemic will we present to the journalists?” The tone had to be positive,
a success story was in the making, and a second World Bank loan was on the horizon. The final report acknowledged that the epidemic had spread widely to different groups and populations, that it was now characterized by impoverishment and feminization, but that there was also a “decreased speed of growth of AIDS in the country.” In March 1997 the Boletim Epidemiológico de AIDS of the Health Ministry reported for the first time numerical evidence of a general decrease in the AIDS incidence rate.

The immediate results of the Brazilian pharmaceutical policy were striking: as of June 1998, fifty-eight thousand AIDS patients were taking AIDS therapies. The National AIDS Program and the Health Ministry had spent $300 million on the medication for the whole year. The program was calculating that the government would save at least $500 million in these transactions. By October 1997 the program was already reporting that this policy was leading to a decline of the number of AIDS deaths and to a decrease of treatment costs. A comparative study produced in the city of São Paulo showed that in the first three months of 1997 there was a reported decrease of 35 percent of AIDS deaths in comparison with the same period in 1996. In Rio de Janeiro, the reported decrease for the same period was 21 percent. The program emphasized that parallel to this decrease was a high reduction in the rates of hospitalization of AIDS patients because of tuberculosis and pneumonia. Emergency services and day hospitals were also in less demand: “In São Paulo, the demand for treatment in day-hospitals decreased 40 percent. The reduction of the demand for this kind of service led to the closure of one of the two floors of the AIDS Unit of the Hospital das Clínicas.”

The economic gains were reported to be immense: “After the treatment begins the patient is less susceptible to opportunistic diseases, and consequently the whole health system stops paying for the treatment of these diseases. By providing this medication the government also saves what it would have to spend in social welfare such as disability compensation and retirement. Since the anti-retroviral therapy increases the patients’ life quality, it is possible for them to remain productive. This cocktail therapy is also important in terms of prevention. . . . With the lowering of the viral count, the risk that the AIDS patient might infect others is also reduced.”

In the words of an epidemiologist who helped implement this AIDS management: “This drug-policy increased self-reporting and as a result, we have achieved near universal registration.” Drugs were now universally available, but the claim of universal reach sounded more like a strategy to bolster the success of the policy and thus add political value to it as a way to ensure sustainability. All this technical infrastructure and medication “is not a gift,” added the epidemiologist: “It is the governmental response to a very well organized social demand.” As one of the National AIDS
Program’s chief pharmacists put it: “It is social mobilization that gives us the political legitimacy to make the medication available. We are an instrument of social mobilization; we give it rationality and make it work. Politicians give priority to this kind of social pressure. It is time now for AIDS to transfer this experience of both social mobilization and treatments to other pathologies, like TB and Hansen’s. We have to revolutionize the health sector.” These committed AIDS professionals and activists were well aware of how to maximize equity within the neoliberalizing state. The AIDS initiative is thus seen as a kind of tool of new democratic politics and ethics.28

Given this innovative management and successful AIDS containment associated with the first World Bank loan, a second loan, “AIDS II,” was approved and began to be implemented in 1998. By 1999 the World Bank was reporting that its joint project with the Brazilian government, NGOs, and regional and municipal AIDS programs had successfully led to “an estimated 30 percent decline in morbidity levels among the leading risk groups.” That same year, the Brazilian Program was named by UNAIDS as the best in the developing world.40 Recently, the economist José Serra, Brazil’s former health minister under Cardoso, told me: “The Bank’s loan is small if compared with what the government has spent on the Program. But the Bank presents it as one of its most important success stories. I would say that they are exaggerating.” Despite its traditional “non-universalistic and focused approach, the Bank never limited the scope of our action,” says Serra. “The Bank’s participation was positive for it obliged us to do something well organized, to make an efficient management and accounting.”31

The World Bank, along with the International Monetary Fund, had been harshly criticized in the mid-1990s for the negative impact that structural readjustment plans were having, particularly on the ability of local governments to reduce the spread of HIV infection.42 The Brazilian success story came at a time when the Bank was seriously reconsidering its mission to eradicate poverty and the need to more directly involve governments in the design of policies.53 As Minister Serra noted, “Informally the Bank’s leading figures told us that we were doing the right thing with medication distribution and challenging the pharmaceutical companies to reduce prices.”34

Pharmaceutical Governance

Most social scientific accounts explain the Brazilian cocktail revolution in terms of the strength of the country’s social mobilization. Gay activist
groups and AIDS activists and experts working at the level of national and international mobilization and law making played a critical role in forcing the state to fulfill its constitutionally mandated health obligations. As Galvão writes: “If the decision to distribute medication can be seen by the technical-political angle, the mobilization of civil society has been key to its maintenance.”

Galvão cites the 1999 and 2000 public mobilization that forced the Ministry of Economics to continue importing medication despite the devaluation of Brazil’s currency and the approval in 2001 by the United Nations of a resolution drafted by Brazil making the access to medication fundamental to the realization of the human right to health. The success of these events is due to local activists’ alliances with international organizations that have politicized patents as a question of fair global exchange and social justice, argues Galvão.

Indeed, much of the inventiveness and success of this policy is due to the encroachment of social mobilization within the state and its transnational ramifications. But this policy is as much social invention as it is state and market extension. In what follows I want to briefly problematize the other political, technological, and market forces that have been determinant to the AIDS policy’s form. First, I want to consider how the antiretroviral law fits into President Cardoso’s plan to internationalize Brazil’s market. Not by mere coincidence, just a few months before the law was approved in 1996, the government had given in to big pharma’s lobby and had legalized patent protection for pharmaceuticals.

Brazil had signed the treaty on Trade-Related Aspects of Intellectual Property Rights known as TRIPS the previous year, and since the government was eager to attract new investments, it allowed a quicker change in legislation than other countries such as India, China, and Argentina, which all have until 2005 to conform to TRIPS. Parallel to the new law on intellectual property, there has been a great increase in the import of pharmaceutical products. The negative commercial balance regarding pharmaceutical products jumped from $417 million in 1995 to $1.277 billion in 1997.

Currently Brazil is the eighth largest pharmaceutical market in the world. In 1998 there were some fifteen thousand drugs being sold in the country, and sales reached $11.1 billion. Some seventy pharmaceutical multinationals operating in the country are competing for a slice of this lucrative market. As Serra puts it: “Today our economy is more open and unprotected than the American one. We did not hesitate to abolish all taxes for the import of medication. We did this to hold the impact of exchange rates on inflation and to increase competition, to stimulate the production of generics.”

By 2010 the developing world is expected to account for approximately 26 percent of the world pharmaceutical market by value, compared
with 14.5 percent in 1999. The majority of growth is estimated for Latin America and Asia, specifically Brazil and India. As a Brazilian adviser to the World Health Organization explains: “Pharmaceutical companies had already gained back their research investment with the sell-off of AIDS drugs in the United States and Europe and now with Brazil, they had a new fixed market and even if they had to lower prices they had some unforeseen return. If things worked out in Brazil new AIDS markets could be opened in Asia and in perhaps Africa.”

A top-ranking director of a pharmaceutical multinational does not put things so explicitly but is adamant that “Patents are not the problem. The problem is that there are no markets for these medications in most poor countries. Things worked out in Brazil because of political will.” The industry has recently put out a pharmaco-economic report on emergent HIV/AIDS pharmaceutical markets—namely, Brazil, Thailand, India, China, and South Africa—and argued that if these governments were to provide the simplest version of the cocktail to 30 percent of the affected populations at 10 percent of the current U.S. price, in 2004 the industry would still make an additional $11.2 billion.

The fact is that the Brazilian antiretroviral law was immediately implemented all over the country through an ailing universal health care system. This specific policy was aligned with a form of health delivery that was pharmaceutically mediated and that was being put into place in the country—and this is the second point I want to highlight: there was a change in the concept of public health from clinical care and prevention to medicamentation. As part of the country’s decentralization and rationalization of universal health care (known as SUS), the government was recasting the costly and inefficient Basic Pharmacy Program whereby municipalities distributed state-funded basic medication to the general population (it had become a source of “political clientelism,” as Marly Aparecida Cosendey and her coauthors put it). States and municipalities were urged to develop their own epidemiologically specific treatment strategies and to administer national, state, and local funds in the acquisition and dispensation of basic medication. This policy should contribute to cuts in hospitalizations and to making families and communities stronger participants in therapeutic processes. This program successfully took root in key states, which then became models for other regions. Overall, however, as I documented in my fieldwork in the south and northeastern regions, the universal availability of medication has in fact been subject to changing political winds; treatments are easily stopped, and more specialized diagnostics and treatments have to be sought in the health market or anticipated in vain in SUS’s endless waiting lists. Local services can rarely plan alternative treatments, for their budgets are as restricted as
their pharmaceutical quotas. State plans and medical demand are uncoordinated. The temporality of this universal and pharmaceutically mediated health delivery is one of discontinuity.

But this is not the case within the model policy. Even though the responsibility for medication distribution has been increasingly regionalized, the lobbies for patients and the pharmaceutical industry kept the state responsible for the distribution of medication classified as exceptional, as well as medication for diseased populations, which are part of special national programs, such as the AIDS Program and the Hansen’s Program. A federal decree on pharmaceutical dispensation was approved in 1995, as was a list of drugs that were officially part of the Health Ministry’s budget. The content of the list was most likely based on interest groups’ demands. Organized patient groups (e.g., around renal disorder and Gaucher disease) seized on this decree and medication list to make sure the federal government keeps importing their medication. Just as in the AIDS case, certain mobilized populations and the state became visible and merged with industry interests. The difficulties of a nationwide operationalization of pharmaceutical dispensation; the compounded and confusing joint action of municipal, regional, and federal government that I have alluded to above; and the tendency toward reducing the federal health budget combined with buying exceptional and expensive medication have consolidated what R. C. S. Silva and J. A. Z. Bermudez refer to as “individualized rather than collective pharmaceutical care.”47 A critical understanding of the success of the AIDS policy must keep in sight this lobbying and political mobilization over inclusion and exclusion, as new markets and regulations, and certain forms of good government and certain political subjects, are being realized. In the last part of this article I show that on the ground, these new mechanisms of governance mediate the emergence of selective forms of biomedical citizenship and what I call local triage states.48

“This new phase of capitalism does not necessarily limit states; it also opens up new perspectives for states,” former president Cardoso told me in an interview in May 2003. “The old producing state had no ways to capitalize and compete. As we broke monopolies we also had to create new agencies and rules to oversee the market for you cannot allow the state not to have voice in these areas.”49 As the AIDS policy evolved, the reforming state was acquiring an effective regulating power and both degovernmentalizing and realizing, in Cardoso’s own words, “a new concept of the state.”50 That is the third point I want to make. Since Cardoso’s two administrations, centralized decision making, clientelism, and corruption, as he sees it, have been replaced by combined state and community actions and the “work on public opinion.” These actions are fundamental for the
maximization of equity and social well-being in the face of the market’s “inevitable” agency in resource allocation and benefits. The work of NGOs and their international counterparts gave voice to specific mobilized communities and helped consolidate actions that were wider and more efficacious than state action alone. “I always said that we needed to have a porous state so that society could act in it. The case of AIDS is the maximum: the state and the social movement practically fused.” In retrospect, Cardoso sees himself as the articulator of an “activist state.”51 Empowered by the National AIDS Program, activists successfully forced the government to draft two additional legal articles that would allow compulsory licensing of patented drugs in a public health crisis, and this legislation created a venue for state activism vis-à-vis the pharmaceutical industry.

State Science and Activism

A politicized science fuels this model policy.52 The strengthening of the country’s scientific infrastructure and pharmaceutical industry has been key to the realization of the antiretrovirals law and the sustainability of the distribution policy. When three-quarters of the Brazilian state business has already been privatized, medication production is arguably one of the country’s most thriving fields. Dr. Eloan Pinheiro, a chemist and former manager of a British pharmaceutical subsidiary, was until early 2003 the director of Farmanguinhos, the Brazilian state’s main pharmaceutical company producing many of the generic antiretrovirals being dispensed. In an interview in August 2001, she told me that her Technological Development Division had already reverse-engineered two drugs that were under patent protection and that they “are ready to go into production if the government deems it necessary.” For Dr. Pinheiro, Brazil’s patent legislation is simply “wrong.” “It makes the country dependent on imports, and hinders local scientific and technological development.”53 In the years following the country’s 1996 new industry property law, Brazil has only requested seventeen pharmaceutical and biotechnological patents, representing 1.4 percent of the world’s total requests (the United States had 46 percent, England 13 percent, and Germany 10 percent).54 She is adamant in her support for state industry: “Nobody can negotiate price without challenging a patented product. We don’t want to compete with richer nations, but we hope to reach a stage of non-dependence.”55

Given the fact that since the 1950s the production of medication in the country “has been a multinational business,” says Dr. Pinheiro, she was not totally surprised when she took over the coordination of Farmanguinhos in the late 1980s and learned that the state’s top laboratory had reduced its
production to three basic drugs. In her work with the British multinational, she had learned much about drug engineering and production, “particularly, how to integrate local materials into the drug’s manufacture.” She also developed a keen understanding of the market maneuvers that keep drug prices high: “I saw how much fat was put into the products and that the final prices didn’t correspond to research expenses at all, it was huge profit, period.” After mentioning her student antimilitary militancy, Dr. Pinheiro said that she had always wanted to see Brazil “a stronger country, incorporating technology.” As she denounces unfair market tactics, she also speaks of the social-mindedness and creativity of local science: “The multinationals must become flexible, and we must all deal with the question of whether new technologies are going to benefit man or exclude him from the possibility of surviving. Justice and equity ought to be defended amid globalization.” Dr. Pinheiro dismisses criticisms that her way of doing science is sheer copying: “We had to develop our own methods of analyzing the drugs. I traveled to China and India to learn techniques and to buy salts from them. . . . Sometimes, if we want the species to survive, we have to regress from some advanced logics that are in place.”

Interestingly, Dr. Pinheiro does not speak of social mobilization as being key to the country’s AIDS initiative. She credits “efficient managers” both in government and in science. Already during Cardoso’s first presidential term, Dr. Pinheiro had been called to Brasília to discuss strategies for drug development. She immediately noted “seriousness and signs of efficiency.” In her negotiation with the state, she made sure that Farmanguinhos would not become simply “a factory” but “a center for technological development”: “We wanted to produce, to sell to the state and then reinvest the profit in technological development with an eye toward endemic diseases.” In 2001 Dr. Pinheiro had a total of 600 people working for her, of which only 173 were paid by the federal government. Under her administration, Farmanguinhos increased its production to sixty-eight drugs, most of them aimed at treating diseases such as TB and Hansen’s, “that are treatable but are of no economic profitability to the multinationals.” This solidarity has been materialized by the National AIDS Program, integrating demand for medication for other patient groups while fighting for AIDS medications.

The antiretroviral policy is emblematic of a new kind of “state/market integration,” adds Dr. Pinheiro, the realized vision of Minister Serra, “a fearless economist with the ability to make the right decisions.” Serra championed the entrance of generics in the Brazilian market and gave incentives to their local production. This was the only way to keep the policy going, says the former health minister, “given extreme budget constraints and the impact that the forthcoming currency devaluation would
have on imported medicines.” In 1999, 81 percent of the government’s expenses with AIDS drugs went to multinationals and only 19 percent to Brazilian companies; in 2000, 41 percent of expenses were already going to national laboratories. As the Brazilian policy created a market for generic drug components, it also raised international competition that led to an overall decrease in drug prices. In 1999, for example, 2.2 pounds of 3TC, an HIV drug, cost $10,000; in 2001, the same 2.2 pounds sold for $700.

On several occasions in the past years, the minister of health has effectively deployed the country’s generic antiretroviral know-how to politicize the practices of big pharma and to negotiate better prices. Pharmaceutical patents have not been broken yet, and Brazil has never even threatened to break international laws governing intellectual property. But the strategy of having the technology and threatening to issue compulsory licensing has proved successful. Brazil was able to obtain a 40 to 60 percent cost reduction on purchases of patented components from Merck and Roche, which are essential to the production of the AIDS cocktail. At some point, the United States threatened to bring sanctions against Brazil at the World Trade Organization, but in the end the two sides reached an agreement: Brazil would not export products resulting from an eventual compulsory licensing, and it would officially notify the American government before it intended to break patents. Here, out of constraint and imagination, global market logics and the politics of science and technology are forced into explicitness and become a new and productive field of tension and negotiation. Inside the Brazilian state, this pharmaceutical activism has occasioned the creation of a strong and autonomous government regulatory agency along the lines of the U.S. Food and Drug Administration. The agency replaced a department within the Health Ministry ripe with corruption and the target of unceasing political pressure and became “an essential ally in the tug-of-war with the pharmaceutical industry,” says Serra.

In sum, at the intersection of technological innovation (the combined antiretroviral therapies), market and state restructuring, and activist invention, the following took form: a new political economy of pharmaceuticals with global and national agencies and particularities, a pilot population through which the state realizes its vision of scientifically based and cost-effective social action, and mobilized groups articulating a novel concept of biomedical citizenship. As Dr. Teixeira, the former national AIDS coordinator, stated in an interview in 2000, “234,000 hospitalizations for opportunistic diseases have been avoided, saving us more than $700 million in medical assistance.” Here human rights are biomedical rights that the state has to fulfill and through which the market, in this case the pharmaceutical one, is moralized. Dr. Teixeira explains: “In the interna-
tional economic field there is a prevalence of unjust and restrictive rules, but nationally we see the universal values that ground public health and also the defense of the individual’s rights to life. These statements resonate with Cardoso’s view of “a solidarity-based globalization,” a concept he developed in his pursuit of a new strategic position for Brazil internationally, and that the new president, Luís Inácio Lula da Silva from the Worker’s Party (PT), is taking further under the banner “not just free but also fair trade.” The fact is that the AIDS model has become an efficient vehicle shaping a perception of the state as transparent, ethical, and with a universal reach. Interestingly, however, the country’s computerized register of individual viral loads and medication distribution does not include social indicators addressing income and level of education, thus it cannot yet give us a profile of where and how this population, whose rights are biotechnologically realized, lives.

As the lives of many AIDS patients are being extended and the international pharmaceutical contract and ethics are being rewritten, I also saw in my ethnographic work in northeastern Brazil that a large number of poor and marginal AIDS victims are actually made absent from epidemiology, policy, and health care and, with no apparent rights, are left to die. These people live in the streets or abandoned buildings. In their troubled existence with AIDS, they have sporadic contacts with governmental services of testing and medical care or with nongovernmental forms of support, but there are no specific programs of prevention, treatment, and support aimed at them. Their experience of dying is ordinary and met by political and moral indifference. In what follows, I show that their dying in apparent invisibility is part of a pattern of local structured noninterventions and explore its paradoxical coexistence with the national AIDS policy and the country’s overall reform.

**Technologies of Invisibility**

The following data are from a social epidemiological study I did with local scientists in the northeastern state of Bahia. Already by 1997 a decrease in AIDS incidence was being reported, and this report was in line with the country’s successful containment measures. We analyzed AIDS death certificates in the AIDS unit of the state hospital in the capital Salvador, which is where the poorest and the homeless are sent for treatment. We counted 571 AIDS deaths at the unit between 1990 and 1996. Only 26 percent of these cases were actually registered by the epidemiological surveillance service. Among these AIDS patients, 297 (52 percent) died during their first hospitalization. One can argue
that when these people finally had access to the hospital, it was largely in order to die.

The categories traditionally used by epidemiology and by the social sciences to map and interpret the impact of social and economic realities on health (such as age, race, and individual risk factors, or gender inequalities, sexual culture, and social representations of risk and safety) are insufficient to account for the rational-technical dynamics at work here. In his 1990 book *The Taming of Chance*, Ian Hacking points to the administrative and moral power of statistical representations, particularly with regards to medico-forensic-political language. Hacking builds on Michel Foucault’s notion that in modern societies there are two poles where politics takes place. One pole is the individual body, and the other is focused on the biological processes of populations. The polarity between human anatomic and the biopolitics of populations is linked together by intermediary relations. Hacking has identified scientific and technical dynamics that intermediate processes by which “people are made up.” Categories and counting, he argues, define new classes of people, normalize their ways of being in the world, and also have “consequences for the ways in which we conceive of others and think of our own possibilities and potentialities.”

If Hacking examines categories and statistics as making up people, I am concerned in this study with how technical and political interventions make people invisible and how these dynamics affect the experience, distribution, and social representation of dying. As I found out in my ethnography, bureaucratic procedures, informational difficulties, sheer medical neglect and moral contempt, and unresolved disputes over diagnostic criteria all mediate how these people are turned into absent things. And I began to call these state and medical procedures and actions “technologies of invisibility.” These technologies routinely intersect with patterns of discontinuity of medical care and of medication dispensation. In these routine exchanges, the dying of many of the abandoned with AIDS gains body.

Interestingly, the AIDS protocols we worked with had no social indicator such as level of education. These are the poorest, those who survive through marginal drug and sex economies. As the unit’s social worker put it: “These are the patients who live in the gutter. Sometimes strangers send them here in a taxi, others are brought in by the police. They come in dying, they have bad skin lesions. The ones who recover just return to the streets where they die. They seldom come back for a follow-up. It is unrealistic to demand that a person who lives on the street adhere to treatment. They never heal. There must be thousands of people in the same situation.” This medical invisibility is not restricted to the AIDS
As the country’s pharmaceutical policy successfully controls the mortality of some, letting die remains an active capacity of the local state, medical profession, and communities. The poorest and marginal are here socially included through a public dying, as if their deaths had been self-generated. I mean: these abandoned only become partially visible in the public health system at the end of life and are then traced as “drug addicts,” “robbers,” “prostitutes,” or “noncompliant,” practices and labels that allow them to be blamed for their dying. They remain at the margins or absent from nongovernmental interventions. In the end, there are no records of their individual and social trajectories, and the complex economic and technical causes that exacerbate infections and immune depressions remain unaccounted for. Most likely, a large group of potential users of AIDS public health services do not even look for any assistance, medical or pharmaceutical. The short-term care of these dying marginal patients is relegated to a mostly sporadic street charity.

My physician-collaborators and I wrote a report to the Bahian Health Division informing them about the existence of a hidden AIDS epidemic. I learned later that this report was never circulated. It was within this kind of unreformed and publicly discredited regional politics that the antiretroviral policy came into effect; it is in these local force fields that the sustainability of the AIDS model remains in question, that a triage-like state gains form, and that social death continues its course.

**Life-Extending Mobilization**

A few of the abandoned with AIDS are selected for social regeneration in community-run sites called houses of support (*casas de apoio*). To uncover this different destiny, I undertook longitudinal work at Caasah, a community-based care center for some of the marginal and poor living with AIDS in Salvador. Caasah was founded in 1992, when a group of
male and female prostitutes, transvestites, and intravenous drug users squatted an abandoned maternity ward on the outskirts of Salvador. City officials and local AIDS activists helped Caasah gain legal status, and by 1993 it became an NGO. With thirty inhabitants, Caasah then successfully applied, with two projects, to the National AIDS Program. The core maintenance of the institution, its technical upgrading and “civilizing processes,” was now closely tied to the funds channeled from the World Bank loan. Indeed, Caasah and similar initiatives were actually being incorporated by local governments and qualified as health services. The question of where to put the diseased poor had fallen out of the state’s purview and had become a pastoral undertaking (by 2000 at least one hundred of the some five hundred registered AIDS NGOs were houses of support). By taking over the task of immediate care of patients and overseeing their medical treatment, as I would discover, Caasah became a venue of an emergent local health triage. It mediated the relationship between AIDS patients and the haphazard and extremely limited public AIDS services. In a more specific way, it selected the patients who could benefit the most from the scarce resources (the state’s AIDS unit had only sixteen beds, for example). Caasah provided means through which these individuals could accede to a distinct (and tentative) form of political and medical accountability previously unavailable to them.

This late-born democratic practice of citizenship through patiethood (or at least a claim to it) would transform in the subsequent years (and at an impressive speed) into a focused and sophisticated practice of care for one’s pharmaceutical well-being. These individuals and their AIDS community would become less confrontational with political forces, local and national, less absorptive of street life, and more integrated with the life-guaranteeing mechanisms and technologies associated with the AIDS program, local and national. Beginning in 1994, strict disciplinary mechanisms led to the expulsion of unruly patients. A reduced group passed through an intense process of normalization coordinated by a therapist sent by the National AIDS Program in 1995. By the end of that year, concerns about internal violence, aggressions, and drug trade and consumption were replaced by concerns for hygiene and house maintenance. The next move involved medicalization, under the guidance of a newly hired nurse. He established an infirmary post with a pharmacy and a triage room.

Caasah had dramatically changed by 1996–97, the year I did my long-term fieldwork there. The main corridor was now crowded with nursing trainees and volunteers wearing white lab coats carrying trays with medicine to their patients. The marginal patients had either left or died, and a higher number of working poor and white people were now living there. Over the past five years, the face of AIDS in Caasah has altered. According
to a volunteer, “In the beginning there were mostly homosexuals in here, you only found a few women and one or two heterosexuals. Now, at the most we have four homosexuals in here. . . . There is the same proportion of men and women. Most of the men got contaminated through drug-use; and most women say they got AIDS from their partners.” Caasah’s president added that there were now fewer people “from the streets”: “The patients who wanted to attend to the norms stayed, the ones who did not want to submit had to leave. They went back to the streets. Many were really from the street, true marginals.” What also changed is the “consciousness of the residents”: “With time we domesticated them. We showed them the importance of using medication; the importance of going to the ambulatory. Now they have this conscience. Today, they fight for their life.”

As Caasah’s inhabitants put their drives into place, so to speak, their biological condition becomes the locus of concentration and fabrication. Many refer to the HIV virus as “my little animal.” Some patients used to say, “I want to let the little animal sleep in me.” I frequently heard comments such as, “The moment you fall back into what you were and stop taking your treatment, the virus occupies your place. And the virus only occupies the place because you let it.” Many live, in their own words, “in a kind of a constant battle.” They know they are trapped between two destinies: dying of AIDS like the poor and marginal, that is, animalized, and the possibility of living pharmacologically into a future, thereby letting the animal sleep and preventing it from consuming the flesh. Irene, Caasah’s first patient to have successfully taken the combined therapies, knows that she is now “another person.” As she puts it: “I have been born again; it is not such a bad thing to have HIV. It’s like not having money. And in Brazil everybody experiences that.”

The fact is that in such houses of support, former noncitizens have an unprecedented opportunity to claim a new identity around their politicized biology, with the support of international and national, public and private funds. Here the immediate access to the language and goods of biomedicine and the administration of health, the politics of patienthood, has priority over the making of metasocial guarantees of social order or over political representation. For the moment, let us conceptualize Caasah as a biocommunity, in which a selective group of poor and marginal diseased have access to a novel social and biomedical inclusion. This citizenship is articulated through pastoral means, disciplinary practices of self-care, and monitored biomedical treatment. At work are new arts of extending life, of being medically treated, and of surviving economically as a diseased but cost-effective citizen.

The new medical and political reality lived by Caasah’s inhabitants adds to Hannah Arendt’s insights on what determines the public sphere
and the human condition these days. Arendt identified a modern political process that progressively eliminates the possibility of human fulfillment in the public realm, excluding masses and reducing them to the condition of animal laborans, whose only activity is that of biological preservation. This preservation is an individual concern; this metabolism is superfluous to the state and to society at large. “They begin to belong to the human race in much the same way as animals belong to a specific animal species.”

Brazilian scholars have been using some of Arendt’s insights to problematize the operational logics of Brazil’s crumbling welfare state. Sarah Escorel, for example, argues that fragmented and stratified concepts of citizenship legitimate a political order in which social policies are unequally distributed according to the citizen’s participation or exclusion from the production processes. Escorel identifies the continuous social exclusion of the poorest masses as a trait of a totalitarian state. For the excluded, she says, “the only social policy is the police.”

I am telling a somewhat different story. In Brazil’s current structural readjustments, novel forms of biosocial inclusion and exclusion are being consolidated. What is distinctive in Caasah is that the diseased biology of these abandoned is not simply an embodiment of marginalization and exclusion to be policed; it is also a technical means of inclusion. While these people learn new scientific knowledge and navigate through new laboratories and treatment regimes, they constitute themselves as biomedical citizens and force an inclusion into a sophisticated form of pharmaceutical control. Processes of social and biomedical regeneration by marginal patients make legitimate the demands to be governed and redistribute (triage) the scope of the state’s remaining governmentality. Against an expanding discourse of human rights, we are here confronted with the limits of the infrastructures whereby these rights are realized, biologically speaking, only on a selective basis, and also with the emergence of a new political economy of pharmaceuticals.

It is within this interrelated context of local, national, and transnational forces shaping an AIDS response that I became interested in how the project to extend life informed institutions and individual agency, particularly at the margins. As I have been arguing, the technical extension of life and death in social abandonment are poles of a continuum in which government, medicine, community, family, and the citizen empirically forge their presence these days. Nongovernmental, sociomedical, and pastoral networks link, through AIDS response, the world of marginality and the state. An ethnographic analysis of these linkages or lack thereof can broaden our understanding of bureaucratic and technological determinants of disease and health among these individuals and groups, as well as the everyday medical and political practices that give form to the line

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between inclusion and exclusion, and can also reveal the extent to which people in the margins learn to use medicine and technology to enhance their claims for social equity and human/biological rights. In my work at Caasah, I could also see how the death of the other actually reinforced one’s sense of a biological belonging to a new medical collective. As Rita, one of Caasah’s founders, a former prostitute and intravenous drug user, puts it: “If they still die with AIDS in the streets, and there are many, it is because they want it.”

**Conclusion**

Despite all its internal paradoxes and challenges, the fact is that the AIDS policy has become an important leveraging tool, both for Brazil as it renegotiates its place in the global economy and for international medical activism as it finds new ways to reinvent itself in terms of new alliances, to bypass local and inefficient state bureaucracies, and to disarm macro-economic dispositives (see the work of Doctors without Borders and Partners in Health). As AIDS has officially become a matter of international security and Brazil has championed the autonomy of nations to break intellectual property rights in the name of securing its citizenry’s health, poor nations’ access to medicines and the import of generics has also become a most contentious issue in the World Trade Organization. The immediate implications of these new developments need to be carefully followed as they redefine the international pharmaceutical contract and the very terms of development in this age of security and ideology; as they challenge poor countries to work on their public health infrastructure to replicate the Brazilian model; as Brazil shares its AIDS managerial and technological know-how with Portuguese-speaking countries in Africa; and as they might also make it possible for Brazil to secure new trade concessions from the United States or even for India to become a key player in the global market of generic drugs.

Over time, the AIDS model has also acquired important political currency inside Brazil. In practice, says former minister Serra, “the AIDS policy worked as counterweight to the economic orthodoxy in place internationally and nationally.” As the policy reaffirmed a universal and public health system and even politics of pricing, it realized a new state voice, he suggests. But as I have documented, a new kind of state distance from the local battlefields over inclusion and exclusion has been formalized as well. During the 2002 presidential campaign, candidate Serra extensively cited the model as emblematic of the new relationship of state and market, soci-
sity and international community that the Cardoso government had worked for and that Serra wanted to keep developing. However, the politicization of the AIDS policy along with other important achievements, such as the control of inflation and fiscal austerity, were defeated by the voters who elected Luis Inácio Lula da Silva as the country’s new president, demanding more comprehensive social reforms. Some political analysts say that ultimately the segments of the 45 million urban poor who live in utter misery have politicized their nonexistence in any policy of the restructuring state and became the decisive contingent to elect Lula.

One wonders which governmental changes are underway and whether this specific AIDS policy will remain a top priority in President Lula’s program of social inclusion. The fact is that despite local generic production, AIDS expenses take up much of the state’s budget for medical treatments. Has the calculus of the cost and benefit of AIDS drugs changed? Will the international financial institutions that were so crucial to the sustainability of the model remain in place? How could a restructuring of the country’s ailing universal health care system impact the experience and politics of AIDS among the poorest and marginal?

In sum, in this article I have tried to historicize and politicize the universality of the pharmaceutical control of AIDS in Brazil, pointing to the inventiveness and most hopeful aspects of this model policy, as well as to ambiguities and gaps, institutional and otherwise. I say hopeful because here we have a much-needed exemplar of how governmental, nongovernmental, financial, and medical-scientific institutions can be inventively reassembled into a Thing that, within limits, works and makes possible new notions of rights, of membership, of accountability. And this hopeful Thing both pioneers ethical representation and demands larger institutional accounting to the tragic unfolding of the AIDS pandemic. It is in this context that I have charted the ingrafting of new mechanisms through which the poorest and marginal, technology, and the state meet, or their distance is established, and distinct life possibilities are realized.

A longitudinal ethnographic engagement can help us chart some of the complex and often contradictory ways in which neoliberalizing health structures, moral economy, and biology are forged in local worlds where biotechnology and structural violence now exist side-by-side. Maintaining these interrelated aspects in view—the multitude, the specific population, and the individual, the political economic and the pastoral, medicine and subjectivity—allows a more effective discourse around changing political cultures and ethics. As I outlined shifts in the concepts of the state (from a crumbling welfare state to an activist state), in the substance of human rights (from political to biological), and in strategies of public health (from
international and public health understood as prevention and clinical care to access to medication), I tried to open up space for people missing in official data, policy decisions, and accounts, and for thinking the work that needs to be done to address this void.

Notes

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3. After the United States, Brazil has the second-highest HIV prevalence in the Americas, with official governmental estimates of some 600,000 infected in a population of more than 170 million people.


14. In 1985 the first GAPA (Group of AIDS Support and Prevention) was created in São Paulo, and it would soon have independent extensions in Porto Alegre and Salvador, for example. GAPAs worked on prevention and also mediated the treatment and legal demands of AIDS victims. Also in São Paulo in 1985, the transvestite Brenda Lee founded the country’s first *casa de apoio* (house of support) for dying patients. In 1986 the activist Herbert Daniel, creator of ABIA (the Brazilian Interdisciplinary AIDS Association), played a key role in the production of AIDS knowledge and dissemination. In 1989 the group Pella Vida was formed in Rio de Janeiro and São Paulo (it was another important outgrowth of the work of Daniel), composed mostly of HIV-positive people and aimed at their medical concerns.

15. Brazil was also of particular interest because of its experimentation with


17. Galvão, A AIDS no Brasil, 106.


23. CN, “Coquetel contra AIDS.”

24. Ibid.


26. Ibid.

27. Interview by the author, January 2000.

28. In her book Inclusion and Democracy (Oxford: Oxford University Press, 2000), Iris Marion Young asks about the democratic process under conditions of structural injustice. Democracy, she argues, might promote justice more if the voices of the excluded can be included—and this entails taking affirmative measures.

30. Coordenação Nacional, Brazilian Response to HIV/AIDS.
42. Interview by the author, August 2000.
43. Interview by the author, June 2003.
45. Cosendey et al., “Assistência farmacêutica na atenção básica de saúde.”
46. F. Acucio, M. Guimarães, and C. Drew, “Accessibilidade de indivíduos infectados pelo HIV aos serviços de saúde: Uma revisão de literatura” (“Access...


52. Cristiana Bastos argues that without state incentive and money, and without the technical know-how to develop original protocols, Brazil’s complex AIDS clinical practice “could not be converted into scientific knowledge that would be accepted by the international system” (Global Responses to AIDS: Science in Emergency [Bloomington: Indiana University Press, 1999], 150). Global pharmaceuticals have recast the workings of this local AIDS science.


54. Bermudez et al., “Implicações do acordo TRIPS.”

55. All of the following quotations from Dr. Pinheiro are from the interview by the author in August 2001.


60. Biehl, Other Life.

61. Teixeira, interview by the author, August 2000.


68. Interview by the author, Salvador, March 1997.


70. In Seeing Like a State: How Certain Schemes to Improve the Human Condition Have Failed, James Scott illustrates why some of the major projects to improve the human condition in the twentieth century have failed and produced tragedy: “The lack of context and particularity is not an oversight; it is the necessary first premise of any large-scale planning exercise” ([New Haven, CT: Yale University Press, 1998], 346).

71. I am here rethinking one of Foucault’s maxims that biopower dominated mortality rather than death: “Power does not know death anymore and therefore must abandon it.” “Del poder de la soberanía al poder sobre la vida” (“From Sovereignty to Power over Life”), in Genealogía del Racismo (The Genealogy of Racism) (Buenos Aires: Editorial Altamira, 1992), 177; Foucault, History of Sexuality; see also Giorgio Agamben, Homo Sacer: Sovereignty and Bare Life (Stanford, CA: Stanford University Press, 1998).

72. Interview by the author, Salvador, December 1996.

73. Ibid.

74. Interview by the author, Salvador, March 1997.


