

The Right to a Nonprojected Future

In his book *A Bias for Hope*, economist Albert O. Hirschman (1971) challenges social scientists to move beyond categorical prejudgments, beyond the sole search for general laws and orderly sequences of what is required for wider social and political transformation. Having in mind the Latin American countries in which he worked (including Brazil), Hirschman challenges us, instead, to engage the *unexpected*.

The study of how beliefs, attitudes, and values are refashioned and molded by “more or less accidentally undertaken practices,” Hirschman argues, “widens the limits of what is or is perceived to be possible, be it at the cost of lowering our ability, real or imaginary, to discern the probable” (p. 28). At stake is helping “to defend the right to a nonprojected future as one of the truly inalienable rights of every person and nation; and to set the stage for conceptions of change to which the inventiveness of history and a ‘passion for the possible’ are admitted as vital actors” (p. 37).

This book addresses the crucial question of what happens when such luminous prospects of social science are politically and technologically operationalized. Brazil has, against all odds, invented a public way of treating AIDS. In 1996, it became the first developing country to adopt an official policy that universalized access to antiretroviral drugs (ARVs), about five years before global policy discussions moved from a framework that focused solely on prevention to one that incorporated universal treatment. Some 200,000 Brazilians are currently taking ARVs that are paid for by the government, and this policy is widely touted as a model for stemming the AIDS crisis in the developing world. This lifesaving policy came into existence through an unexpected alliance of activists, government reformers, development agencies and the pharmaceutical industry. *Will to Live* moves between a social analysis of the institutional practices shaping the Brazilian response to AIDS and the stories and lives of people affected by it.

HIV/AIDS is the first major epidemic of present-day globalization. Of more than 40 million people estimated to be HIV-infected worldwide, 95 percent live in middle- or low-income countries, causing life expectancy to drop dramatically in those countries worst hit. In late 2003, with only about 400,000 people receiving treatment, the World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) announced their goal of having 3 million HIV-positive people on antiretroviral therapy by 2005. The results have been mixed, but by any account Brazil has been a leader in the effort to universalize access to treatment. By the end of 2004, the number of people on ARVs had increased to 700,000 globally—in the developing world, this figure stood at 300,000, of which half lived in Brazil (UNAIDS 2004). And when the deadline arrived at the end of 2005, with an estimated 6.5 million people requiring treatment, 1.2 million were on ARVs—encouraging, but still short of the target (UNAIDS 2006). Brazil, with less than 3 percent of the world's HIV/AIDS cases, still accounted for nearly 15 percent of people on ARVs.

Throughout this book, I examine the value systems and the political and economic factors underlying the Brazilian AIDS policy, and identify the novel power arrangements (both national and global) that are crystallized in the policy, in its articulation and implementation. As I probe the policy's social and medical reach, particularly in impoverished urban settings where AIDS is spreading most rapidly, I also inquire into the micro-politics and desires that invest ARVs, making survival possible.¹ I draw from research I carried out over the past ten years among people working in state, corporate, scientific, and nongovernmental institutions, and also from fieldwork among marginalized AIDS patients and grassroots care services.

To understand the radically different world of AIDS post-treatment access I had to move in time and space, back and forth between a difficult analysis of how the afflicted understand themselves—born of careful ethnographic work and long-term conversations I was privileged to have—and a more experience-distant investigation into how therapeutics mix with activism and political economy: locally, nationally, and globally.² Fieldwork allows us to see these various actors and forces at work, reminding us that there is no short cut to understanding the multiplicities of reality and the practical articulations through which technologically extended life happens. Ethnography remains, in my

view, a vital social scientific antidote to what Hirschman identifies as “compulsive and mindless theorizing.” As he writes, “Quick theoretical fix has taken its place in our culture alongside the quick technical fix” (1970, p. 329).

Although much of my research stands within the traditional boundaries of ethnography (charting the lives of individuals and institutions over time through open-ended interviews and participant observation), I also make use of alternative forms of evidence—some of them quantitative—developed in collaboration with researchers and practitioners from other disciplines, including epidemiology. Yet during my fieldwork, I often found myself returning from what I “[saw] and heard with bloodshot eyes and pierced eardrums.”³ Where words and numbers fell short, I teamed up with photographer Torben Eskerod; his photographs, interspersed throughout these pages, highlight the plight and singularity of the abandoned AIDS patients with whom I worked.

Examining this constellation of evidence from an anthropological perspective sheds light on how scientific and technological developments, medicine, and political-economic institutions do their work over time and across cultures. Biotechnological innovations engender unlikely coalitions that both expose the inadequacies of reigning public health paradigms and act to reform, if to a limited extent, global values and mechanisms (of drug pricing and types and scope of philanthropic and humanitarian interventions, for example). Mediated by an activist state, these therapeutic coalitions also expose national contradictions and bring about novel institutions, modes of life, and inequalities. Brazil’s response to AIDS thus provides a unique opportunity both to apprehend shifting public-private involvements in a neoliberal landscape and to assess their immediate and long-term effects.

Some of the questions that guided my ethnographic and social epidemiological investigation include: Which public health values and political and technological practices make this therapeutic policy possible, and what guarantees its sustainability? How has the AIDS policy become a kind of public good, emblematic of the state’s universal reach, even though it is not enjoyed by all citizens? What networks of care emerge around the distribution of lifesaving drugs? How do the poorest understand and negotiate medical services? How do their lifestyles and social support systems influence treatment adherence? What happens

to poverty as these individual sufferers engage the pharmaceutical control of AIDS? What do these struggles over drug access and survival say about the state of human rights, politics, and equity on the ground and globally? Which forms of health are sufficient to liberate life, wherever it is confined?

Universal Access to Lifesaving Therapies

Brazil is the epicenter of the HIV/AIDS epidemic in South America and accounts for 57 percent of all AIDS cases in Latin America and the Caribbean.⁴ AIDS was first reported in Brazil in 1980, and through mid-2002, the Ministry of Health had reported nearly 240,000 cumulative cases. HIV prevalence in Brazil is higher than in most of its neighbors, although this is in part due to more accurate reporting. At the end of 2001, an estimated 610,000 individuals were living with HIV/AIDS (an adult prevalence of 0.7 percent).

Social epidemiological studies show considerable heterogeneity in HIV infection rates, with large numbers infected among vulnerable populations and a fast-growing number of heterosexual transmissions. In 1998, 18 percent of sex workers tested in São Paulo were HIV-positive, and in certain areas of the country, intravenous drug users contribute to almost 50 percent of all AIDS cases. Since 1998, the death rate from AIDS has steadily declined, an achievement attributed to the country's AIDS policy (Okie 2006; Dourado et al. 2006).

In the Brazilian AIDS world, the vital actors with a passion for the possible were not just professional politicians. Throughout the 1990s, a range of different groups and institutions—activists and local nongovernmental organizations (NGOs), central and regional governments, and grassroots organizations, along with development agencies such as the World Bank—came together, helping to address what was earlier perceived to be a hopeless situation. This combination of social organization and education, political will (at various levels of government), and international cooperation made it possible for Brazil to overcome AIDS denial and to respond to an imminent crisis in a timely and efficient way.

Social mobilization forced the government to democratize its operations further. AIDS activists and progressive health professionals migrated into state institutions and actively participated in policy making.

They showed creativity in the design of prevention work and audacity in solving the problem of access to AIDS treatment. In their view, the prices pharmaceutical companies had set for ARVs and the protection they received from intellectual property rights laws and the World Trade Organization (WTO) had artificially put these therapies out of reach of the global poor. After framing the demand for free and universal access to ARVs as a human right, in accordance with the country's constitutional right to health, activists lobbied for specific legislation to make the drugs universally available.

The Brazilian government was able to reduce treatment costs by reverse-engineering drugs and promoting the production of generics in both public- and private-sector laboratories. Had an infrastructure for the production of generics not been in place, the story being told today would probably be different. For its part, the Health Ministry also negotiated substantial drug price reductions from pharmaceutical companies by threatening to issue compulsory licenses for patented drugs. Media campaigns publicized these actions, generating strong national and international support.

The result—a policy of biotechnology for the people—has dramatically improved the quality of life of the patients covered. According to the Health Ministry, both AIDS mortality and the use of AIDS-related hospital services have subsequently fallen by 70 percent (MS 2002). Known for its stark socioeconomic inequalities and its perpetual failure to develop to its full potential, Brazil has faced down AIDS, at last becoming “the country of the future” that idealist Stefan Zweig (1941) imagined in the 1940s.

The Brazilian treatment rollout has become an inspiration for international activism and a challenge for the governments of other poor countries devastated by the AIDS pandemic.⁵ This policy challenges the perception that treating AIDS in resource-poor settings is economically unfeasible, and it calls our attention to the ways in which biotechnology can be integrated into public policy even in the absence of an optimal health infrastructure.⁶ It likewise opens up the political and moral debate over delivering life-extending drugs to countries where patients are poor and institutions have limited capacity, as well as the debate over the immediate and long-term medical implications of doing so.⁷

By 2000, the Brazilian national AIDS program had been named by UNAIDS as the best in the developing world, and in 2003 it received

the \$1 million Gates Award for Global Health. Brazil is now sharing its know-how in a range of ways. It has taken on a leadership role at the WHO's AIDS program and it is supporting international networks aimed at facilitating treatment access and technological cooperation on HIV/AIDS. In the past years, the Brazilian government has also been leading developing nations in WTO deliberations over a flexible balance between patent rights and public health needs.

We are still far from achieving international justice in the realm of AIDS, but the Brazilian response has at least helped to expose the failures of reigning paradigms that promote public-private partnerships for the resolution of social problems. Brazil's national response has also shown the limits of international development agencies when confronted with the need to act directly on behalf of the poorest. Practically speaking, Brazil 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 structural inequalities that destine their populations to disease and ill health.

A Political Economy of Pharmaceuticals

Although a compacted and all-encompassing sovereignty is hard to locate in today's geopolitical order, states do not necessarily weaken amid economic globalization.⁸ But they do reform and reconfigure themselves, developing new strengths and novel articulations with populations. Brazil's response to AIDS "is a microcosm of a new state-society partnership," Fernando Henrique Cardoso, Brazil's former president (1995–2002) and the country's most prominent sociologist, stated in an interview with me in May 2003: "I always said that we needed to have a porous state so that society could have room for action in it, and that's what happened with AIDS."

Cardoso had no qualms about extrapolating, using the AIDS policy as evidence of the "success" of his state reform agenda—a state open to civil society, decentralized, fostering partnerships for the delivery of services, efficient, ethical, and, if activated, with a universal reach. "Government and social movement practically fused. Brazilian society now organizes itself and acts on its own behalf." From this perspective, the state appears through its model policies.

As with all things political and economic, the reality underlying the AIDS policy is convoluted, dynamic, and filled with gaps. The politicians involved in the making of the AIDS policy were consciously engaged in projects to reform the relationship between the state and society, as well as the scope of governance, as Brazil molded itself to a global market economy. One of this book's central arguments is that on the other side of the signifier *model policy* stands a new political economy of pharmaceuticals, with international and national particularities. As NGO activism converged with state policy making, and as the public health paradigm shifted from prevention to treatment access, political rights have moved toward biologically based rights.

Neoliberal governmentality has taken a new shape. Rather than actively seeking areas of need to address, the new market-oriented state selectively recognizes the claims of organized interest groups that “represent” civil society, leaving out broader public needs for life-sustaining assistance—in the domains of housing, economic security, and so forth. To be “seen” by the state, people have to join these groups and engage in lobbying and lawmaking.

Ethnography helps to uncover the circumstances and contradictions that are inherent to this novel form of therapeutic mobilization, already abstracted in Cardoso’s articulation of a “mobilized Brazilian society” and a “porous and activist state.” Ethnography complicates. It is a way of grounding and dissecting such abstractions, illuminating the contingency, multiple interests, and unevenness of the political game that is under way.

Given the increasingly global frames of disease control, the way a state deals with AIDS reveals its statecraft: in the Brazilian case, engagement with—and submission to—the forces of globalization. Just a few months before approving the AIDS treatment law in November 1996, the Brazilian government had given in to industry pressures to enshrine strong patent protections in law. Brazil was at the forefront of the developing countries that supported the creation of the WTO, and it had signed the Trade-Related Aspects of Intellectual Property Rights treaty (TRIPS). Parallel to the new patent legislation, pharmaceutical imports to Brazil have increased substantially. Currently, Brazil is the eleventh largest pharmaceutical market in the world.

As the AIDS policy unfolded, Brazil attracted new investments, leading to novel public-private cooperation over access to medical technologies. While Brazil experimented with new modes of regulating markets for lifesaving treatments, pharmaceutical companies took the conflicts over drug pricing and the relaxation of patent laws at the WTO as opportunities both to 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 at the same time successfully downplayed the WTO as they lobbied for strict bilateral and regional trade agreements that made local production of generic drugs unviable.

Global markets are incorporated via medical commodities. This process is mediated by development organizations and has crucial implications for the nature and scope of national and local public health interventions. Magic-bullet approaches (i.e., delivery of technology regardless of health care infrastructure) are increasingly the norm. The Brazilian AIDS policy was aligned with a pharmaceutically focused form of health delivery that was being put into practice as part of the government's vision of cost-effective social actions (involving the decentralization and rationalization of assistance amid the dismantling of public health institutions). In recent years, Brazil has seen an incremental change in the concept of public health, now understood less as prevention and clinical care and more as access to medicines—what I call the *pharmaceuticalization of public health*.

The medical accountability at stake in this innovative policy has drastic implications for Brazil's 50 million urban poor, either indigent or making their living through informal and marginal economies. Despite the allegedly universal reach of the AIDS policy, poor AIDS patients have not been explicitly targeted for specific governmental policies related to housing, employment, or economic security. The urban poor gain some public attention during political elections—even then only in the most general terms—and through the limited aid of international agencies. Through AIDS, however, new fields of exchange and possibility have emerged.

Medicines, as I argue throughout this book, have become key elements 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.” In May 2007, for example, Brazil broke the patent of an AIDS drug (Efavirenz, produced by Merck) for the first time—a step recently taken by Thailand—and authorized the import of a generic version from India. Activists worldwide hailed this sovereign decision as a landmark in struggles over the sustainability of countrywide treatment rollouts. Yet, while new pharmaceutical markets have opened, and ARVs have been made universally available (the state is *actually* present through the dispensation of medicines), it is up to individuals and communities to take on locally the roles of medical and political institutions.

This pharmaceuticalization of governance and citizenship, obviously efficacious in the treatment of AIDS, nonetheless crystallizes new in-

equalities.⁹ My ethnography illuminates how this medical intervention—funded and organized by the state alongside international institutions and produced by the pharmaceutical industry—has resulted in effective treatment for working-class and middle-class Brazilians, meanwhile leaving those in the marginalized underclass by the wayside. These individuals cope by using survival strategies that require extraordinary effort and self-transformation.

Persistent Inequalities

Just as the complex Brazilian response to AIDS must be understood within the wider context of the country's democratization and the restructuring of both state and market, so too must it be seen in light of its interaction with local worlds and the subsequent refiguring of personal lives and values.¹⁰

I was in the coastal city of Salvador (the capital of the northeastern state of Bahia) conducting fieldwork when ARVs began to be widely available in early 1997. For the previous two years I had been charting the local politics of AIDS and documenting life with AIDS among the homeless and the residents of Caasah, a grassroots health service.

Considered by many the "African heart of Brazil," Salvador has an estimated population of 2.5 million and is a center of international tourism. The capital of the country until 1763, it was the entry point for millions of slaves brought from West Africa. Bahia, the largest state in the northeast region of Brazil, has a population of some 12.5 million.¹¹ Forty-one percent of Bahia's families live below the country's poverty line, and the top income quintile holds 69.5 percent of the wealth in the state. With about 70 percent of the total AIDS cases of the state, Salvador lies at the center of Bahia's AIDS epidemic.

Local epidemiologists and public health officers in the late 1990s had claimed that AIDS incidence was on the decline in both the city and the region, ostensibly in line with the country's successful control policy. But the AIDS reality I saw in the streets of downtown Salvador contradicted this profile. A large number of AIDS sufferers remained epidemiologically and medically unaccounted for, thereafter dying in abandonment. Meanwhile, community-run initiatives triaged care for some of the poorest and sickest.

A central concern of my ethnography has been to produce alternative epidemiological evidence and to generate some form of visibility and accountability for the abandoned subjects with AIDS.¹² As anthropologist-

physician Paul Farmer has shown in the context of AIDS in Haiti and the United States, inequalities of power, ranging from poverty to racial and gender discrimination, determine who is at risk for HIV infection and who has access to what services (1992, 1999, 2003). By working closely with those who deliver care to the neediest and by attending to and documenting these patients' voices and experiences, one can identify and weigh the social factors promoting HIV transmission. One can also illuminate variations in the course of disease and in the value systems that lie within medical infrastructures. How, I wondered, would the ARV rollout fare in that context of multiple scarcities and ineffective regional politics? How would the most vulnerable transform a death sentence into a chronic disease? Which social experimentation could make such medical transformation possible?

Here, Hirschman's "right to a nonprojected future" begs for enactment and institutionalization. Caasah, a focal point of my research, was founded in 1992, when a group of homeless AIDS patients, former prostitutes, transvestites, and drug users squatted in an abandoned maternity ward in the outskirts of Salvador. "Caasah had no government," recalled Celeste Gomes, Caasah's director. "They did whatever they wanted in here. Everybody had sex with everybody, they were using drugs. There were fights with knives and broken bottles, and police officials were threatening to kick us out."

Soon, perhaps surprisingly, Caasah became an NGO and began to receive funding from a World Bank loan disbursed through the Brazilian government. By 1994, eviction threats had ceased and the service had gathered resources for basic maintenance. Caasah had formalized partnerships with municipal and provincial Health Divisions, buttressed by strategic exchanges with hospitals and AIDS NGOs.

Throughout the country, other "houses of support" (*casas de apoio*) like Caasah mediate the relationship between AIDS patients and the haphazard, limited public health care infrastructure. They address the paradox that medication is available, but public institutions are barely functioning. By 2000, at least one hundred of the country's five hundred registered AIDS NGOs were houses of support. However, in order to belong to these makeshift institutions of care, people must break with their old habits, communities, and routines as they forge new biographies.

By the mid-1990s, the unruly patients in Caasah had been evicted, and a smaller version of the group began to undergo an intense process

of resocialization mediated by psychologists and nurses. Eighty “out-patients” remained eligible for monthly food aid. Patients who wanted to stay in the institution had to change their antisocial behaviors and adhere to medical treatments. Caasah now had a reasonably well-equipped infirmary post, with a triage room and a pharmacy. Religious groups visited the place on a regular basis and many residents adopted religion as an alternative value system.

As Celeste put it, “With time, we domesticated them. They had no knowledge whatsoever, and we changed this doomed sense of ‘I will die.’ Today they feel normal, like us, they can do any activity, they just have to care not to develop the disease. We showed them the importance of using medication. Now they have this conscience, and they fight for their lives.”

Caasah’s residents and administrators constituted a viable public that effectively sustained itself in novel interactions with governmental institutions and local AIDS services. In this “AIDS-friendly environment,” people did not have to worry about the stigma that came with having AIDS “on the outside,” and there was scheduled routine and an infrastructure that made it easier to integrate drug regimens into the everyday. At least for some, this unvarnished public—as desperate as it was creative—came to shape not only adherence to the ARVs but another chance at life.



To document this particular public, to do justice to the singularity of its many lives, photographer Torben Eskerod joined me in the field in March 1997. With a simple chair and a black cloth against a wall, we improvised a photography studio outside Caasah’s main building. Torben photographed each person as he or she wished to be portrayed, and I recorded their stories, past and present.

When we returned in December 2001, things had changed dramatically. Caasah had been relocated to a new state-funded building (though it remained an NGO). With treatment regimens available, functional residents had been asked to move out, and Caasah had been redesigned as a short-term care facility for ill patients (a “house of passage,” *casa de passagem*) and a shelter for HIV-positive orphans. The hospice now had a team that worked directly with local hospitals and admitted the patients

that “fit into the institution and its norms,” in the words of Celeste. Disturbingly, there was no systematic effort to track these patients and their treatment actively once they left.

At the state hospital I learned of a triage system for AIDS patients, of which Caasah is part. “Homeless AIDS patients remain outside the system,” one of the hospital’s social workers told me. “Doctors say that they do not put these patients on ARVs for there is no guarantee that they will continue the treatment. They are concerned about the development of viral resistance to medication.” The hospital’s leading infectious disease specialist confirmed that “in theory, obviously, the doctor cannot withhold ARVs from drug users and homeless patients . . . but the fact is that the homeless patient does not return for routine ambulatory checkups. So what I do is tell the patient that he has to come back. If he returns and demonstrates a strong will, we begin treatment. . . . But they never, or rarely, come back.”

We looked for our former collaborators and tracked down those who had left Caasah. Some had died; others had survived, married, and had children. As Torben took their portraits once again, they told us about all sorts of financial pressures, battles over discrimination, and the difficulty of obtaining access to quality health care. They told us about their *will to live*.

The patients photographed by Torben intimately engage us, their faces and words relating personal travails and the larger issues surrounding AIDS treatment and social inequality. Their very presence, brought so close to us through Torben’s lens, establishes an alternative register of engagement and meaning that animates this book: How do these subjects both reflect one another and differ among themselves? What makes them visible or invisible in their neighborhoods? What is their place in a nation’s order and in new medical regimes? How do we relate large-scale institutions and forces to local politics and personal trajectories? What is the staying power of these subjects’ interior force of life? What might their stories, standing alone and taken collectively, suggest through their concatenation? Each dimension merits a closer look.

In this ethnographic work, double takes were both literal and figurative. Our 1997 work redoubled when we returned to Caasah four-and-a-half years later, providing us with a distinctive longitudinal perspective. And comparing these different moments in time—then and now—in turn

opened a critical space for examining *what happens in the meantime*. Our methodology thus operated in dialogic, open-ended, and reflexive fashion: moving back and forth, across time and space, to offer a distinctive understanding of private and public becoming in the face of death and AIDS therapies.