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Treating AIDS in Brazil

Brazil's groundbreaking AIDS Program combines safe-sex prevention and harm reduction campaigns with the free distribution of antiretroviral therapies (ARVs). In 2005 some 170,000 people were taking anti-HIV drugs funded by the Brazilian government.[1] According to the Health Ministry, both AIDS mortality and the use of hospital services have fallen by more than 50 percent in Rio de Janeiro and São Paulo, the most affected areas of the country (MS 2002). Mother-to-child HIV transmission is said to have been reduced by two-thirds, and Brazil's initiative is widely touted as a model for stemming the AIDS crisis among the poorest (Galvão 2000; Farmer et al. 2001; Rosenberg 2001:28).[2]

Of the more than 40 million people living with HIV worldwide, 95 percent are in the developing world. 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.[3] In the face of the devastation brought about by AIDS, the unlikely availability of a vaccine in the near future, and the relatively few interventions that seem replicable, Brazil's is a most welcome success story. The Brazilian response to HIV-AIDS challenges the perception that treating AIDS in resource-poor settings is economically unfeasible, and calls our attention to the possible ways in which biotechnology can be integrated into public policy even in the absence of an optimal health infrastructure. It also opens up the political and moral debate over delivering life-extending drugs to countries where patients are poor and institutions have limited capacity, and the immediate and long-term medical implications of doing so.

In this chapter, I discuss how this life-extending policy came into existence through an inventive combination of activist forces and the interests of a reforming state, transnational organizations, and the pharmaceutical industry—all in a context of deeply entrenched inequality. I then assess the policy's medical and social reach, particularly in impoverished urban settings where AIDS is spreading most rapidly. Among the questions my ethnographic and social epidemiological work addresses are: Which political institutions and technological practices make this large-scale drug rollout possible, and what guarantees its sustainability? What networks of care emerge around the distribution and use of ARVs among the poor and marginalized? What makes them visible or invisible in their communities and within this pharmaceutical regime? How do individual sufferers fare in the long term as they engage with AIDS treatments? Which models of public health and of citizenship are unfolding?

Throughout the chapter I show that the development of the AIDS policy dovetails with former president Fernando Henrique Cardoso's efforts to internationalize Brazil's economy. Drawing from research I carried out among people working in state, corporate, scientific, and nongovernmental institutions, I was able to identify some of the practices and means through which the AIDS policy materialized and yielded change: AIDS activism within the state; international partnerships (e.g., World Bank); centralized and business-like management of an AIDS expert community; regional AIDS programs and epidemiological monitoring making some AIDS populations visible; revitalization of the state-run pharmaceutical sector, which was in ruins; a decentralized universal care system facilitating drug distribution; a well-orchestrated mobilization for drug price differentiation in favor of developing countries.

The medical accountability at stake in this innovative policy has drastic implications for Brazil's fifty million urban poor (some 30 percent of the population), who are either indigent or make their living through informal and mar-

ginal economies. Despite the alleged universal reach of the AIDS policy, these people have not been explicitly targeted for specific governmental policies related to housing, employment, and security, among others. They gain some public attention during political elections—even then only in the most general terms—and through the limited aid of international agencies. However, through AIDS, new fields of exchange and possibility have emerged.[4]

Medication has become a key element in the state's arsenal of action. As AIDS activism migrated into state institutions, and as the state played an increasingly activist role in the international politics of drug pricing, AIDS became, in many ways, the "country's disease." While new pharmaceutical markets have opened, and anti-HIV drugs have been made universally available (the state is *actually* present through the dispensation of medication), it is up to individuals and communities to take on locally the roles of medical and political institutions. This redefinition of governance and citizenship, obviously efficacious in the treatment of AIDS, also crystallizes new inequalities.

In sum, this chapter illuminates the political and social implications of a shift that the Brazilian AIDS policy 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 as a new and selective form of patient citizenship takes form.[5]

These are not straightforward realities with predetermined outcomes. I approach the AIDS policy as a contemporary "form/event," to use Paul Rabinow's terminology, through which novel political rationalities and infrastructures of care are actualized. Mobilized individuals and groups must continuously maneuver this particular form/event to gain medical visibility and have their claims to life addressed. "Analytic attention to forms/events," writes Rabinow, "brings us closer to the shifting practices, discursive and otherwise, as well as to the shifting configurations that both shape and are shaped by such practices" (1999:179; also see Rabinow 2003).

AIDS and Democratization

With a population of more than 170 million, Brazil is the most populous country in Latin America. While HIV prevalence is estimated to be below 1 percent nationally, this low prevalence hides serious local epidemics. In certain cities, for example, some 60 percent of injecting drug users are infected with HIV (UNAIDS 2004).

HIV/AIDS emerged in Brazil in the early 1980s concurrently with the demise of the military state. Its growth coincided with the country's democratization amid a ruined economic and social welfare system (Parker and Daniel 1991; Parker et al. 1994; Galvão 2000). Epidemiological surveillance services registered the first HIV/AIDS cases in 1982: seven homosexual or bisexual men (later, one HIV/AIDS case from 1980 was found in São Paulo). In 1984, 71 percent of all HIV/AIDS cases were among men who have sex with men; injecting drug users and hemophiliacs were also affected. The virus was most prevalent in urban centers—as of 1985, 89 percent of the reported cases came from São Paulo and Rio de Janeiro (Castilho and Chequer 1997). But over the following two decades, this epidemiological profile would rapidly and dramatically change (Bastos and Barcellos 1995, 1996).

For example, in May 2000, the homosexual/bisexual mode of transmission accounted for less than 30 percent of the total number of AIDS cases registered since the beginning of the epidemic; and transmission through intravenous drug use accounted for 20 percent (MS 2002). By the late 1980s and early 1990s, heterosexual transmission had become predominant, and the number of women infected grew considerably. In 1985, there were 25 men for every woman with HIV/AIDS; by 1990, the ratio had reached 6:1, and in 2000 it arrived at 2:1. The feminization of the epidemic also led to a gradual growth of mother-to-child HIV transmission. In 1990 vertical transmission was responsible for 47 percent of HIV infections among children; and in 2002 this number had risen to 90 percent.

The epidemic has also rapidly spread among the poor and disadvantaged. In 1985, for example, 79 percent of the reported HIV/AIDS cases involved individuals who had at least high school education; by 2000, 73.8 percent were illiterate or had only finished elementary school (Fonseca et al. 2000).

By 1985, all regions in Brazil had reported AIDS cases. The Ministry of Health and the media, however, continued to stigmatize HIV-AIDS and treat it as an issue confined to homosexuals and posing no threat to the "general popula-

tion." According to pioneer AIDS activist Herbert Daniel, since its beginnings AIDS in Brazil was thought of as "something foreign and strange," as well as "something inevitable, almost a kind of price to be paid for the modernity of our cities" (1991:542). The National AIDS Program was put into place in 1986, but the minister of health made it clear that while the government considered AIDS "a serious disease . . . [it] is not our priority" (in Parker and Daniel 41991:77). The government's initial refusal to seriously address the particularities of the spread of AIDS in the country and systematic nonintervention would play a determinant role in the unfettered course of the epidemic among most vulnerable populations (Scheper-Hughes 1994; Parker 1994).[6]

In those early years of AIDS—amid fear, stigma, and lack of national and international support—effective responses sprang from grassroots movements, most notably from gay activist groups that pressured municipal and regional health services for information and treatment, and that also carried out their own prevention campaigns. Founded in 1980, GGB, the Gay Group of Bahia was already actively at work during Carnival 1982, distributing brochures that alerted people to the "gay plague" or "pink cancer." In São Paulo, groups like Outra Coisa and Somos also distributed information on the disease and played a key role in creating a province-wide public health HIV/AIDS program in 1983, the first of its kind in Latin America. Its supervisor, Dr. Paulo Teixeira, would bring his know-how to the National AIDS Program and later also to the World Health Organization (WHO; see Teixeira 1997). Here grassroots and local-state interventions were not antithetical to each other. Already, a mutual implication of activism and state—that is, activism within the state—becomes characteristic of AIDS mobilization. The local activists and governmental actors had a common progressive political commitment; both understood the need to integrate information and care, as well as to pragmatically establish alliances with health professionals and philanthropic and religious institutions—these interventions proved to be quite efficient (Galvão 2000:59).

The HIV/AIDS epidemic also occasioned the creation of several new nongovernmental organizations (NGOs) throughout the country, bringing together AIDS patients, progressive intellectuals, and activist migrants from other social movements on the decline. In 1985, the first GAPA (Group of Support and Prevention Against AIDS) was created in São Paulo; it soon set up affiliates in Porto Alegre and Salvador. The GAPAs worked on prevention and also mediated the treatment and legal demands of AIDS sufferers. In 1986, Herbert Daniel created ABIA, the Brazilian Interdisciplinary AIDS Association, which played a key role in the production and dissemination of HIV/AIDS knowledge. ARCA (Religious Support against AIDS) was created in 1987 to mobilize response in religious institutions. In 1989, the group Pella Vida (another important outgrowth of Daniel's work) was formed in Rio de Janeiro and São Paulo, mostly composed of HIV-positive persons and aimed at addressing their medical and treatment concerns. A language of solidarity and citizenship punctuated the various initiatives of these NGOs.

These organizations played a decisive role in shaping AIDS prevention policies; they also helped to shape legislation that made the registration of AIDS cases compulsory in 1986 and to reform dangerous blood bank practices (Galvão 2000:73).[7] The groups galvanized demands and actions aimed at securing AIDS patients the rights to healthcare mandated by Brazil's new progressive constitution. "Health," the 1988 constitution reads, "is a right of every individual and a duty of the state, guaranteed by social and economic policies that seek to reduce the risk of disease and other injuries, and by universal and equal access to services designed to promote, protect, and recover health" (Constitution of the Federative Republic of Brazil 1988). The principles of universality, equity, and integrality in health services were supposed to guide the new Brazilian health care system known as Sistema Único de Saúde or SUS (Fleury 1997). In practice, however, the right to healthcare would have to be realized amid fiscal austerity, decentralization, and community- and family-centered approaches to primary care. In 1989, for example, the federal government spent $83 on health per person; in 1993 this amount plunged to $37.[8]

Representing socially vulnerable groups such as homosexuals and sex workers, AIDS activists developed a strong public voice in the dispute over access to ever-scarcer public and medical resources. In 1988, for example, activists successfully lobbied the Congress to extend disability status and pensions to all people with AIDS (Law 7670; see Teixeira 1997:61). As the underfunded and understaffed state public healthcare services were increasingly incapable of ad-

dressing the growing complexities of AIDS, grassroots and pastoral spaces of healthcare began to emerge—until today the so-called *casas de apoio* ("houses of support") bear the medical and social burden of the AIDS crisis among the poorest.[9]

Transnational Policy Space

Amid major political changes (including the impeachment of President Fernando Collor de Melo), the National AIDS Program was restructured in 1992. That same year the Brazilian government and the World Bank approved a $250 million aid package for the creation of a new national AIDS program designed to reverse what international experts were already calling the "Africanization" of AIDS in Brazil.[10] Experts were predicting that by the year 2000, Brazil would have 1.2 million people infected with HIV. The country's epidemic was neither "nascent" (as in Chile or Morocco) nor "generalized" (as in Sub-Saharan Africa), the experts said. Rather, it was "concentrated"—meaning that HIV was found in more than 5 percent of the so-called risk groups and in less than 5 percent of all women undergoing prenatal care—and was thus technically manageable.

In the 1990s, with the IMF and World Bank figuring prominently into policy decisions, fiscal austerity was on the rise and the social contract was on the decline. The well-known "Washington Consensus"—with all its support for structural readjustment, market deregulation, and trade liberalization—was developed specifically in response to Latin America's problems (Williamson 1990). According to the international financial institutions, governments had let budgets get out of control, loose monetary policy had led to rampant inflation, and excessive state intervention in the economy had thwarted sustained economic growth.

Alongside these policy shifts, AIDS became increasingly cast as a development problem, prompting social mobilization and demands for public intervention. Various circumstances and actors met in an empty "space of policy" (Hirschman 1995:179). According to Dr. Paulo Teixeira, one of the key articulators of the changes in the national AIDS program, "There was a strategic convergence of interests. . . . Of course, the World Bank was interested in the country's overall economic restructuring, but Brazil was also a concrete site for the Bank to test the financing of such an abstract area: the control of an epidemic through prevention, in the absence of a vaccine" (personal communication, June 2005).

With new national and international funds available, both mobilized citizens and governmental institutions were to infuse this policy-space with specific rationalities, technologies, and claims of human and medical rights. Activists gave up their antagonism toward the state and organized, together with politicians, social scientists, and public health professionals, an impressive apparatus of HIV/AIDS control. The infrastructures and networks previously developed by NGOs and afflicted communities became a key asset in the development of a centralized and efficient AIDS program, dealing with international monitoring and regional demands for intervention. Epidemiologists, demographers, and statisticians working within both the program and local health systems were also beginning to make the human scope of the epidemic legible.

Just as in other policy areas, the World Bank attempted to shape the Brazilian AIDS program. But this time, according to Dr. Teixeira, "The Bank's team included experts that had very progressive views, very similar to those we defended. They supported actions compatible with our national needs—for example, work with injecting drug users. They also agreed that NGOs would have access to the financial resources and would execute the projects. . . . Of course, our view of the NGO was more of a grassroots type, and they had in mind something much more institutionalized" (personal communication, June 2005).

The main disagreement between the World Bank and the Brazilian AIDS policy-makers was over treatment, states Richard Parker, who also participated in the first meetings with the Bank's experts: "In this negotiation process, the Bank's pressure not to have free dispensation of medication was always in the air. There was pressure for the resources to be used mainly for prevention, because within a neoliberal logic of costs and benefits, it is prevention that would bring more economic benefits. This was the logic that guided the Bank's work to a certain degree, and in spite of some changes, continues to guide the Bank's investments in health and in AIDS in general" (Parker 2001).

The politically progressive and socially minded activists and health professionals that now run the AIDS program kept open the possibility of medical

assistance being part of the government's response to the epidemic and, in many ways, fought for it to happen on a larger scale. In 1988, medications to treat opportunistic diseases were already available, if on a limited basis, in the public health care system. Then in 1991, the government signed into law the free distribution of AZT and medication for opportunistic infections, but in practice, the supply and dispensation remained irregular (Galvão 2002:214).

The majority of new AIDS funds were allocated to prevention, mostly through NGOs (which grew in number from 120 in 1993 to more than 500 in early 2000) and to the institutional development of regional and municipal AIDS programs that operated like NGOs. Massive, community-mediated prevention projects sought to contain the epidemic's growth, with a particular focus on safe-sex education, condom distribution, HIV testing, behavioral change and harm reduction (CN 2000a; Galvão 2000; World Bank 1999).

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 subjectivity in public health sites through testing technologies; and (3) the shaping of an ideal form of communitarian sociality. Social ties were being recast in nongovernmental sites, anonymous epidemiological clinics, and in short-term community initiatives (Biehl 2001b; see also Larvie 1997).

At any rate, at that moment in the AIDS policy's existence, NGOs represented afflicted populations within the state, and at a local level, the NGOs themselves were ruled by what the anthropologist Jane Galvão calls "the dictatorship of projects" (2000). Also at local levels, religious and philanthropic institutions were triaging AIDS patients' access to welfare and medical goods.

After researchers presented the combined antiretroviral therapies at the Eleventh International AIDS Conference in Vancouver, in 1996, Brazilian 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 Brazil became the first developing country to adopt an

official policy of universalizing access to life-extending drugs. President Fernando Henrique Cardoso signed a law (proposed by senator and former president José Sarney) that made antiretrovirals available to all registered HIV-AIDS cases. The law obliged the public health system to freely dispense these drugs. Technical specialists at national and regional levels generated criteria for identifying AIDS patients and for implementing this intervention through SUS, the universal healthcare system. Doctors were required to report cases to the Ministry of Health in order for patients to be able to obtain the medication from their local public health services.

The immediate results of this pharmaceutical policy were striking: as of June 1998, fifty-eight thousand AIDS patients were taking ARVs. By the end of the previous year, the National AIDS Program was already reporting that the therapies were decreasing the number of AIDS deaths and treatment costs (CN1997h). In São Paulo, the number of reported AIDS deaths during the first three months of 1997 was 35 percent lower than the numbers of deaths in the same three-month period in 1996. The reported death decrease for the same period in Rio de Janeiro was 21 percent (Oliveira et al. 2002). In considering these shifts, the Program emphasized that the decrease in AIDS deaths paralleled a substantial reduction in hospitalization rates among AIDS patients for diseases such as tuberculosis and pneumonia. Use of emergency services and day-hospitals was also said to be on the decline: "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" (CN1997c). The economic gains were reported to be immense. Although the National AIDS Program and the Ministry of Health had spent some $300 million on anti-HIV medication in 1998, the policy saved the government at least $500 million.

"This drug-policy increased self-reporting and as a result, we have achieved near universal registration," epidemiologist Pedro Chequer told me in an interview at the Health Ministry, in August 2000. He had been director of the AIDS program since 1996 and played a key role in the implementation of the drug rollout. Indeed, antiretroviral therapies were now available, but the claim of universal access and demand sounded like a strategy to bolster the success of

the policy, and thus add political value to it, as a way to ensure sustainability. As I will show later, the supply of AIDS services in public hospitals in poorer regions remained precarious, and many AIDS victims were left without adequate care. All this technical infrastructure and medication "is not a gift," added Chequer, "it is the governmental response to a very well organized social demand. . . . The state has to continue to invest in pharmaceutical production, and it will."

One of the National AIDS Program's chief pharmacists noted: "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" (personal communication, January 2000).

These committed health professionals/activists are well aware of how to maximize demands for equity within the reforming state. With an agenda of social inclusion, they defend national autonomy and a productive state (at least to account for medical needs). At the same time, they also articulate an awareness that social policy should be cut to fit the logic of international market institutions. "Now we have concrete data on the decline in mortality, showing that the investment has been worthwhile," Chequer told me: "The talk on rights and ethics is nonsense for people in the economic area of the government. . . . You must say [to them] we spent that much, we saved that much, the policy is valuable because of this. We demonstrated that even though the investment is high, the indirect savings are higher in terms of treatment of opportunistic diseases, less family disruption and loss of productivity. . . . The AIDS experience also challenges other disease-areas to work from this management perspective and use us as a template" (personal communication, August 2000).

Given this innovative management and apparent HIV/AIDS containment associated with the first World Bank loan, a second loan, "AIDS II," was approved and 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 led to "an estimated 30 percent decline in morbidity levels among the leading risk groups" (World Bank 1999; Garrison and Abreu 2000). The new estimate had 600,000 people infected out of a population exceeding 170 million. That same year, UNAIDS named the Brazilian program the best in the developing world (CN 2000a).

José Serra, an economist and Brazil's former health minister (see Serra 2002), told me in an interview in June 2003 at the Institute for Advanced Study at Princeton, where he was spending the year: "The [World] Bank's loan is small if compared with what the government has spent on the AIDS Program. But the bank presents it as one of its most important success stories." Serra had run for president the previous year, and the AIDS policy played an important role in his campaign. In spite of its traditional "nonuniversalistic and focused approach, the bank never limited the scope of our action," said Serra. "Overall, the bank's participation was positive, as it obliged us to do something well organized, to manage things efficiently, to have a transparent accounting of all projects."

The World Bank, along with the International Monetary Fund (IMF), 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 (Lurie at al. 1995). The Brazilian success story came at a time when the bank was seriously reconsidering its mission to eradicate poverty and was exploring the need to more directly involve governments in the design of policies (Stiglitz 2002). As Serra (currently the mayor of São Paulo) 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." Evidently, the state does not completely compromise its regulatory functions as it negotiates loans and adjustment plans with international agencies. Nevertheless, acts of governing and concepts of development are definitively recast in the process.

AIDS Markets

Most accounts by social scientists explain the Brazilian "antiretroviral revolution" in terms of the strength of the country's social mobilization. Gay activist

groups, AIDS activists, and experts on the disease all played a critical role in forcing the federal government to fulfill its constitutionally mandated health obligations. "If the decision to distribute medication can be seen from the technical-political angle," Jane Galvão writes, "the mobilization of civil society has been key to its maintenance" (2002:16). Galvão cites the 1999 and 2000 public mobilization that forced the Ministry of Economics to continue importing medication in spite of the devaluation of Brazil's currency. In 2000, at the World AIDS conference in Durban, a manifesto from the AIDS program demanding treatment for all in need and offering aid to other developing countries stirred international debate. Brazil also coordinated efforts that led the United Nations to pass a resolution in June 2001 that recognized access to medication as a fundamental ingredient for the human right to health. The success of these events, argues Galvão, is due to local activists' alliances with international organizations that have politicized patents as a question of fair global exchange and social justice.

Indeed, much of the inventiveness and success of the AIDS policy is due to the encroachment of social mobilization within the state and its transnational ramifications (CN2002). Other political, technological, and market forces have also been determinants of the AIDS policy's form and course, and I will briefly consider their contributions below. I will also elaborate on the *pharmaceutical form of governance* that comes out of these new configurations of collective action, a neoliberalizing state, and the pharmaceutical industry.

Let us consider first how the antiretroviral law fits into former president Cardoso's plan to internationalize Brazil's economy. It was no coincidence that just a few months before the antiretroviral law was approved the government had given in to industry pressures to legalize patent protection. Brazil had signed the Trade-Related Aspects of Intellectual Property Rights treaty, known as TRIPS, the previous year, and because the government was eager to attract new investments, it allowed a quicker change in legislation than other countries such as India, China, and Argentina (Sell 2003). Brazil's new intellectual property legislation became effective in May 1997. Meanwhile, parallel to the new legislation, pharmaceutical imports to Brazil have increased substantially. Between 1995 and 1997, the trade deficit in pharmaceutical products jumped from $417 million to $1.277 billion (Bermudez 2000:6).

"Brazil bet a lot on the World Trade Organization [WTO] and dove into it, body and soul," former health minister José Serra told me in an interview in June 2003. "We adopted all trade rules that the developed world wanted." The U.S. government always put patents on the negotiating table, said Serra: "They had a few hanging things with Brazil, the nuclear thing, human rights, indigenous people and patents, these were always on the agenda in the early 1990s." Middle-income countries were offered a very strong "developmental" justification for adhering to TRIPS, as is often the case in the call for neoliberal reforms. You provide patent protection in your country, the logic goes, and we, the investors, feel confident in investing there, which translates to more foreign investment and development for you.

According to Serra, neoliberalization developed "abruptly; it anticipated events. In one or two years Brazil changed commercial policies in place since the 1930s. From a closed and protected economy we went to the opposite. Today, Brazil is an economy that is much more open and unprotected than the American one. This openness was unilateral. It was not a negotiating process through which the country gained something in return. The developed countries didn't make any concessions with textiles and agriculture, for example."

Serra suggested that the early and mid-1990s was a transition period that left little time to critically reflect on the wide-range implications of the terms of economic readjustment—"Things were not so clear." The long-term effects of TRIPS did not generate a great deal of public debate, for example, other than recognition that it marked countries' conformity to global trade reforms. In particular, there was a lack of discussion over the impact of pharmaceutical patents on drug prices and accessibility. The president and his team took hasty and legally binding decisions. And from this new landscape defined by globalization, government was built. "We did not hesitate to abolish all taxes for the import of medication," Serra recalls. "Many in the national industrial sector complained, but we did this to hold the impact of exchange rates on inflation and to increase competition, to stimulate the production of generics."

Brazil is among the ten largest pharmaceutical markets in the world (Bermudez 1992, 1995). In 1998, approximately fifteen-thousand drugs were sold in the country, with sales reaching $11.1 billion (Cosendey et al. 2000; Luiza 1999). Some seventy pharmaceutical multinationals compete for a slice of Bra-

zil's lucrative market. The Brazilian case is much in line with global trends; by 2010, the developing world is expected to account for approximately 26 percent of the world pharmaceutical market in 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 infectious disease specialist and adviser to the World Health Organization explains: "Pharmaceutical companies had already recouped 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 perhaps in Africa" (personal communication, August 2000).

An executive of a pharmaceutical multinational that sells anti-HIV drugs to Brazil and whom I shall call Dr. Jones does not put things so explicitly, but he asserts, "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" (personal communication, May 2003). Here "no markets" dovetails with local governments' lack of a holistic vision of public health, in which the public and private sector work in tandem: "We see an evolution in countries which have coordinated efforts, a strong national AIDS program, partnership with private sectors, and the country's leader supporting intervention."

Brazil recognized the impact of the disease immediately, this pharmaceutical executive claimed, and "it also approached the problem from a multisectoral perspective." In Dr. Jones's recollection (which bypasses the national government's initial disregard of AIDS), campaigns for education and destigmatization led to public dialogue, coupled with a changing vision of public health: "Health is not an area that the Brazilian government allowed to deteriorate anywhere near the degree of what we see in other developing countries. You had an existing structure of STD clinics and World Bank funding helped to strengthen the infrastructure." In this rendering, Brazil's "political will" to treat AIDS coincides with the country's partnership with both international financial institutions and the pharmaceutical industry: "Different than in Africa, in Brazil we had a successful business with our first antiretroviral products. And we will continue to have tremendously successful businesses based on our partnership approach with the government. Brazil continues to be an example of how you can do the right thing in terms of public health, understanding the needs of both the private sector and the government and its population. The government was able to take advantage of existing realities. There was no intellectual property protection for our early products, and given Brazil's industrial capacity, they were able to produce the drugs."

I asked Dr. Jones how the pharmaceutical industry reacted to this strategy. "We were angry," he said. But rather than withdraw from Brazil, the company used the incident over pricing and generics to negotiate broader market access in Brazil. "The down side could have been 'why bother and continue to invest in Brazil?' But anti-HIV products are not the sole bread and butter of most companies. So from a portfolio perspective, any private company balances its specific activities vis-à-vis the entirety of what it is doing. This one sector was being affected but our company had been in Brazil for a long time and we continued to be ranked as a top company there. So we had to look at it in a much broader perspective than an action taken in one product category."

The industry's capacity to neutralize and redirect any form of counterreaction to its advantage is indeed remarkable. In the last few years, following the consolidation of the Brazilian policy and other successful treatment initiatives (by organizations such as Partners-in-Health and Doctors Without Borders), an international consensus has emerged over the feasibility of delivering antiretroviral therapies to the neediest in resource-poor settings. The industry is again exercising its flexibility and turning these unexpected fields of medical action into market opportunities.

As I continued the interview, I told Dr. Jones that I had recently read a pharmaco-economic report on emergent HIV/AIDS pharmaceutical markets—namely Brazil, Thailand, India, China, and South Africa—that argued that if these governments were to provide the simplest version of the "AIDS cocktail" to 30 percent of the affected populations at 10 percent of the current U.S. price, the industry would still profit an additional $11.2 billion. He refuted this idea of emergent AIDS markets in the developing world, evoking Africa and corporate philanthropy once again: "We will supply ARVs to Africa at low

cost, there will be some demand, there will be increase in volume of products sold, but by definition it is not a market for us. . . . We know that the more we sell the more we lose."

As I engaged the pharmaceutical executive's arguments and juxtaposed them to those of policymakers such as Serra, I was able to sketch the logic of the form of pharmaceutical governance represented in the Brazilian AIDS policy. Global markets are incorporated via medical commodities. This process is mediated by international public organizations (WHO, UNAIDS, the World Bank, for example) and has crucial ramifications for the nature and scope of national and local public health interventions. More specifically, once a government designates a disease like AIDS "the country's disease," a market takes shape—a captive market. Here, political will means novel public-private cooperation over drugs. As this government supposedly addresses the needs of its population, which is now (unequally) refracted through the "country's disease," the market possibilities of the pharmaceutical industry are taken in new directions and enlarged, particularly as older lines of treatment (generic ARVs) lose their efficacy, necessitating the introduction of newer and more expensive treatments (still under patent protection) that are demanded by mobilized AIDS patients. Patienthood and civic participation are thus conflated in an emergent market. As Dr. Jones puts it:

> We are seeing changes there where governments try to find out the role they can play in the field of health, health as a fundamental issue they need to deal with. At what point does it get to the government that today citizens put a huge premium on access to health? And it is not just a matter of guaranteeing access to the available medications but of the new ones being developed. If you don't have the capacity to produce this new medication, then you have to find a way to align yourself and partner and trade with those who are doing it. With a global disease like AIDS you must play together and not on your own.

The Pharmaceuticalization of Public Health

This pharmaceutical logic implies a magic-bullet approach in international health (that is, delivery of technology regardless of immediate attention to health care infrastructures). In Brazil, this logic was deeply involved in the health policies that Cardoso's administration devised. The antiretroviral law was immediately implemented across the country through the ailing universal health care system. The new AIDS policy was aligned with a pharmaceutically focused form of health delivery that was then being put into place: Brazil has indeed seen an incremental change in the concept of public health, from prevention and clinical care to community-based care and drugging—that is, public health is increasingly decentralized *and* pharmaceuticalized.

As part of Brazil's decentralization and rationalization of universal healthcare, the government recast the costly and inefficient Basic Pharmacy Program whereby municipalities distributed state-funded basic medication to the general population. Provinces and municipalities were urged to develop their own specific treatment strategies and to administer federal and local funds in the acquisition and dispensation of basic medication (Ministério da Saúde [MS] 1997, 1999; Yunes 1999; Wilken and Bermudez n.d.). The localized policy should contribute to cuts in hospitalizations and to making families and communities stronger participants in therapeutic processes. This program took root in key states, which then became models for other regions (Cosendey et al. 2000).

Overall, however, as I discovered in my fieldwork in the southern and northeastern regions, the universal availability of essential medication has been subject to changing political winds; treatments are easily stopped, and people have to seek more specialized services in the private health sector or, as many put it, "die waiting" in overcrowded public services (Acurcio et al. 1996; Arrais et al. 1997). 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 flow of this universal and pharmaceutically mediated health care delivery is discontinuous.

But the problem is not universal. Even though the responsibility for distributing medication is being increasingly regionalized, the lobbies for patients and the pharmaceutical industry have kept the federal government 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. 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. The fact is that an increasing number of patient groups—many funded by the pharmaceutical industry—are legally forcing the government to keep importing their extremely expensive medication. According to Jorge Bermudez, a public health expert, what is being consolidated is "an individualized rather than collective pharmaceutical care" (Bermudez 2000). An understanding of the success of the AIDS policy must keep in sight this mobilization and lobbying over inclusion and exclusion as new markets and regulations, and certain forms of "good government" are being realized. In the last part of this chapter I will show that on the ground, these new mechanisms of governance are mediating the emergence of *local triage states* and selective forms of *patient citizenship*.

"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." The AIDS policy evolved within this paradoxical space of a downsizing of the role of central government and the need to create, in Cardoso's own words, "new rules for the political game." During Cardoso's two administrations, centralized decision making, clientelism, and corruption, as he sees it, were 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 nongovernmental organizations and their international counterparts gave voice to specific mobilized communities and helped to 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," Cardoso told me. In retrospect, Cardoso sees himself as the articulator of an "activist state."[11]

Empowered by the National AIDS Program, activists 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. As Cardoso put it: "All the nongovernmental work, [the] change in legislation, [and the] struggle over patents are evidence of new forms of governmentality in action . . . thereby engineering something else, producing a new world."

I asked José Serra whether the state had the capacity to address other large-scale diseases pharmaceutically. "Without a doubt. But the problem does not lie in government," he said. "The government ends up responding to society's pressure, and with AIDS, the pressure was very well-organized. You must have a huge mobilization. See the case of TB. It is easier to treat than AIDS, and much cheaper. The major difficulty lies in treatment adherence. But you are unable to mobilize NGOs and society for this cause. If TB had a fifth of the kind of social mobilization AIDS has, the problem would be solved. *So it is a problem of society itself*" (personal communication, June 2003).

For Cardoso, too, the management of AIDS is clear evidence that politics have definitively moved beyond the control of parties and ideologies: "There is no superior intelligence imposing anything . . . a party, a president, an ideology . . . but there are assemblages, alliances, strategies," he stated in the interview in May 2003. "Today, Brazilian society is much more open than people imagine and very mobilized. In reality, people do not live in a state of illusion as intellectuals and journalists generally think of them; they have learned to mobilize and know how to make pressure and activate those in Congress with whom they have affinities."

This is also true for the pharmaceutical industry and its powerful lobby, I added. Cardoso replied: "Indeed, they also mobilize because there is a struggle going on. A bet on democracy leads to this kind of diversity. The government has to navigate amid all these pressures. It must set some specific objectives and develop directives to that end amid this confusion. It cannot just be on this or that side, it must more or less pilot."

Public Sector Science

Brazil's AIDS policy is fueled by a politicized science sector.[12] The strengthening of the country's scientific infrastructure and pharmaceutical industry has

been key to its realization of the antiretrovirals law and the sustainability of the distribution policy. Dr. Eloan Pinheiro, a chemist and former manager of a British pharmaceutical subsidiary, was until early 2003 the director of Far Manguinhos, Brazil's main pharmaceutical company and the one producing many of the generic antiretrovirals that are being dispensed (see Cassier and Correa 2003). In an interview in August 2001 she told me that public laboratories accounted for some 40 percent of Brazilian ARV production, and that her Technological Development Division had already reverse-engineered two drugs that were under patent protection and were "ready to go into production if the government deems it necessary."

Dr. Pinheiro views Brazil's patent legislation as simply "wrong." "It makes the country dependent on imports and hinders local scientific and technological development." In the years following the country's 1996 new industry property law, Brazil has requested only seventeen pharmaceutical and biotechnological patents, representing 1.4 percent of the world's total requests (the USA had 46 percent, Great Britain 13 percent, and Germany 10 percent; Bermudez et al. n.d.). Dr. Pinheiro 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 independence."

Given the fact that the production of medication in Brazil "has been a multinational business" since the 1950s, says Dr. Pinheiro, she was not totally surprised when she learned that the state's top laboratory had reduced production to three basic drugs by the time she took over as coordinator of Far Manguinhos in the late 1980s. In her work with the British multinational, she had learned much about drug engineering and production, "particularly, how to integrate adequate 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 militancy against the military government, Dr. Pinheiro said that she had always wanted to see Brazil "a stronger country, incorporating technology."

As Dr. Pinheiro denounces unfair market tactics, she also speaks of the social-mindedness and creativity of local scientists: "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." She 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." Far Manguinhos thus plays a key role in the acquisition of knowledge on anti-HIV drugs, which, Maurice Cassier and Marilena Correa note, "it can then transfer either to Brazilian public-sector laboratories or to private-sector pharmaceutical laboratories in Brazil and, in the future, in other countries in the South" (Cassier and Correa 2003:91).

Interestingly, Dr. Pinheiro does not speak of social mobilization as being key to the country's antiretroviral initiative. She credits "efficient managers," both in government and in science, and the mobilization of experts as foundational. 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 ensured that Far Manguinhos would become "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 600 people working for her, of whom only one quarter were paid by the federal government. Under her administration Far Manguinhos increased its production to sixty-eight drugs, most of them for diseases such as TB and Hansen's disease, "which are treatable but are of no economic profitability to the multinationals." The AIDS Program is to a large extent responsible for generating this development by integrating demand for medication for other patient groups into the fight for anti-HIV medications.

The antiretroviral policy is emblematic of a new kind of "state-market integration," added Dr. Pinheiro during our interview. It is 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 of keeping the policy going, the former health minister told me, "giving extreme budget constraints and the impact that the forthcoming currency devaluation would have on imported medicines" (personal communication, June 2003). In 1999, 81 percent of the money the government spent for AIDS drugs went to multinationals and only 19 percent to Brazilian companies; in 2000, 41 percent was going to national laboratories, both public and private (Cassier and Correa 2003; CN 2001a; Galvão 2002). 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 anti-HIV drug, cost $10,000; in 2001 the same 2.2 pounds sold for $700.

On several occasions in the past few years the minister of health has deployed the country's generic antiretroviral know-how to politicize the practices of big pharma and negotiate better prices (Paraguassú 2001). Pharmaceutical patents have not been broken yet. But the strategy of having the technology and threatening to issue compulsory licensing has proved successful. In 2002, for example, Brazil was able to obtain 40 to 60 percent cost reduction on purchases of patented components from Merck and Roche that are essential to the production of the AIDS cocktail.

The United States threatened to bring sanctions against Brazil at the World Trade Organization in 2001, but in the end the two sides reached an agreement: Brazil would not export products resulting from broken patents, and it would officially notify the American government before breaking patents. Here, out of constraint and imagination, global market logics and the politics of science and technology are forced into explicitness, and this produces a new 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 FDA. The agency replaced a department within the Ministry of Health that was ripe with corruption and the target of unceasing political pressure; it became, according to Serra, "an essential ally in the tug-of-war with the pharmaceutical industry" (personal communication, June 2003).

In sum, at the intersection of a "technological surprise" (the HIV antiretroviral therapies), social mobilization and the restructuring of both state and market operations, the following is taking form: a new political economy of pharmaceuticals with global and national agencies and particularities, a pilot population through which a reforming state realizes its vision of scientifically based and cost-effective social action, and a contingent of mobilized groups articulating a novel concept of patient citizenship. As Dr. Paulo Teixeira, the former national AIDS coordinator, states: "In the past years, 234,000 hospitalizations for opportunistic diseases have been avoided, saving us more than $700 million in medical assistance." In Brazil, human rights are biomedical rights that the state has to fulfill and through which the pharmaceutical market is moralized. Teixeira explains: "In the international 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 right 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 which the new president, Luis Inácio Lula da Silva from the Worker's Party, is taking further under the banner "Not just free but also fair trade." The AIDS policy reflects a sense of political responsibility, national and transnational, and has become an efficient vehicle shaping a perception of the reformed state as open to the public, rational and coherent, efficient, and ethical. Interestingly, however, the country's computerized register of individual viral loads and medication distribution does not include data on income, education, or any other social indicators. As a result, it cannot yet give us a detailed profile of who this population whose rights are biotechnologically realized is and how it lives.

The transformations of the state and of the concept of public health that my political, scientific, and activist informants emphasized look rather differently at the margins. In my ethnographic work in the northeastern city of Salvador, I observed many poor AIDS patients extending their lives with free access to antiretrovirals. These patients worked hard to keep philanthropic, nongovernmental, and medical support in place to guarantee the effectiveness of the antiretroviral therapies. Fighting for food and housing is concurrent with learning new scientific knowledge and navigating through laboratories and treatment

regimes that now coexist with scarcity. However, although some marginalized AIDS victims exercise their "will to live" and acquire a form of patient citizenship, many others remain epidemiologically and medically unaccounted for and die in abandonment. In what follows, I show that their dying in apparent invisibility is part of a pattern of local nonintervention that coexists with the national AIDS policy and the country's overall reform.

A Hidden Epidemic

The data I discuss in this section are from a social epidemiological study I did with local scientists in the northeastern state of Bahia (Dourado, Barreto, Almeida-Filher, Biehl, Cunha 1997). 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 with 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 epidemiologists and social scientists to map and interpret the impact of social and economic realities on health-disease-death processes (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 book *The Taming of Chance*, Ian Hacking identifies scientific and technical dynamics that mediate the processes by which "people are made up" (1990:3; see also Hacking 1999). 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" (1990:6). Hacking views categories and statistics as making up people, but I am concerned with how technical and political interventions make people invisible and affect the experience, distribution, and social representation of dying. As I found out in my ethnography, bureaucratic procedures, informational difficulties, sheer medical neglect, moral contempt, and unresolved disputes over diagnostic criteria mediate the process by which these people are turned into absent things. During the course of my study I began to call these state and medical procedures and actions "technologies of invisibility." These technologies routinely intersect with patterns of discontinuous medical care and dispensation of medication.

Interestingly, the AIDS protocols we worked with had no social indicators such as level of education. But, 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 epidemic and its local and regional management. Local epidemiologists affirm that during Salvador's 2000 dengue epidemic only one of every one hundred cases were registered; that more than 40 percent of deaths in the state of Bahia have "no known cause"; and that maternal death, which is very high among the poor, is 200 percent higher in the northeastern region.[13]

Specialized health care is provided only to those who dare to identify themselves as AIDS patients in an early stage of infection at a public institution, and who autonomously search (they literally have to fight for their place in the overcrowded services) for continuous treatment—those whom I call patient citizens. While the national AIDS policy does help some of them, local and state medical professionals and communities allow others to die unaided.[14] The poorest and most marginal AIDS patients are in a sense blamed for their own deaths.[15] They are referred to as "drug addicts," "robbers," "prostitutes," or "noncompliant." It is difficult for individuals burdened by these labels to self-identify or be identified as AIDS victims deserving of treatment and capable of adherence. At best they are at the margins of nongovernmental interventions. In the end, there are no records tracing 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 assis-

tance, 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 this hidden AIDS epidemic. I learned later that this report was simply shelved. 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

Some of the poorest and homeless AIDS patients abandoned by local government organizations self-select for social and medical regeneration in community-run "houses of support" (*casas de apoio*). To learn more about this different destiny I undertook a long-term study at Caasah, a grassroots care center in Salvador. Caasah was founded in 1992 when a group of male and female prostitutes, transvestites, and intravenous drug users moved into an abandoned maternity ward in the outskirts of this city of 2.5 million people. City officials and local AIDS activists helped Caasah to gain legal status, and by 1993 it had become a nongovernmental organization. With thirty inhabitants, Caasah then successfully applied to the National AIDS Program for funds for two projects involving technical upgrading. The core maintenance of the institution was thus closely tied to the funds channeled from the World Bank loan. Indeed, Caasah and similar initiatives were actually being incorporated by the state 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 philanthropic and nongovernmental undertaking (by 2000 at least one hundred of the five hundred or so registered AIDS NGOs were houses of support). By taking over the task of immediate care of patients and overseeing their medical treatment, Caasah became a venue of triage as well. It mediated the relationship between AIDS patients and the haphazard and extremely limited public AIDS services and selected the patients who could benefit the most from the scarce resources (the state's AIDS unit only had sixteen beds, for example).

Caasah provided a means through which these marginalized 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 via patienthood (or at least a claim to it) would transform in the next few years into a focused and sophisticated practice of pharmaceutical well-being. These individuals and their AIDS community became less confrontational with political forces, local and national; less a part of street life; and more integrated into the mechanisms and technologies associated with the AIDS program, local and national. Beginning in 1994, strict disciplinary measures led to the expulsion of "unruly" patients. The 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, aggression, and drug selling and consumption were replaced by concerns for hygiene and house maintenance. The next move involved medical treatment under the guidance of a newly hired nurse who established a reasonably consolidated infirmary post and pharmacy.

Thus Caasah had dramatically changed by 1996–1997, the year I carried out my long-term fieldwork there. The main corridor was now crowded with nursing trainees and volunteers wearing white lab coats carrying trays of medicine to their patients. The marginal patients had either left or had died, and more working poor and white people were now living there. Over the past five years, the face of AIDS in Caasah has altered. According to Caasah's Vice President Naiara: "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." There were now less people "from the streets," added Celeste Gomes, Caasah's president: "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. They had no knowledge whatsoever and we changed this doomed sense of 'I will die.' We showed them the

importance of using medication. Now they have this conscience, and fight for their lives."

Caasah's inhabitants are now focused on their biological condition; their disease has become an entity and a personal foe. Many refer to the HIV virus as "my little animal." Some patients 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, aided by ARVs, into a future, thereby letting the animal sleep and preventing it from consuming the flesh. Irene, the first Caasah patient to have successfully taken the combined therapies, knows that she is now "another person." "I have been born again," she says; "it is not such a bad thing to have HIV. It's like not having money. And in Brazil everybody experiences that."

In houses of support such as Caasah 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, 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 (Alvares, Dagnino, Escobar 1999).[16] For the moment, let us think of Caasah as a *biocommunity* in which a selected group of poor and marginal diseased people have access to a novel social and biomedical inclusion. This citizenship is articulated through biotechnology, pastoral means, disciplinary practices of self-care, and monitored 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 the masses and reducing them to the condition of *animal laborans* whose only activity is that of biological preservation (1958:320–325). This preservation is an individual concern; it is superfluous to the state and to society at large. "They begin to belong to the human race," Arendt claims, "in much the same way as animals belong to a specific animal species" (1973:302).

Brazilian scholars have been using some of Arendt's insights to problematize the operational logics of Brazil's crumbling welfare state. Sarah Escorel (1993), 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, there are no social policies, "the only social policy is the police" (1993:36).

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 AIDS 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 patient citizens and force their inclusion into a very sophisticated form of pharmaceutical governance (Biehl 1999; Rabinow 1999; Rapp 1999; Knorr Cetina 2001; Petryna 2002). Processes of social and medical regeneration legitimate marginal patients' demands to be governed and redistribute the scope of the state's authority. Against an expanding discourse of human rights, we are here confronted with the limits of the official structures whereby these rights are realized, biologically speaking, on a selective basis, and also with the emergence of a new political economy of pharmaceuticals.

It was 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, both the technical extension of life and death in social abandonment are elements through which the state, medicine, community, family, and the citizen empirically forge their presence. Nongovern-

mental, sociomedical, and pastoral networks link, through AIDS response, the marginal world and the state. An ethnographic analysis of these linkages or their lack 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 between inclusion and exclusion; it can also reveal the extent to which people in the margins learn to use technology and medicine 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 a rather individualized and depoliticized existence. As Rita, one of Caasah's founders, a former prostitute and intravenous drug user, put it: "I know what I have to do to live. If they still die with AIDS in the streets, and there are many, it is because they want it."

Conclusion

Brazil's policy of biotechnology for the people has dramatically reduced AIDS mortality and improved the quality of life of the patients covered. This policy has become an inspiration for international medical activism and a challenge for the governments of other poor countries devastated by the HIV/AIDS pandemic. Brazil is now sharing its know-how in a range of ways, among them taking on a leadership role at the WHO's "3 by 5" program, helping to rebuild a state-owned pharmaceutical plant in Mozambique, and providing Doctors Without Borders with ARVs for a pilot treatment program in South Africa. In past years, within the limits imposed by international trade agreements, the Brazilian government has exerted its own force through AIDS, as it has been leading developing nations in WTO deliberations over a flexible balance between patent rights and public health needs.

The Brazilian response might not have achieved international justice in the realm of AIDS, but it has at least helped to expose the fallacies of reigning paradigms of public-private partnerships in the resolution of social problems and the limits faced by international development agencies to truly act on behalf of the poorest. Practically speaking, it has opened channels for horizontal south-south collaborations and devised political mechanisms (as fleeting and fragile as they may be) for poor countries to level out some of the pervasive unevenness in international power relations and in disease and health outcomes.

But as with all things political and economic, the reality underlying the policy is twisted, dynamic, and filled with gaps. On the other side of the signifier "model policy" there is a new political economy of pharmaceuticals with international and national particularities. As the AIDS policy unfolded, Brazil attracted new investments, and novel public–private cooperation over access to medical technologies ensued. While Brazil experimented with new modes of regulating markets for life-extending treatments, pharmaceutical companies took the incidents over drug pricing and the relaxation of patent laws at the WTO as opportunities to both negotiate broader market access in Brazil and to open up unforeseen AIDS markets in other countries. The industry has also been able to expand clinical research in Brazil, now run in partnership with public health institutions. American pharmaceutical companies have also successfully downplayed the WTO as they lobbied for strict bilateral and regional trade agreements that made local production of generic drugs unviable.

As ways of mobilizing and extending life are shaped, ethnography takes on the task of illuminating the trajectories that determine these forms and approximating the paths through which people become the physicians of themselves and of their world amid the growing tension between health as public or private good. By keeping these interrelated aspects in view—political economy and activism, biotechnology and public health, population and individual, medicine and subjectivity—one orchestrates a more effective discussion concerning changing political cultures and ethics in a time of unprecedented crisis.

As I outlined shifts in the concept 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 prevention and clinical care to access to medication), I also opened space for people missing in official data, policy decisions and accounts, reflecting on the work necessary to address this void. All this said, it is encouraging that this time, discussions about Brazil have shifted to the maintenance and advance of a life extending policy already well under way.

Notes

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1. ARVs and laboratory testing are estimated to cost approximately $2,000 per patient.
2. There is by now a very significant body of activist and social scientific research and literature on the evolution of the Brazilian response to HIV/AIDS, particularly vis-à-vis political forces and cultural influences, as well as vast documentation of the unfolding of the policy and its programs that the National AIDS Program itself has made available. See Parker and Daniel 1991; Parker 1994; Parker et al. 1994; Bastos and Barcellos 1995, 1996; Castilho and Cherquer 1997; Bastos 1999; and Galvão 2000. My work has unfolded in dialogue with this highly relevant literature.
3. See the report Consensus Statement on Antiretroviral Treatment of AIDS in Poor Countries (Boston: Harvard School of Public Health, 2000).
4. See Caldeira 2001 for a discussion of democratization and human rights in Brazil, and Paley 2001 for a discussion of health movements and democratization. See Das 1999 for a critique of the measures, practices, and values related to international health interventions; and Appadurai 2002 for a discussion of the urban poor and new forms of activism and governmentality in India.
5. My discussion of patient citizenship is informed by Adriana Petryna's work on "biological citizenship," a concept she developed in the context of people's struggle for care and accountability in the Chernobyl aftermath (Petryna 2002).
6. The government's delayed attention to the epidemic followed patterns of slow development of anti-AIDS policies at international levels: only in 1986 did the United Nations, for example, recognize AIDS as an important problem to be addressed (see J. Galvão 2000: 92).
7. In 1988, activist mobilization also helped to defeat a congressional resolution to restrict the entrance of HIV-positive people into the country.
8. Conferência de saúde possibilita intercâmbio, *Jornal NH*, 7 November 1994.
9. In 1985, transvestite Brenda Lee founded the country's first *casa de apoio* (house of support) in São Paulo.
10. See O sexo inseguro, *Isto É/Senhor*, 21 November 1991:52. See also Galvão 2000.
11. See Ferguson's and Gupta's (2002) discussion of new forms of neoliberal government and Nancy Scheper-Hughes's (2003) discussion of changes in the concepts of bodily integrity, sociality, and human values in the context of the global market in human organs for transplantation.
12. In *Global Responses to AIDS*, 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" (1999:150). Global pharmaceuticals have recast the workings of this local AIDS science.
13. Naomar de Almeida Filho, personal communication, August 2000.
14. In *Seeing Like a State*, James Scott illustrates why some of the major projects to improve the human condition in the twentieth century 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" (1998:346).
15. I am here rethinking one of Michel Foucault's maxims that biopower dominates mortality rather than death: "power does not know death anymore and therefore must abandon it" (1992:177; 1980; see also Agamben 1998).
16. See Ana Maria Doimo's discussion of Brazilian social movements: "that indiscriminate posture of negativity *vis-à-vis* the institutional sphere . . . gave room to selective and positive relations with the political and administrative sphere" (1995:223).