

THE POLITICS OF PUBLIC HEALTH EMERGENCIES: AIDS EPIDEMICS IN
INDIA AND SOUTH AFRICA

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This dissertation examines the policies related to the AIDS epidemics in India and South Africa, with a special focus on the politics of knowledge. Drawing on research in social studies of science, the study asks how national governments conceptualized AIDS-related policies, and how these policies were shaped by international technical institutions and non-governmental organizations. The study revealed that international technical institutions such as the World Bank and the World Health Organization often provided prior templates for how governments should manage AIDS epidemics. These templates included established technologies for epidemiological modeling, set categories for conceptualizing risk, and generic models for public health interventions. On a different register, non-governmental organizations used a rights-based discourse to establish novel conceptions of expertise and citizenship. The research showed that the South African and Indian governments responded differently to international expertise and activism. India availed of many frameworks and funds brought in by international experts. This embrace of global knowledge sat alongside a silencing of local experiences and history, as the vast lessons from India's own public health past were neglected in designing national AIDS policies. South Africa, in contrast, was skeptical of international expertise; it portrayed the global epidemic management machinery as a vehicle for expressing and legitimating old racial stereotypes. To justify its controversial policies and skepticism of mainstream AIDS-related science,

the South African government pointed to a history of racism in medicine. This dissertation's comparative analysis of AIDS-related policymaking in two crucial democratic countries illuminates the broader shifts taking place in the conceptualization of public health in the global south. Public health policy, which used to be primarily in the domain of the national government, is increasingly in the purview of international technical organizations and non-governmental groups. No more is public health solely associated with large-scale prevention and primary health care for the larger collective. Instead, the emerging conceptions of public health focus on individual-oriented, rights-based, access to treatment. These changing conceptions of public health reflect new logics of democratic politics and globalization.

BIOGRAPHICAL SKETCH

Manjari Mahajan has a B.A. in Government from Harvard University, and a M.Sc. in Science Policy from the Science Policy Research Institution (SPRU) at Sussex University.

For my parents

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Chapter 1. Introduction

The Question

This dissertation addresses the politics related to the AIDS epidemics in India and South Africa. In particular, I ask the question: how are public health policies related to AIDS conceptualized by national governments in two crucial democratic nations? In both South Africa and India, the epidemic has led to dramatic policy resolutions, new social movements, radical legal decisions, and novel conceptions of citizenship. The emergence of these political configurations at the national level has been thoroughly enmeshed with the workings of international institutions, funding, expertise and technologies. AIDS has mirrored countries' social history, political institutions, and deepest moral commitments, while at the same time embodying how these national aspects are intertwined with or resistant to particular forms of globalization. As such, the AIDS crisis and attendant politics of knowledge provide a good window into the relationship between democratic politics, scientific expertise, and international technical institutions.

The examination of AIDS policies and policymaking illuminates how the concept of public health writ large is being reconstituted in the historically marked contexts of countries in the south. Public health traditionally has been that domain of government policy that has sought to enhance the physical wellbeing and capabilities of a people at large. Its typical mandate has included issues such as vaccinations, access to clean water, and primary health services. In its concern with the health of a population as a whole, it has been a surrogate for the common good. This dissertation uses AIDS policymaking to examine how this traditional conceptualization of public health is being transformed as nation-states, their civil societies, and scientific expertise are

increasingly tethered to transnational institutions and norms, and are marked by new types of democratic politics. In other words, public health, and AIDS policies in particular, are used as a lens through which to examine the changing nature of the democratic state and its relationship to its citizenry, and emerging logics of globalization.

Knowing Epidemics

The dissertation tracks how different sets of actors offered often conflicting ways of comprehending and addressing the AIDS epidemic. Different actors proposed different epidemiological models, varying categories of risk, conflicting conceptions of expertise, and contrasting approaches to prevention and treatment. The dissertation, in its analysis, focuses on this business of “knowing epidemics.” This business of knowing epidemics – articulated through definitions of experts, choice of epidemiological models, construction of risk categories, and choices of interventions - shaped the knowledge about AIDS that in turn became foundational for policymaking.

In the following paragraphs, I will briefly describe the three main sets of actors involved in this business of knowing epidemics, and in AIDS policymaking. These actors included the state, a global socio-technical machinery constituted by international agencies, and non-governmental organizations (NGOs).

A Global Socio-technical Machinery

AIDS has clearly been a global phenomenon. The disease had already spread to at least three continents by the time of its first discovery. Since then, it has affected millions of people in dozens of countries, rich and poor, in the south and north. However, AIDS has not only been a global phenomenon, but also in important and

distinct ways has manifested, and enabled, particular forms of globalization.

Globalization has become one of the most frequently used, and widely contested, terms both in the popular media and in academic debates. The term is often used as a short hand to denote processes that connect different parts of the world with unprecedented speed and on an ever increasing scale. Anthony Giddens summarized globalization as “an intensification of worldwide social relations which link distant localities in such a way that local happenings are shaped by events occurring many miles away and vice versa” (1990, p.64). Some studies of globalization have emphasized new forms of “universality” that have increasing purchase in far flung parts of the world, with little respect for traditional national boundaries or geographical divides (Featherstone, 1990; Sassen, 1991, 1998; Sklair, 1993). However, many other theorists of globalization have challenged this picture of increasing cultural or institutional homogeneity. They have emphasized the unevenness of the process, and the diversity in the different manifestations of globalization (Scott, 1997; Appadurai, 1996; Abu Lughod, 1991). I have offered only the most rudimentary sketch of what are complicated and voluminous debates in the social sciences. For the purposes of this dissertation, I emphasize globalization as an uneven and sometimes counterintuitive process that does not seamlessly produce homogeneity.¹ I ask how the processes of globalization manifest themselves at the level of knowledge practices? I ask how international institutions, experts, and activists have traveled around the world in response to the epidemic, and reordered relationships of power and inequality.

¹ In his work on the defense industry, John Lovering (2001) has suggested that the term “globalization” should be replaced with “Americanization.” In this work, I do not use the term Americanization despite the fact that the United States, in various forms, is the dominant purveyor of expertise and funds. Nonetheless, Americanization does not capture the role and interactions of other nations and a range of non-national actors that mutually constitute processes of what I refer to as globalization.

A testament to how AIDS has enabled globalization lies in the number of international institutions that have been created in response to the epidemic. For instance, the United Nations (UN) has had a series of sub-organizations and programs devoted to AIDS. Most prominently, it instituted a Joint United Nations Program on HIV/AIDS, commonly called UNAIDS, in 1996. UNAIDS is co-sponsored by ten different UN agencies. There is no comparable organization within the UN that is devoted to any one disease or health issue. Similarly, the multilateral Global Fund to Fight AIDS, Tuberculosis and Malaria was established in 2002. While the Global Fund formally focuses on AIDS, malaria and tuberculosis, it was in large part primarily created to address the AIDS epidemic, and a majority of its funding is pledged to combat AIDS (Merson, 2006). In the United States, the President's Emergency Plan For AIDS Relief, commonly called PEPFAR, serves as another example of an institution created to focus on AIDS in an international context. PEPFAR was initiated by George W. Bush in 2003. The World Bank has been highly proactive in AIDS-related lending since 2000, as have various government aid agencies of countries such as the United Kingdom and the United States. Finally, philanthropic organizations such as the Clinton Foundation and the Gates Foundation have been increasingly prominent and powerful in international AIDS-related work.

The combination of international technical agencies such as UNAIDS, multilateral donors such as the World Bank and the Global Fund, aid agencies of governments of the north, and philanthropic organizations such as the Gates Foundation constitute what I call a "global socio-technical machinery" for AIDS management. I use global socio-technical machinery as a term to refer to the complex assemblage of social and technical actors, practices, abstractions, and artifacts that address AIDS. The use of

this term is similar to what Deborah Johnson and Jameson Wetmore have referred to as “sociotechnical systems” in the context of engineering projects (Johnson and Wetmore, 2008). The use of a concept such as global socio-technical machinery, like that of a sociotechnical system, helps highlight the ways in which organizations, the technologies that they purvey, and the political and normative commitments of the actors are all entangled with each other. The notion of a socio-technical machinery highlights that technologies and technical practices, such as of epidemiological modeling, are animated and constituted by social and political relationships. Technical and scientific practices and artifacts are not insular, stand-alone, factors but involve “arrangements of people, what people do, and the way they interact with one another” (Johnson and Wetmore, 2008, p. 575). By using the word machinery, however, I do not mean to imply a single, integrated, well-coordinated machine. Rather, I want to use the word machinery to indicate a complicated contraption, with many actors and parts, not all of which are coordinated and in touch with each other. The machinery may occasionally even work at cross-purposes with itself.

I refer to the socio-technical machinery as a global apparatus because while many of its actors are international, the goal or the underlying “imaginary” of this machinery is decidedly global. The actors in this machinery frame AIDS as a boundary-less, interconnected problem that spans the entire world. Correspondingly, the knowledge to manage the epidemic is typically not constrained by national boundaries. The knowledge that animates this global machinery has a universal coherence; what was relevant in India was also applicable to South Africa.

A prominent characteristic of much of this global machinery is its focus on treatment programs rather than prevention programs. The emphasis on treatment became

especially prominent after 2001 when the Declaration of Commitment on HIV/AIDS was signed by almost 200 countries. Thus the Global Fund hoped to provide antiretroviral therapy for over a million people over five years (Global Fund, 2008); the WHO had a much touted “3 by 5” program which aimed to provide 3 million HIV positive people with treatment by 2005 (WHO, 2008); PEPFAR was focused on treatment in sub-Saharan Africa and hoped to reach 2 million people by 2008 (PEPFAR, 2008); and the World Bank increasingly provided assistance for treatment programs (World Bank, 2008).

The AIDS epidemic has been accompanied by a strident discourse of emergency. Consequently, this global machinery has obtained and dispersed billions of dollars in development aid over the last decade. The international actors in this global machinery typically obtain their funding and expertise from the north, but have their mandates and projects in countries in the south. It is not tied to any one part of the world, but typically travels to different countries carrying its package of expertise, technologies, and funds. The machinery manifests itself through direct contact between international and national experts, through extensive documentation – much of which is on the Internet, and through ideas circulating through international conferences and networks. There is contact with local organizations and experts; however, the local knowledge fills in the framework that is provided by the global machinery. The local seldom provides the framework. The global machinery does not manifest itself homogeneously all through the south; there have been different projects, programs, and emphases at different times in different target countries. However, when it touches down in a particular country, it has clearly recognizable features. These features include uniform technologies of counting often represented in epidemiological models that measure the number of HIV-positive people in a country;

previously established risk categories; prior ideas of what count as successful public health interventions. These features of the global machinery constitute what I refer to as a “foreknowledge” about the AIDS epidemic. This foreknowledge has a prior template of what an AIDS epidemic is supposed to look like.

A central concern of this dissertation is to examine how this machinery, through its categories, models, monies, discourses, and technologies, has *globalized* the AIDS epidemic. How has this machinery of AIDS management “touched down” in South Africa and India? How has it affected the way epidemics are understood and addressed? How has it influenced AIDS-related policies and the conceptualization of public health more broadly?

States

Public health policy has traditionally been in the purview of national governments. This dissertation examines how governments adopt different paradigms of public health, which in turn lead to very different policies. Two public health paradigms that I place in a schematic binary include a “biomedical” paradigm and a “structural socio-economic” paradigm². Each paradigm has varying definitions of disease causation, prevention and treatment. The biomedical model emphasizes discrete biological causal mechanisms whereas the structural model emphasized the social and economic forces that lead to disease. The different focus on what causes disease corresponds to different conceptions of expertise. Thus, the biomedical paradigm emphasizes the expertise of doctors and scientists, while the structural paradigm encompasses a

² I refer to this binary as being between biomedical and structural models. However, the positions denoted by these models – one reductionist and focused on pathogen-mechanisms, while the other holistic and more inclusive in its conception of disease – have asserted themselves at different times by different actors under different names. The historian of medicine Charles Rosenberg discusses the trajectory of some of these models (1992) as does the historian of public health Simon Szreter (2005).

broader range of relevant expertise to address the social and economic factors. Similarly, each paradigm demands a rather distinct response of national health systems.

I am of course drawing overly stark contrasts between the two models, but mainly to emphasize the distinct orientations within each. By comparing two different public health paradigms and their attendant conceptions of expertise, interventions, and accountability, the dissertation aims to analyze the social choices and historical legacies that are embedded in apparently neutral technical systems. It attempts to query how the choice of paradigms profoundly influence the types of debates and decision-making that follow. Moreover, the dissertation enquires how the choice of public health models reflect states' redefining their roles in the context of more strident politics of civil societies and increasing influence of international organizations.

Non-Governmental Organizations

The landscape of the AIDS epidemic is marked by the prominence of a large number of non-governmental organizations (NGOs). In many ways, the proliferation of AIDS-related NGOs accompanies the general efflorescence of patient and health advocacy groups (Rabeharisoa, 2003; Rapp et al., 2001). A number of commentators have suggested that the growing numbers and the increasing political visibility of such groups in countries in the north reflect the more skeptical attitudes towards traditional forms of authority in doctors, scientists and other experts (Brown and Zavestoski, 2004; Epstein, 1996). Other scholars have pointed to how these civil society groups fill voids left by state organizations (Petryna, 2002; Rose and Novas, 2005). In the dissertation, I argue that these above reasons only partially explain the prominence of

NGOs in India and South Africa. The proliferation of NGOs is also due to the funding and pervasive influence of international organizations, and more generally, the international expansion of rights-based social movements.³

The NGOs working on AIDS in South Africa and India have a highly varied taxonomy. Some of the groups work very closely with disenfranchised communities such as of prostitutes and intravenous drug users, and have local sources of funding and expertise. Other groups are more cosmopolitan and internationally mobile. They attend international conferences, receive funds from international organizations, and are party to a global discourse about AIDS and activism. In general, India is marked by a diverse proliferation of NGOs that have benefited from the massive international relief funds that have recently entered the country. South Africa, in contrast to India's noisy and varied panoply, has a more cohesive social movement which is dominated by an activist group called the Treatment Action Campaign.

The NGOs in both countries are similar in their embrace of a rights-based discourse. While Indian groups have emphasized rights against various types of discrimination, the Treatment Action Campaign and its allies in South Africa have been marked by their activism for positive economic rights, such as to antiretroviral treatment.

Through their rights-based activism and relief work, NGOs in both countries have been extremely powerful in shaping policy by generating a common discourse about AIDS that is increasingly recognizable across countries. In their activism and lobbying for various rights, NGOs have performed "boundary work" in establishing lines between seemingly distinct realms of "science" and "politics" (Gieryn, 1983). In

³ On the proliferation of rights-based social movements and the "new" social movements which emphasize embodied experiences of disease, see Epstein (1995, 1996), Silverman (2004), and Layne (2003).

adopting a boundary work approach, the dissertation examines the processes through which NGOs contextually and flexibly render “science” and “politics” as preordained, separate categories, and then use these categories to bolster their advocacy.

Part of NGOs’ boundary work involved defining legitimate expertise; they constantly negotiate over who counts as credible and relevant scientific experts. Thus, the study of NGOs in AIDS policymaking becomes a means to reconsider problems of expertise, and locate the new loci of scientific knowledge making. The dissertation examines how NGOs’ allocations of credibility promoted, and simultaneously produced, distinct ideas of medical expertise, along with conceptions of sexuality and morality.⁴ Finally, the dissertation investigates how NGOs affected the relationship between the state, international organizations and scientific institutions, and in the process became pivotal to the production of authoritative public knowledge about the AIDS epidemic.⁵

Research Design

Two Prongs

In examining the politics of public health and policymaking related to AIDS, the dissertation focuses on the relationships between the state, NGOs and the global socio-technical machinery. Specifically, it examines:

- First, the relationship between the national government and the global machinery of managing AIDS which includes powerful international technical organizations such as the World Bank, UNAIDS, and the Global Fund. I ask

⁴ For science studies work on how non-governmental organizations change biomedical knowledge, see Clarke (1998, 2000), Hardon (2006), and Epstein (1996).

⁵ See Nathanson (1999), Saguy and Riley (2005) and Epstein (2007) on how NGOs in the United States and the United Kingdom have influenced state policy.

what frameworks, units of analyses, and technical practices this global machinery brings to the national setting. How do the interactions between national and the international programs, policies and organizations shape conceptualizations of risk, expertise and intervention? How do these interactions determine the “knowing of the epidemic”?

- Second, the relationship between the national government and local NGOs which are increasingly central to producing knowledge and expertise about the epidemic -- and about sexuality, culture and morality. I ask how these NGOs intervene in policy debates and processes. How do NGOs mold the public knowledge about the epidemic? How do they create new priorities and new forms of accountability in public health?

The Comparison

The research project undertakes a comparative study of AIDS policies in two democratic nation-states. India and South Africa make for good comparisons because both countries are large, pluralistic, postcolonial democracies with vibrant civil societies. Both South Africa and India are categorized as “economically developing” nations and have typical associated problems of poverty, illiteracy and malnutrition. However, both countries complicate what it means to be a developing nation for their poverty and deprivation is juxtaposed against a sophisticated scientific and medical infrastructure. Both countries have longstanding universities and research institutions. Each has a large, trained workforce of scientists and engineers. Both have made large investments in science-based industry such as information technology, biotechnology, nuclear energy and telecommunications.⁶ These complicated manifestations of “development” are central to the project as in the variegated multiplicity of

⁶ Since 1998, South Africa has abandoned its nuclear program.

development as seen in India and South Africa lie new ways of conceiving of the relationship between science, global norms, and postcolonial politics.⁷

Both nations have had the dubious distinction of having among the largest AIDS epidemics in the world. UNAIDS estimated that South Africa had between 4.5 to 6.2 million HIV positive people in 2007 (UNAIDS, 2007). At the time of commencing dissertation fieldwork in 2005, the estimated number of HIV positive people in India was close 5.5 million. However, over the course of the dissertation research, the prevalence estimate in India dropped from 5.5 million in 2005 to 2.2 to 2.5 million in 2008. I interrogate the politics of counting that underlies the slashing of prevalence numbers by more than half in India.

Not only are the AIDS epidemics in both countries very large, they have also been distinct from what was seen in the west. In both South Africa and India, experts understand the epidemic to have spread mainly through heterosexual contact. Its victims include almost as many women as men. While homosexual men are an affected group, they are by no means the largest or most vulnerable “risk population.”

The comparable absolute size of the epidemics in India and South Africa can occlude what are significant differences (see Table 1). Most prominently, epidemiologists understand AIDS to be a generalized epidemic in South Africa, with a high prevalence in very large sections of the population. In mid-2007, the South African Department of Health estimated approximately over 18 percent prevalence in people between the

⁷ By postcolonial politics, I refer to politics in countries which were once colonies. But I use this term not only in a temporal or chronological sense, that is, I use it not only to denote politics produced in India and South Africa after “Independence Day.” Rather, I use the term to denote politics that engages with and challenges the structures, hierarchies and discourses of colonialism. For other work on science and postcolonial politics, see Anderson (2002), Prakash (1999), and Rajan (2001).

ages of 15-49 years. These prevalence rates are not too different from the latest UNAIDS figures for the country, which indicate about 11 percent prevalence in the general population and 18 percent in the sexually most active population. In India, epidemiologists understand the epidemic to be mainly concentrated in relatively discrete “high-risk” populations such as prostitutes, intravenous drug users, and men who have sex with men. HIV prevalence in the general population is estimated to be at 0.36 percent. These rates vary significantly between different states, with six states labeled as the high-prevalence states in the country. Despite these highly varying prevalence rates within the general population, the two countries’ epidemics have often been juxtaposed. In the new millenium, international agencies and the media often warned that India was headed on an “African trajectory,” the next disaster waiting to happen.⁸

Table 1. Comparing India and South Africa

	South Africa	India
Population (millions)	48.3	1001
Gross national per capita income (US\$)	11,710	3,800
Life expectancy at birth (years)	51	63
Per capita government expenditure on health (US\$)	811	100
Health expenditure as % of GDP	9%	5%
Number of HIV persons (millions)	5.5	2.5
HIV prevalence (%)	11%	0.36%

Source: World Health Organization, 2008

The two countries’ governments have dealt with their epidemics in distinct ways, and promoted very different models of public health and AIDS policy. South Africa bucked much international advice and mainstream scientific consensus. It forwarded what have been widely considered heretical understandings of the disease. The South

⁸ For instance, Richard Feachem, the first executive director of the Global Fund, frequently pronounced how the Indian epidemic was on an African trajectory. See for instance Boseley (2003).

African government and its policies have been widely criticized for their lack of urgency and attention to AIDS.

In contrast, India's recent policymaking has been hailed by international organizations such as the World Bank as exemplary for other countries in the south. The government has been routinely criticized for poor policy implementation and for channeling insufficient resources to the epidemic. Nonetheless, at the level of policymaking, the World Bank, UNAIDS and the World Health Organization have praised the government's inclusive conception of stakeholders, its receptivity to international technical expertise, and its openness to learn from other countries' experiences. The differences between India and South Africa's AIDS policies and policymaking allow for productive comparisons of how and why democratic regimes adopt very different paradigms for public health.

Although the dissertation is organized around a comparison, the comparative perspective does not aim to evaluate which nation and policymaking apparatus performs *better* in addressing a devastating epidemic. Indeed, one of the underlying themes of this project is that it is rather difficult to prescribe easy lessons from others' experiences. My research reveals that policies and public knowledge are animated by deeply historical legacies and nationalist aspirations that cannot be easily supplanted and deemed immediately relevant in other places. The imperative to compare, therefore, is not one of providing better managerial techniques, or what Sheila Jasanoff has referred to as "prescribing decontextualized best practices for an imagined global administrative elite" (Jasanoff, 2005, p 15). Instead, the motivation for comparison is to understand better the relationship between science and politics in the south.

Methodology

Methods

This dissertation deployed qualitative research methods. It is based on thirteen months' fieldwork; I spent eight months in South Africa followed by five months in India. I conducted interviews with a range of different actors including state officials, doctors, scientists, officials at international health and donor agencies, NGO workers, and AIDS activists. I conducted forty interviews in South Africa, and twenty seven in India. The interviews were semi-structured, and were occasionally tape recorded. Very often, interviews conducted with government officials in India were not recorded. In these cases, I took notes by hand. Interviewees in South Africa were in general more open to having their interviews taped.

The interviews were supplemented with examination of legal judgments, policy documents, and public health data. I perused national-level health and specifically AIDS policies since 1985 of both countries. In these policies and associated documents and white papers, I probed how governments were articulating institutional architectures and priorities within public health. I was also interested in how historical precedents featured in, or were erased from, formal and informal policy discussions about AIDS management. In addition to national policy documents, I examined country reports prepared by international organizations such as the World Bank and UNAIDS. I tried to access and collect MOUs (memorandums of understanding) between national governments and international organizations. Finally, I followed and observed meetings of two national-level public health committees, one in India and one in South Africa. It was in such policymaking sites that I could often observe the relationship between officials of the state, non-governmental organizations, and international technical agencies.

The AIDS Epidemic As A Site for Investigation

The AIDS epidemic provides a methodologically compelling site for addressing questions about the relationship between states and science. Because it is a relatively new disease, much about AIDS's epidemiology, etiology and sociology is incompletely understood and routinely contested. This allows for an analysis of "knowledge in the making." In other words, the epidemic allows for an analysis of how new knowledge and new technologies gain authority in a public domain in concert with particular forms of democratic politics.

The AIDS emergency is additionally interesting for another methodological reason. Studying emergencies and humanitarian crises like AIDS is obviously important in itself. However, emergencies also provide a highly productive site from a methodological perspective. It is in emergencies that norms are changed. Old rights get suspended, and new legal arrangements are instituted. Conventional contracts, such as of intellectual property monopolies, are challenged, and drugs are sold at cheaper prices. Regulatory mechanisms, such as clinical trials for approving new drugs, are modified to accelerate access to promising ameliorative technologies. These stark shifts away from the norm render the norm more visible. In other words, emergencies make explicit the rationales that underwrite extant policy regimes, epistemic systems, and ethical frameworks. The AIDS crisis lays bare patterns of institutional and political practice and how they shift under varying pressures.⁹

⁹ Scholars in science studies and sociology have often used "trouble," "controversy" and "disruption" to render visible taken-for-granted norms. For instance, see Garfinkel (1967), Pinch (1992), Collins (1987), and Rajan (2002).

Theoretical Themes

Social Movements and Non-Governmental Organizations

AIDS NGOs, through their activism, have helped mold public conceptions of the disease; they have been instrumental in determining what new scientific knowledge is entitled to societal endorsement and economic valuation; through their political mobilization around issues of privacy and treatment, these groups have irrevocably steered policies in new directions. Much work within science studies and sociology has tracked the development of civil society groups in health activism and advocacy in many western countries (Rapp et al., 2001; Rabeharisoa, 2003; Epstein, 2007; Allsop et al., 2004). This dissertation fills a research gap by analyzing the role of health-related NGOs in countries in the south¹⁰.

In tracing relationships between local NGOs and international organizations, the dissertation examines how NGOs in the south are influenced by international expertise and funding, leading to new forms of transnational alliances and convergences¹¹. Even as these NGOs exemplify “grass roots” movements, with their democratic, non-expert participation in policymaking, so too do they affirm globalized norms and expert-driven biomedical policy models. Thus, this project also interrogates one prevailing precept in democratic theory and science studies which presumes that civil society participation typically facilitates a pluralistic, local agenda in policymaking.¹²

Scholars have examined new conceptions of patients’ rights and the general expansion of rights-based movements in health activism (Brown & Zavestoski, 2004; Layne,

¹⁰ A few scholars have written on health-related NGOs in the south. For instance, see Misra (2006) and Robins (2005).

¹¹ For work on how health advocates in the south connect to their counterparts in the north, see Whyte et al (2002), Bell (2003), and Barbot (2006).

¹² See for instance, Leach et al. (2005), Petryna (2002), and Keck and Sikkink (1998).

2003; Silverman, 2004; Epstein, 1995; Petryna, 2005; Robins, 2005). This project examines the relationship between NGOs' rights-based discourse, and understandings of public health and science that accompany it. In other words, it examines the knowledge claims that underlie and are sometimes necessary for demanding various types of rights.

Finally, the dissertation examines how NGOs, in their involvement in scientific issues, are creating a central role for institutions of law. It explores how NGO activism leads to the realm of law becoming a credible site for technical knowledge-production.

Science and Postcolonial States: Questions of Expertise and History

The relationship between science and the nation-state is a central theoretical concern of the dissertation. Science studies scholars have typically characterized the relationship between science and the state, two foundational modern institutions, as being co-equal and cooperative. They have argued that states use science as an important resource for legitimating statecraft, while institutions of science have often leaned on political institutions and procedures for funding and credibility.¹³

It is not always possible to study the terms and limitations of this relationship because what one sees is a manifest cooperation between states and international and national scientific institutions. The case studies in this dissertation, however, allow for a closer analysis. The dissertation interrogates this seemingly smooth façade of the relationship between democratic politics and scientific expertise, showing that it is neither straightforward nor predictable. In South Africa, there is a breakdown of cooperation

¹³ The thesis of science and the state's cooperation can be found as far back as in Thomas Hobbes Leviathan (1651). More contemporary examples of such arguments in Science Studies literature are made by Yaron Ezrahi (1990), David Guston (1999), Shapin and Schaffer (1985), and Jasanoff (2002).

between the national government on the one hand, and the domestic and international scientific mainstream on the other. This disruption throws the relationship between science and the state into stark relief, rendering visible the terms of cooperation between two foundational institutions of modernity.

This co-dependence between science and the state is often highly visible in economically developing nation-states; faced with poverty and a history of colonial suppression, these states tend to be committed to the project of development, scientific emancipation and technological prowess. However, these case studies reveal that postcolonial states do not always embrace progressive visions of science. They equally often attribute uncertainties, ambiguities and historical biases to science and/or the versions of science and medicine promoted by international organizations. They seldom completely reject science and medicine purveyed by international organizations; but they do often promote what they bill as alternate conceptions of science. In comparing India and South Africa's AIDS policies, the dissertation attempts to analyze the different ways in which postcolonial states have constructed the meanings and significance of science and scientific expertise.

The case studies also bring to the fore changing norms of the relationship between states and science in light of the increased dominance of international modes of funding to science as opposed to more traditional forms of state patronage and sponsorship. International networks and organizations are instrumental in providing credibility to scientists in postcolonial nations. In both India and South Africa, international funding and networks have led to new, innovative renderings of who is allowed to represent and question science, and who is allowed to represent the public and public interest. The locus of "public interest" shifts with who claims to represent

it. International organizations call upon a correspondingly international “public,” while national governments call upon a different sets of boundaries. The dissertation aims to examine how the jockeying among representatives results in the drawing and redrawing of lines between science and democratic politics.

Finally, the dissertation seeks to extend science studies scholarship by examining how the relationship of science and the state is affected by postcolonial politics. Both India and South Africa have colonial legacies that vividly frame their national identities and politics. In both countries, governments have used historical narratives to resist or abet the globalized discourse of international technical organizations. In these narratives, the AIDS epidemic and the epistemic and policy contestations surrounding it underwrite new imaginings of postcolonial nationhood. At the same time that the AIDS epidemic struck South Africa, the country was commencing a massive transition from apartheid into a liberal and democratic polity, and constructing a new political identity for itself. I suggest that the AIDS controversy and the process of post-apartheid identity-construction are inextricably intertwined. Esoteric debates about HIV are closely linked with the government’s attempts to carve a space for itself in the international arena, make more room for local contexts, and forge historical connections with a larger Africa; connections that had been denied during the apartheid era. In a similar vein, India’s policies are intimately related to its emerging geopolitical status and desire to play on a global stage. Questions of history and imaginations of postcolonial nationhood may appear distant from matters of institutional design, public policy choices, and everyday political struggles concerning the terrain of AIDS. Yet my research suggests that the opposite is in fact the case, and I shall argue that public health policy and conceptualization of epidemics articulate and reflect abstract nationalist desires and historical legacies. Accordingly, this project

seeks to extend scholarship on the relationship of science, democratic politics and postcolonial states by examining how the enduring effects of colonial legacies and processes of national identity-construction shape health policies.¹⁴

International Governance

This dissertation examines the role of international governance in constructing scientific knowledge. The case studies at hand are obviously state-centered. However, purely state-centered analyses are inadequate for studying global phenomena like the AIDS epidemic especially as international institutions and exchanges increasingly influence, overwhelm and occasionally contradict national understandings and production of knowledge. This dissertation examines how the production of scientific knowledge and public policies are shaped by a global machinery of epidemic management. As such, the project extends literature on international institutions as principals of change rather than as merely passive and reactive agencies in a terrain dominated by nation-states.¹⁵

The dissertation also contributes to a body of literature that examines how new regimes of international governance are shifting concepts of national sovereignty (Mbembe, 2000; Comaroff and Comaroff, 2006). It examines the political and epistemic consequences in the shifts in traditional functions of the state, such as public health delivery and science and health policymaking. It enquires into the emerging modes of “government-by-franchise” and the attendant norms of accountability in public health (Petryna, 2007).

¹⁴ For work on science and postcolonial politics, see for instance, Moon (2007), Jasanoff (2002), Viswanathan (1997), Biehl (2007), and Suder Rajan (2006).

¹⁵ See for instance Finnemore (1993).

Social Studies of Disease

Scholars of social studies of disease have struggled with a complicated dilemma. On the one hand, there is a vast scholarship that has used the register of “social construction” of disease and illness. In general, these scholarly works have emphasized how disease definitions and diagnoses have been vulnerable to cultural and historical contexts and contingencies. They have tended to emphasize that disease does not “exist” until it is acknowledged, labeled, and categorized. They have argued that once named and categorized, diagnostic procedures, therapeutic technologies, and health care systems are built around the disease, reifying and reaffirming its existence. However, even within the register of social construction of disease, there has been much confusion and contestation about what the term “social construction” refers to and what exactly is being constructed (Hacking, 2000). Different authors have used the term of “socially construction of disease” with a variety of meanings in mind; some of have suggested that a nosological category is constructed (Hacking, 2000), while others have implied that disease is often “a fiction” with social consequences (Fishman, 2004). Yet others have argued that it is the social legitimacy of disease that is constructed, and not its essential biological reality (Aronowitz, 1998). Many, though by no means most, of these works have focused on psychiatric conditions such as hysteria, depression, and schizophrenia where discrete pathological mechanisms have not been proven.

Many critics have found the register of “social construction of disease” to be highly problematic. Some have objected that narratives of social construction do not adequately acknowledge the “reality” of diseases. To them, narratives of social construction imply that disease definitions are determined somewhat arbitrarily, that biological features can be easily modified with changing contexts. Social construction,

to them, denotes irony and a lack of respect about diseases that are experienced by many patients as painful and debilitating. Other critics have objected to having their conditions and behavior “medicalized” through a narrative of disease and disease-construction.

This dissertation does not engage with the debate about the “social construction” of disease. It does not question AIDS’s “reality.” Rather the dissertation examines the processes and policies that various actors use to understand and address the AIDS epidemic. In examining public health policies, I adopt a constructivist approach. That is, I analyze how different technologies, historical memories, and institutional arrangements contribute to the making of distinct public health models. Once established, these public health models, through their conceptions of risk and pathology, change the identity of patients and other citizens. Moreover, they facilitate transformations of social norms and moral sensibilities, as well as material changes in health care. These various transformations in individual subjective identities, social institutions, and moral norms “loop back” and change the knowledge about AIDS (Hacking, 1986, 1988). In other words, the policies about AIDS feed back into how the epidemic is understood, which in turn mold new policies related to the disease. Thus, the policies to address the disease are inextricably intertwined and coproduced with the knowledge about the disease.

Public Health

The dissertation aims to bring the insights and analytical tools of science studies to debates on public health, health policy and epidemiology. It inquires into how the choice and constitution of frameworks, models and categories shape the ways in which disease and health are understood and experienced. As such, this project contributes to

a growing body of research on “critical epistemology” of emerging infectious diseases and public health (Farmer, 1998, p. 40).¹⁶

More broadly, while the dissertation is about AIDS and public health at one level, at another level, it uses AIDS and public health as a sampling device for analyzing broader political shifts. The epidemic becomes a lens through which to examine the shifting logics of how local and national bodies interact with international organizations; and of changing modes of governance as states outsource their traditional roles to private actors. As such, the dissertation contributes to literature, in anthropology and science studies, which suggests that understanding new forms of biopolitics has to take place in conjunction with an accounting of emerging institutions, epistemologies and norms within both national and global systems.¹⁷

Outline of Chapters

The dissertation contains four substantive chapters. Two chapters are on South Africa, and two are on India. One chapter for each country interrogates the response of the state to the epidemic, while a second chapter for each country examines the role of civil society organizations.

Chapter 2, titled *Designing Epidemics: AIDS, Policymaking and Global Norms in India*, examines how the AIDS epidemic comes to be understood by India’s national policy establishment. The Indian government, in contrast to the South African government, embraced international expertise regarding AIDS. I argue that the Indian policymaking process and its choice of technologies have to be contextualized in a

¹⁶ Also see Kleinman (1989), McMichael (1995, 2001), Garrett (1995), Farmer (1998), Beaglehole and Bonita (1997).

¹⁷ Sunder Rajan (2006), Rose (2006), Biehl (2006, 2007), Petryna (2002), and Nguyen (2005).

framework that was dominated by global actors, global categories and a globalized discourse about AIDS. The global actors brought with them a “foreknowledge” about the epidemic. This foreknowledge provided an already existing template that anticipated the “shape” of an AIDS epidemic. It helped the government manage an unknown epidemic by anticipating patterns of risk and contagion. It invoked public health “best practices” that favor targeted interventions aimed at high-risk groups. However, the prior models, categories and information that such foreknowledge brought into play left relatively little room for surprises and new lessons.

Chapter 3, titled *Governing Through the Non-Governmental: Shifting Terrains of Public Health in India’s AIDS Epidemic*, examines the role of NGOs in India’s AIDS epidemic. The Indian government’s response to the AIDS epidemic was marked by a significant departure from past public health initiatives in the country: the national government relied heavily on non-governmental organizations (NGOs) for the delivery of AIDS-related health services. Such a strategy stood out in stark contrast to the history of India’s public health. This chapter examines the political and epistemic consequences of the state’s “outsourcing” of its functions to NGOs. By revealing the politics between international donors, the national government, and civil society groups, the chapter analyzes how NGOs became central to the production of knowledge and expertise about AIDS, and also about sexuality, culture and morality in India. The chapter argues that by being highly vulnerable to the capital provided by international donors and the government, AIDS NGOs facilitated an emerging model of *contractual accountability* in public health. This model of public health, and its constitutive logic, tended to focus on “risk groups” and “risk factors,” often at the cost of broader programmatic approaches that examined structural economic and political constraints.

More broadly, AIDS NGOs in India provided a window into transformations in public health in the context of increasing globalization. The chapter suggests that public health was no longer solely in the domain of the national and local government. Rather, it was increasingly in the purview of international technical agencies and civil society organizations. The state – almost voluntarily – was attenuating its own administrative reach, and assigning more and more of its traditional functions to private actors. Implicit in the emerging conception of public health was an entire image of the nature of the state and its changing relationship to its citizenry.

Chapter 4, titled *Expertise and Politics in Post-Apartheid South Africa's AIDS Epidemic*, examines the South African government's controversial AIDS policies. It focuses on how the AIDS epidemic becomes a crucial terrain in which the relationship between expertise and political power gets molded in post-apartheid South Africa. I argue that the government proposed a model of public health that explicitly took into account how structural socio-economic factors influenced epidemics. In such a model, analyses of poverty *and* virological studies were equally important; traditional healers and molecular biologists were both considered relevant experts to understand illness and disease; history was deemed a relevant lens through which to comprehend health. In such a model of public health, traditional boundaries between “science” and “politics” got redrawn. Understandings of expertise shifted. There were challenges to established relationships between the local and the global, the national and the international, the center and the periphery. New conceptions of the role of history and imagined futures in public health policymaking were brought to the fore. In other words, a much broader range and variety of stakeholders and the abstractions associated with their “stakes” were deemed relevant in formulating AIDS policy. In

the end, however, the South African government's attempt to institute a new way of thinking about AIDS and public health eventually failed. The government garnered more attention, and notoriety, for its challenges to mainstream science, than for its attempts to build holistic frameworks for understanding disease causation and treatment.

Chapter 5, titled *Treatment Activism in South Africa: Contestations Over Science, Citizenship, and Public Health*, discusses the role of non-governmental organizations in shaping South Africa's national AIDS policy. Specifically, it focuses on the Treatment Action Campaign (TAC), which is South Africa's most prominent non-governmental organization working on AIDS. The TAC's goal is to increase access to AIDS treatment for South African people living with HIV. The group's activism centered around demanding *rights* to anti-AIDS drugs. The chapter examines the intimate relationship between the TAC's rights-based political demands and its epistemic commitments. I argue that the TAC's tight coupling of political and epistemological commitments was crucial for understanding the emerging norms that increasingly authorized public knowledge and public health priorities in post-apartheid South Africa.

Chapter 2. Designing Epidemics: AIDS Policymaking and Global Norms in the Indian Government

Introduction

In November 2007, the United Nations (UN) dramatically lowered its estimates of the number of HIV-positive people in the world. It slashed HIV prevalence numbers by about 20 percent, bringing down an older estimate of 40 million to 33 million.¹⁸ An important, and equally surprising, precursor to the UN's lowering of global HIV prevalence figures was an announcement by the Indian government. In July 2007, India's health minister sharply reduced the estimated number of HIV-positive people in India from 5.7 million cases to 2.2 to 2.5 million cases.¹⁹

How does a country go from having 5.7 million HIV-positive people to less than half that number? How are these numbers, which profoundly influence how an epidemic is imagined and addressed, determined? To answer these questions, this chapter examines how the AIDS epidemic in India gets conceptualized and counted within the national policy establishment. In particular, it investigates the technical practices – such as of epidemiological modeling, risk categorization, and public health interventions, that the government deployed to determine the size and shape of the epidemic.

These technical practices serve as an extraordinarily useful site within which to examine the shifting politics between the national government and international technical agencies that constitute the global socio-technical machinery around AIDS.

¹⁸ For instance, see reports in the *Los Angeles Times*, November 20, 2007 (Chong, 2007) and in the *New York Times*, November 20, 2007 (McNeil, 2007).

¹⁹ For instance, see reports in the *New York Times*, July 12, 2007 and the *Times of India*, July 11, 2007.

The process of designing epidemiological models reflects how the national government has to constantly negotiate, contradict and comply with international agencies such as the World Health Organization (WHO) and UNAIDS. Similarly, the designing of public health interventions provides a window into how expertise furnished by the World Bank and the Global Fund influences national policymaking. Thus, while this chapter is about AIDS-related policymaking in India, it is in part also about the emerging logics of globalization. It illuminates the workings of a global machinery for managing epidemics as it “touches down” in the south and confronts cherished democratic values such as national sovereignty.

I will argue that the global socio-technical machinery and its experts bring to local settings what I call a “foreknowledge” about the epidemic. This foreknowledge provides an already existing, generic template of an AIDS epidemic. It comes with established technologies of counting, set risk categories, and prior models of intervention. The foreknowledge informs the government about what an AIDS epidemic is *expected* to be, and thus assists the state in planning for a potential crisis. It profoundly shapes the government’s choices about how to conceptualize, measure, and respond to the epidemic. However, the prior models, categories and information that the foreknowledge brings in leave little room for surprises —and arguably reduce the possibility of learning new lessons. The generic nature of the foreknowledge brought in by global actors entails that even when national particularities gave local policy a different hue, the color was drawn from a global palate.

Below, I first briefly discuss the Indian government’s policies on AIDS over the last decade and a half. Next, I discuss how the *size* of the epidemic was calculated using epidemiological models. Then, I discuss how the *shape* of the epidemic was

determined; that is, where were the estimated five million infected people in a population of one billion? I then describe the government's vision for the appropriate public health intervention. Finally, I use the discussion about the size and shape of the epidemic and the strategies of intervention to delineate the characteristics of the "foreknowledge" that helps mold national policies.

Background: Where the Global and the National Come Into Contact

The first confirmed case of AIDS in India was reported in 1986 in the southern city of Chennai (then called Madras). Shortly afterwards, the government constituted the National AIDS Committee whose deliberations resulted in the first national AIDS policy statement, released in 1987. It was a modest, and critics would say ineffectual, statement that discussed policies for surveillance, blood safety and enhancing awareness (NACO 1997-1998). In 1992, the Indian government formed the National AIDS Control Organization (NACO). NACO became the main nodal institution charged with AIDS policy. Though located within the ministry of health, it was constituted as a stand-alone, "vertical program" with considerable financial and administrative autonomy. The vertical institutional structure, which implied relative autonomy within the ministry of health, was widely attributed to pressures from the World Bank (interviews; Chhabra, 2007). Several former bureaucrats stated that one of the conditions for the World Bank's initial \$84 million loan for AIDS was the setting up of NACO as a quasi-autonomous structure. As a retired senior NACO official explained, "There was big money coming into the country. The World Bank did not want the AIDS funds to be mired in the red tape that they associated with business-as-usual workings of the ministry" (interview D, April 2006). The scale and direness of the AIDS epidemic demanded a more "urgent and responsive machinery" which NACO provided.

In any given year, NACO's budget runs into millions of dollars. Much of this comes from multilateral donors such as the World Bank, the Global Fund, and aid agencies of the governments of the United States, the United Kingdom, Canada and Australia. Within the first few years of NACO's inception, its budget exceeded the budgets for any other disease program. In 2007, NACO's budget exceeded the entire remaining budget of the health ministry. Both the vertical autonomy of the national policymaking organ, and the massive amounts of international developmental capital pumped into it, are integral to understanding AIDS policy in India.

Over the last fifteen years, NACO has released three successive national AIDS policies. The National AIDS Control Program-1 (NACP-1) extended from 1992 to 1999; the second phase, NACP-2, ran from 1999 to 2006, and the most recent NACP-3 covers the time period from 2007 to 2014. The budgetary allocations for each successive policy grew sharply; the US \$516 million allotted for NACP-2 climbed to over US\$2.4 billion for NACP-3. Moreover, all three policy plans received a significant, if not the majority, of their funding from international donors (NACO 2005a, 2006a, 2007).

In addition to being significantly driven by international funds, the three successive policies have been marked by considerable consistency in their approach to the epidemic. The national policies have emphasized prevention and care. Treatment of AIDS through anti-retroviral drugs, which has become an important component of public health policies in countries such as Brazil and South Africa, is markedly missing in the Indian context. The Indian policies have also been marked by a progressive decentralization. State and municipal-level committees have been created. Perhaps most strikingly, thousands of non-governmental organizations have been

enlisted to provide AIDS-related services. In other words, that which is explicitly “non-governmental” has been recruited to provide services that have traditionally been in the ambit of the government (Mahajan, forthcoming). Finally, public health strategies have focused on “targeted interventions” aimed at “high-risk groups.” These high-risk groups are marginalized sections of the population such as prostitutes, homosexuals, drug-users, and truck-drivers. The public health intervention aimed at the general population has consisted of “AIDS-awareness” messages broadcast through the mass media.

Technologies of Counting: Epidemiological Modeling of AIDS

Epidemiological numbers are often a starting point for public health policy. These numbers seek to capture basic aspects of an epidemic such as how many people are infected with the disease, how fast the disease is spreading, and which sections of the population are most vulnerable. The numbers guide public health officials’ efforts to develop strategies of prevention and treatment, and help in the allocation of crucial resources. But these numbers, the usual starting point for imagining an epidemic, are themselves the end product of considerable work. They are the result of a complex and iterative process that involves assiduous and often antagonistic negotiations as different actors struggle to assert their respective visions of the epidemic.

To understand this process, the first point worth underlining is that epidemiological calculations – such as of HIV prevalence and incidence - are estimates, and not the result of an *actual* count of infected persons.²⁰ The HIV prevalence estimates are

²⁰ It is, after all, not easy to conduct blood tests of India’s entire population of one billion people (itself an estimate), especially given the country’s rudimentary public health infrastructure. For instance, in 2005, the country had a mere 703 public seroprevalence testing centers for HIV, which meant that, on an aggregate basis, each centre was responsible for roughly 1.4 million people.

guided by seroprevalence data, but they are not a direct and straightforward representation of these data.²¹ Rather, the prevalence estimates are produced by a range of models that make a number of assumptions in order to come up with a picture of the population and how the disease is coursing through it. The models typically use the language of mathematics and software programs. A growing academic and technical industry works on the epidemiology of AIDS, and there is a correspondingly large number of models in use. Some of these models are fairly simple. For instance, a model might consist of a simple spreadsheet which describes how HIV might spread by means of a single mechanism, say intravenous drug use, through a small, contained population. Most models that represent countrywide epidemics tend to be more complex, containing detailed demographic and epidemiological information in the hope of representing HIV/AIDS epidemics more fully. The estimation and projection packages used by UNAIDS, for instance, contain multiple models and spreadsheets that are often nested within each other. For instance, a software package called the Estimation and Projection Package (EPP) is used for estimating adult HIV prevalence in countries with generalized epidemics. This package uses available surveillance data from various sites and years. If data from national population-based surveys are unavailable, then data from pregnant women who attend antenatal clinics are adjusted to be a proxy. The resultant national prevalence projections produced by the EPP are then fed into a larger and more complicated “suite of policy models” called SPECTRUM. The SPECTRUM models calculate many more epidemiological details including the number of new infections and deaths, and the resultant impact on family income, orphans, treatment needs, the rate of mother to child transmission, and much

²¹ Seroprevalence represents the number of persons in a population who test positive for a specific disease based on blood serum specimens.

more.²²

The more complicated models consist of a large number of variables which aim to capture various properties of the country's population. For instance, there are variables for the size of the population, different age groups, populations in rural versus urban areas, emigration and immigration levels, the number of sexual partners people have, rates of homosexual contact, use of intravenous drugs, probabilities of used needle exchanges, and potential exposure to contaminated blood transfusions. There are variables for tuberculosis infections, levels of condom use, access to antiretroviral drugs, rates of breastfeeding, and the use of contraception. In other words, these models attempt to code for culture and sociology, for history and economics. They attempt, albeit selectively, to encapsulate entire societies.

But despite the attempt to represent various behavioral, demographic and sociological aspects of a population, there is something profoundly generic about many HIV/AIDS models. Their generic nature allows the same models to be used in countries around the world. Their one-size-fits-all nature is vividly illustrated in the fact that UNAIDS and WHO make software and modeling packages available on their websites. They exhort countries to use these modeling tools, and expect the same models to work for a range of countries.²³ The website provides a user manual, formatted excel spreadsheets and software programs that can be downloaded. It guides the user step-by-step on how to use the software, what data to insert, and what functions to operate. UNAIDS also conducts series of training workshops around the world to facilitate the

²² For instance, see

http://www.unaids.org/en/KnowledgeCentre/HIVData/Epidemiology/epi_software2007.asp

²³ UNAIDS recommends that countries with generalized epidemics use a separate package from countries that have low-level or concentrated epidemics. Other than for this gross distinction, the same modeling tools are expected to work for a range of different countries.

adoption of the models. Testifying to how the models are used across a range of countries, UNAIDS proclaims on its website, “The large majority of low- and middle-income countries now use the above methods”

(<http://www.unaids.org/en/KnowledgeCentre/HIVData/Methodology/default.asp>).

However, for these models to be generic and for them to travel across the world, they have to contain standard categories that are easily recognized in diverse countries.

Thus, in the UNAIDS model used to calculate prevalence in countries with concentrated epidemics, there are default high-risk categories: injecting drug users, men who have sex with men, female sex workers, and male clients of female sex workers. Similarly, the default low-risk categories include partners of injecting drug users, female partners of men who have sex with men, and partners of clients of female sex workers. The user has the option of adding new risk categories but in general, the same default groups get used in each country. The generic quality of the models thus carries a moral valence; in designating prior risk categories, the models organize epidemics in different countries under common universal rubrics.

Consequently, they potentially obviate alternative conceptualizations of risk that might be unique to particular countries.

The foreknowledge that is carried within the epidemiological models manifests itself in various ways. First, the generic templates organize an incoherent present by providing coherent categories and rubrics. Second, the models create future predictions about the course of the epidemic, which help governments to plan for the future. Third, the foreknowledge can also become a self-fulfilling prophecy about the epidemics they are meant to predict. In other words, the models are not only descriptive, but can also be prescriptive. For instance, epidemiological models, as

purveyed by international technical agencies, occasionally reach a country *before* there is any large-scale group awareness of an epidemic. The early arrival of these models means that they can be critical to shaping how the epidemic is understood and experienced by a people.²⁴

Touching Down in India

When an epidemiological model touches down in a new country, along with it come various embedded variables, categories and assumptions. Often, experts and institutional machinery of international technical agencies also travel with these models. For instance, in epidemiology workshops organized under the auspices of India's latest AIDS policy, NACP-3, doctors, scientists and epidemiologists from Indian research institutions shared the table with international experts from the World Bank, UNAIDS and the United States' Centers for Disease Control. The international experts from Washington D.C. and Atlanta would sometimes be beamed in through video conferencing facilities into workshop meetings. The workshops aimed to produce HIV prevalence estimates for India. This required that values be assigned to the various variables in the epidemiological models. To ascertain these values, it helped to have as much prior information as possible. These prior data were typically derived from say, seroprevalence tests or behavioral surveys. But such prior data do not always exist. For instance, in some NACP-3 modeling workshops, it quickly became clear that there were no reliable estimates of female partners of men who have sex with men, nor of female partners of injecting drug users. Similarly, it was apparent that there was little reliable survey data on breastfeeding or condom use in India. In the absence of reliable national data, various experts around the table

²⁴ See Stacey Pigg (2001) on how international technocratic organizations can facilitate the sense of an 'expected' AIDS epidemic.

considered suitable proxies. Could the seroprevalence rate from a small number of antenatal clinics be used as a proxy for the general female population? Could breast-feeding statistics from other Asian countries stand proxy for India, or could condom-use rates from other developing countries be used as substitutes? In the absence of reliable prior data, the experts had to use their experience, intuition and opinions. The values of the variables were seldom determined in a rash or flippant manner; national-level experts and their international counterparts would occasionally provide alternative understandings of behavior, and this would lead to a deliberative process of iterative alignment. And so in these workshops, migration levels would be moved down, morbidity data tweaked, demographic trends adjusted. Assumptions, survey data, sampling data, census figures, anecdotal evidence, and overall perceptions build on each other to provide the information needed to crunch out estimates and projections. In these deliberations, what was striking was how much room there was in the mathematical models for subjective input. Secondly, in the absence of data from the ground, often assumptions were drawn from the experience of other countries. In other words, the foreknowledge -- even though undergirded by seemingly objective technologies such as mathematical models that were driven by data -- had embedded in it subjective assumptions. Moreover, this foreknowledge often privileged geographical comparisons.

In these deliberations, international experts, such as from the World Health Organization, would often carry an imprimatur of expert credibility because of their experience with AIDS epidemics in other parts of the world. However, by no means were local actors absent in this process. Local doctors and scientists claimed local knowledge and experience, which was also an important source of credibility. However, because international experts brought *prior* knowledge with them, the local

actors were typically put in the position of *reacting* to the already established knowledge. In other words, it was not as though local experts lacked credibility, or that there wasn't scope for iterant changes to the content or design of models. However, the structure of foreknowledge, which had already been established, put local actors in the mode of reacting rather than setting the original terms of how the epidemic should be understood. Since the international experts came with prior frameworks and data, it was difficult to challenge and displace. While this already formed knowledge, often based on comparative experiences in other parts of the world, played a helpful role in addressing a new epidemic, it arguably stood in the way of learning new lessons.

The mixed and messy data that were input into the models eventually emerged in the form of a neat number. Sometimes it was 5 million, and sometimes it was 3 million. When such numbers emerge from the bowels of the culture-crunching models, perhaps unsurprisingly, they were sometimes contested. For instance, in India, the estimates of the HIV-infected population have been repeatedly contested. Contestations around these numbers followed a typical pattern. The national government claimed that the numbers provided by international organizations were exaggerated and unrepresentative of the reality on the ground. International authorities, often supported by non-governmental organizations, claimed that the numbers provided by the government are deflated. They typically accused the government of “being in denial” about a serious epidemic.

It was difficult to disprove – or prove – any of the results of the models. After all, disconfirming or confirming the estimated number of HIV infected persons - extant, past and future - in a population would require comprehensive seroprevalence data

which were typically lacking. In most cases, the ‘reality’ did not exist independent of the model. Indeed the model and the foreknowledge it brought helped design the parameters of reality. Thus, in the case of competing models, and competing realities, it was not always easy to adjudicate claims and counter claims. Typically the claims and counterclaims were adjudicated on the basis of the credibility of the institutions that produced the numbers. The contestations over the numbers got resolved over whether one trusted, say, UNAIDS, or, the Indian government.

Scaling Up, Scaling Down: Validating New Numbers

Since the first case of AIDS was detected in India, the national government has repeatedly disagreed with the HIV prevalence numbers provided by organizations such as the WHO and UNAIDS. These conflicts have often become highly public disagreements between international technocrats and Indian officials. For instance, in a much publicized statement, Richard Feachem, until recently the Executive Director of the Global Fund to Fight AIDS, Tuberculosis and Malaria, declared in 2003 that India had the world’s largest AIDS epidemic, surpassing even South Africa. “The Indian epidemic is the one to watch – it is going to be absolutely enormous. The Indian epidemic is on an African trajectory running about 15 years behind. The rates are rising extremely rapidly and there is little that is going on today that is going to make a serious difference” (Feb 18, 2003, *The Guardian*). “The official statistics,” referring to the numbers provided by the national government, “are wrong,” insisted Feachem. His comments mirrored the opinions of a range of international leaders who also believed that the Indian epidemic was on an “African trajectory,” and that by disputing this prognosis, the India was denying the seriousness of the epidemic.²⁵

²⁵ For instance, see *Newsweek* August 15, 2005, *Businessweek* February 1, 2006.

In response to these claims by international organizations, the Indian government denied that the size of its epidemic was as large as it was being made out to be. Consecutive directors of NACO also denied that the Indian epidemic was following an “African” path, calling such claims irresponsible and alarmist. The government’s own epidemiological models came up with prevalence estimates that were significantly lower. Moreover, the government produced different prevalence estimates despite using the *same* seroprevalence sample data that the international organizations employed. To gain credibility for its own numbers, the government pointed to what it claimed were different behavioral trends between African and Indian populations. For instance, in a Lancet article, the director of NACO claimed that a National Behavioral Surveillance Survey had reported far less “extramarital sexual contact” than found in some “African and western countries”(Ganguly, 2004). Similar claims were made about the extent of homosexual contact, about drug use, about how frequently men visited prostitutes.

What was often at the heart of the contestation were differing assumptions about behaviors, social structures, and historical legacies, that were being coded into the models. The contestations over the different prevalence estimates were articulated through questions such as: Are we being called a promiscuous people? Do we have strong families? How common is homosexuality? How common is extra-marital sex? Do middle-class men visit prostitutes? Not surprisingly, when the government’s far more conservative behavioral assumptions were put into the models, the estimates of HIV prevalence were much lower than those provided by UNAIDS/WHO.

In July 2007, the Indian government announced that the AIDS epidemic was less than

half of what had been estimated by the WHO/UNAIDS. According to the new numbers, the country had not 5.5 million but closer to 2.2 million people with HIV. The prevalence rate was now estimated to be 0.36 percent (down from a previous estimate of 0.9%), and back calculations based on these new estimates indicated that the epidemic had not risen much during the previous decade and had perhaps even had stabilized in 2006.

While these numbers were startling, this time around, most international donors like the World Bank and the WHO, in addition to the Global Fund and the Gates Foundation, agreed with the government's numbers. They publicly supported the new numbers, and many of their websites have been revised to display the lower estimates. Thus there was a dramatic change in both the epidemiological estimates and the credibility attributed to the new estimates.

The new consensus between the government and international technical agencies around the lower HIV numbers was built partly around new data that were released from a National Household Survey. This survey had been recently conducted in India with funding from the United States, under auspices of the National Institutes of Health. As a part of this survey, voluntary blood samples were taken from 102,946 people. These new blood samples had been drawn from randomly selected people from the general population, and not from 'high-risk' categories alone. This sampling strategy provided HIV infection rates that were considerably lower than indicated in the samples obtained from antenatal clinics that had thus far been considered a good proxy for the general population. In addition to blood samples, the household survey was used as a source for extensive behavioral and sociological data. Moreover, the new epidemiological numbers took into account data from 400 new seroprevalence

sentinel sites which had been added since 2006. These new sites marked a fifty percent increase in the number of public seroprevalence sites in the country. This large body of evidence was instrumental in granting validity to the new numbers.

However, data were not enough. The consensus backing the new estimates also demanded a change in the relationship between international and local experts. This came about through the drawn out, highly consultative process through which the NACP-3 was developed. From 2005 to 2007, the government undertook an arduous process of consultation and collaboration in order to prepare the new AIDS policy. Over a dozen subcommittees and working groups met over two years, and held discussions with a range of stakeholders from civil society, the government, scientific experts, and international technocrats. During the making of the NACP-3, a subcommittee under the leadership of the World Bank was organized to address epidemiological modeling, estimating and planning. This subcommittee conducted consultations with experts of the CDC, World Bank, UNAIDS, the Global Fund, WHO, the Indian Ministry of Health, various scientists from Indian institutes, and NGO representatives. These consultations resulted in a more unified voice between international and national experts. During the making of NACP-3, representatives of NACO, UNAIDS, WHO and the World Bank took pains to underline that they were largely in agreement with each other in their understanding of the epidemiology of the disease. In contrast to the often sharp and public disagreements that have taken place over estimating the size of the epidemic, the NACP-3 consultations seemed to provide a stage for concurrence and agreement between various international institution stakeholders and the government.

The consensus over the new numbers also came at a time when there was a shift

taking place within the epidemiological community regarding the results of widely accepted models. There seems to be a growing recognition that extant AIDS epidemiological models typically *overestimate* HIV prevalence. As a senior scientist who works on AIDS epidemiology models in a prominent school of public health in the United States explained, “I am aware of no model or study that has under-predicted the future case load in a developing country” (interview Z, December 2007). He pointed to earlier prevalence estimates for some countries in Africa such as Kenya and Uganda. These estimates have now been scaled back significantly in light of new seroprevalence data from the ground. Another academic epidemiology expert in the United States, who has been critical of the UNAIDS modeling techniques, stressed, “It is not that the epidemic is necessarily declining, and that’s why these estimates are being lowered. Rather, what the models were projecting earlier was incorrect. The UNAIDS/WHO models seem to have exaggerated infection rates in especially those countries which had scanty surveillance data” (interview Y, November 2007).²⁶

The most common reasons cited for the overestimation is that sample seroprevalence data were often misrepresentative of the general population. This seroprevalence data are often taken from clinics that serve high-risk groups, or from pregnant women at selected antenatal clinics. The latter especially have been relied upon as a proxy for infection rates among women in the general population. Critics point out that the antenatal clinics tend to be in urban areas and often tend to serve lower income communities, and thus may be in danger of systematically overstating infection rates in the general population. Experts have also pointed out that the initial number of infected people in a population has often been overstated. This initial number is

²⁶ Academic opinions regarding the overestimating of the AIDS epidemic are also reflected in an increasing number of academic articles on the subject (Chin, 2006; Halperin, 2007; Yan, 2006).

crucial for calculations of HIV infection rates, growth rates, prevalence, and much more. “This initial estimate was presumed to be much larger than what we now believe to be the case,” explained a scientist in South Africa who leads actuarial research (interview X, November 2007). He pointed to the initial number for Uganda was rolled back by forty percent, as were the numbers for Kenya and for Tanzania. HIV/AIDS models also often failed to account for individuals’ efforts to change behavior and protect themselves from infection. Some of these behavioral changes could increase with prevalence, but these shifts are seldom accounted for in most models. Indian bureaucrats argued that their new, lower numbers were the result of more accurate assumptions being built into epidemiological models.

Nevertheless, the Indian government’s scaling back HIV numbers from 5.5 million to 2.2 million was not easy, not least because funding from many international institutions and funding hinged on portraying AIDS as a growing and devastating epidemic. Many non-governmental organizations are still openly skeptical of the new numbers. However, in India, there is a consensus among the international technocrats and the government around these lower estimates. This new consensus required not only new data from the ground, but also social exercises that involved new cooperative consultations between the government and international technocrats, and a shift in the assessment of models within the professional realm of epidemiologists.

Traveling Categories of Risk

In addition to determining size, policymakers have to ascertain the shape of an epidemic. In the Indian case, this involved assessing where in a population of one billion the epidemic might reside. Are the 5 (or 2) million infected person evenly distributed, or are they found in small concentrations? For NACO, this process of

ascertaining the shape of the epidemic involved identifying “high-risk populations”: groups considered most vulnerable to the disease and the most likely carriers of HIV. Identifying “high-risk populations” entailed much more than conducting seroprevalence tests throughout the population. What had first to be determined were the social and demographic categories that were appropriate candidates for high-risk populations. For the counting to be meaningful, first there had to be classification.

International and national policymakers presumed that social categories of ‘high-risk groups’ in India were likely to be similar to high-risk groups in Thailand, Uganda, Botswana, and other developing countries where heterosexual contact was the main mode of transmitting HIV. So prostitutes and truck drivers became the relevant “high-risk” categories, along with homosexuals or “men who have sex with men,” hemophiliacs and intravenous drug users. The UNAIDS epidemiological models used these categories as the “default high risk groups” and they became the default high risk categories for the Indian government. These groups were monitored as vulnerable populations. Surveillance and testing was focused on them.²⁷ Since prostitutes, homosexuals, truck drivers and drug users were tested and surveyed, they were tautologically confirmed as being the relevant risk populations. In this sense, the foreknowledge that was imported through international policy rubrics served as a self-fulfilling prophecy. Other possible correlates of high-risk, deriving from specifically Indian conditions - such as endemic diseases, nutritional deficiencies, and high rates of sexually transmitted diseases (STDs) - were generally not tested for, and perhaps unsurprisingly, these potential risk categories were not accounted for in the policy

²⁷ An analysis of the recently established sentinel testing sites shows that almost half of them were targeted at specific high risk groups. A survey of biomedical literature on AIDS in India conducted by Karnik (2001) reveals how categories of high risk in India were borrowed from a dominant policy and biomedical discourse established outside the country. A study of AIDS national policy documents from 1990 to 2006 also revealed how categories of high risk are presumed to be the same as in other countries.

process. Alternative sources for determining high risk categories, such as historical public health data were also not deemed relevant. Presuming that India had the same high-risk categories as other countries foreclosed other understandings of the epidemic.

The designated high-risk categories, however, were not always clearly defined and identifiable in the Indian context. For instance, India had a far less clearly defined homosexual ‘community,’ than found in the United States. Indeed, there was extensive debate over whether “homosexuality” as a category made sense in the Indian context where gender and sexual roles were different from what was normally perceived in parts of the west (Cohen, 2005). Similarly, hemophiliacs didn’t have a social identity nor a recognizable demographic presence, but were nonetheless initially assigned as a high-risk group (Banerji, 1996; Karnik, 2001; NACO, 1997, 2004). Even when high-risk categories, such as truck drivers or prostitutes, were identifiable, they and their behavior didn’t necessarily represent the same cultural phenomena as presumed in other countries.

While the adoption of these categories conflated, glossed over or contradicted local conditions, they did frame the Indian epidemic in a way that made it more susceptible to generic policy rubrics prevalent in the international AIDS world. It framed categories in a way that made the Indian epidemic comparable to other countries’ epidemics, and therefore susceptible to many of the same policy prescriptions. The adoption of categories from preexisting global templates reproduced a globalized discourse of risk in the Indian AIDS scene. It structured how epidemiological data were collected, how the spread of the infection was understood, and which research questions were asked. And perhaps most consequentially, the adoption of a globalized

discourse of risk guided the government's public health interventions.

Targeted Interventions

Viewing the epidemic through the lens of “high-risk populations” shaped the choice of policy instruments deployed to combat the epidemic. Such a framing rationalized a focused, group-specific response, rather than a broader, structural, socio-economic policy. AIDS policy in India, accordingly, was characterized by “targeted interventions.”

In the global AIDS machinery, ‘targeted interventions’ have become a powerful and accepted form of what counts as the most effective public health strategy. While they have proliferated over the years and take many forms, the main pillars of targeted interventions still consist of offering condom distribution, education programs, and counseling and care in high risk groups. The goal of these interventions has been to increase awareness about the disease in the populations considered vulnerable with the hope to facilitate change in behavior. In India, as elsewhere, particular success stories are commonly cited as justification for various targeted intervention programs.

Thailand's condom distribution and education program for prostitutes is constantly referred to. Uganda's public health programs are held up as another important success story, as are its condom distribution, social marketing and education programs.

Brazil's treatment and prevention program with gay communities provides another analogy to policy-makers.

At one level, public health interventions focused at high risk populations seem like an obvious and sensible course of action, especially if the epidemic is conceptualized as concentrated in a few discrete groups. But advocacy of this mode of intervention

takes place against a backdrop of a broader debate about what constitutes an appropriate public health paradigm and policies. AIDS program designs have been overwhelmingly guided by a biomedical paradigm of public health that has emphasized that disease is caused through discrete mechanisms. Correspondingly, appropriate interventions to prevent or treat disease could be similarly discrete. The biomedical paradigm has emphasized individual behavior change. It has presumed that armed with adequate information, individuals will adopt more risk-averse behavior.

But there is another paradigm, which I refer to as a structural socio-economic paradigm of public health, which draws attention not to cognitive processes but rather social and political contexts that put individuals in the position of vulnerability.²⁸ According to this paradigm, public health programs should be attending to how economic and social conditions lead to illness. It calls attention to how socio-economic orders are reflected in relationships, sexual behavior, and decisions pertaining to health more broadly. Thus, it is not just a deficiency in information that leads to risk-prone behavior, but rather absence of access to alternative paths of economic and social viability and power. In more concrete terms, this would mean that effective public health policy should not be about merely distributing condoms and airing advertisements about the dangers of unprotected sex and sharing needles. Rather, public health policy would involve designing AIDS programs that were integrated with primary health systems and social infrastructure, and were cognizant of the socioeconomic parameters of the population.

This debate between targeted intervention versus an integrated health approach, or in

²⁸ For instance, see Farmer, 1998, 2003; Pigg, 2001; Halfon, 2007.

other words, between a biomedical paradigm versus a more holistic structural socio-economic paradigm, have played out in India's public health history prior to the AIDS epidemic. India's long-standing Population Control Program (later called the Family Planning Program, and currently termed the Reproductive Health and Family Welfare Program) was the site of a similar debate for several years. In its various incarnations, the program dealt with how to change sexual behavior. Its efforts were aimed at people roughly in the age group between 16 and 48 years, the sexually most active years, and the technologies it marketed included condoms and other 'barrier methods.' The lessons of five decades of this program, albeit often learned through failures, included the fact that marketing technological interventions, such as condoms and pills, had little impact on changing reproductive behavior nor on birth rates. The only technological intervention that had a discernable impact on birth rates was female sterilization operations which were conducted, often coercively, on a large scale in some states in the 1970s (Mamdani, 1972; Jeffrey et al, 1996). After decades of failed targeted interventions aimed at behavioral change, the policy consensus within India, and outside, was that betterment of indicators of reproductive health, maternal and infant mortality, and population growth rates required not condoms but better literacy, higher income levels, and better health infrastructure. There was an especial emphasis on "women's empowerment" which replaced "population control" in international population policy (see for instance Halfon, 2007). In other words, it required an integrated approach to the wellbeing of the family, with a focus on the woman and child. At an administrative level, what proved to be most successful was getting rid of stand alone vertical programs, and integrating reproductive health into the larger primary health infrastructure.

One would think that these very issues of population policy – namely of behavioral

change, reproductive technologies, administrative efficacy- that the AIDS policy has to grapple with. But the dozens of consultations and policy documents produced by NACO, make little reference to this history. In several interviews with NACO bureaucrats and officers in international organizations working in India on AIDS, the relevance of population policy history was seldom brought up. Obviously, the AIDS epidemic cannot be equated with a public health enterprise of ‘population control.’ However, the history of ‘population control’ has created vast learning in India which is not referenced in the AIDS policy literature and consultations. This history furnishes some of the reasons why vertical stand alone programs and targeted interventions don’t work very well if the end goal is a broad-based social change which implicates personal behavior. The family planning program vividly showed how concentration of funds and expertise on a single health issue can have an erosive effect on primary health care infrastructure and delivery systems as doctors, money and expertise are drawn away from primary care into well-funded vertical programs. However, these legacies of public health history are disregarded in NACO’s broad consultative processes. Poverty – which links the various high risk groups of prostitutes, truck drivers, and drug users – is seldom the focus of AIDS policies. Rather, condom distribution, gay rights and sex education are the centerpiece of most interventions.

NACO, with its stand alone structure and focus on targeted interventions, seems to reproduce precisely those mistakes that the health ministry had tried to remedy over the past decade with regards to population policy. From the time of NACO’s inception, there has been almost a voluntary denial of knowledge that could have been drawn from India’s own public health history. While NACO’s autonomy potentially facilitated openness to international funds and lessons from other countries’

experiences, it also seemed to facilitate a remaindering of lessons from national public health history. In providing a template for the future that could be easily translated across countries, the foreknowledge remaindered lessons from a local past.

Conclusion

Martha Finnemore, in her work on international organizations as “teachers of norms,” analyzes how international institutions such as UNESCO taught states the value of science policy organs (Finnemore, 1993). These “teaching missions” facilitated the creation of similarly designed science bureaucracies in a number of states. Finnemore argues that the organizational innovation and the normative impulse (of the need for modern state to have science policy bureaucracies) were supplied from outside (Finnemore, 1993, 1996, Barnett and Finnemore 1999).

In this chapter, I discussed how the conceptualization of the AIDS epidemic is influenced and shaped by international actors and practices that constitute a global sociotechnical machinery of epidemic management. This machinery too has “teaching missions;” UNAIDS routinely conducts workshops which train scientists from various countries about how to map and model AIDS epidemics. However, the “teaching” does not take place primarily through normative or prescriptive language. Rather the lessons are encoded in pre-designed technical practices. Technical practices such as of epidemiological modeling, risk assessment, and targeted interventions become a crucial site where contending conceptualizations of the epidemic get negotiated and stabilized. The design of these technical practices provides a window into how the national policymakers continually engaged with a globalized discourse about the disease. The globalized discourse, which constitutes what I call a foreknowledge, provides a prior template about what an AIDS epidemic is expected to look like.

This foreknowledge has particular characteristics: it is highly generic; it comes with technologies of calculation, in the form of epidemiological models, that travel across borders; it comes with prior social categories, such as of high risk groups, which are presumed to be same across countries; and it has established modes of public health interventions, such as the successful strategy of condom use in Thailand, and abstinence campaigns in Uganda.

The foreknowledge is crucial for the technical conceptualization of the AIDS epidemic and for designing public health interventions; it also determines the social meanings of the disease. It furnishes models, categories and trajectories that aim to stand in for the reality on the ground. It provides the government with policy rubrics even in the absence of such data. However, the representation within these models is selective: some features, often unique to a particular country, get occluded while other features that are presumed to be common across countries, get highlighted. Consequently, what gets rendered in the foreknowledge is often reflective of what has *already* been conceptualized, and not necessarily what is the 'reality on the ground.' Precisely because this foreknowledge comes equipped with *prior* models, categories and information, there is relatively little room for the unexpected. There is little orientation toward new patterns in the way a disease might spread through a population.

I do not want to suggest that this foreknowledge dominates national policymaking in a seamless fashion, for there are numerous resistances, as described in the controversy over epidemiological numbers. However, I am choosing to characterize this discourse in an overly stark fashion in order to bring out some of its distinctive and

homogenizing tendencies. While national actors do manage to mold globalized instruments to accommodate local contours, they also have to acknowledge the legitimacy of the dominant definitions to make grand significations.

The foreknowledge that dominates the policymaking process tends to silence local experiences and history. Thus, lessons from India's long history of 'family planning' are conspicuously absent from India's AIDS policies. Similarly, the institutional architecture of policymaking bodies such as NACO are inured to the failures of older 'vertical' public health programs. This silencing of the past sits alongside a privileging of ties of geography. So while India's history of family planning is rendered irrelevant for AIDS policymaking, Uganda and Thailand's experiences in combating AIDS are considered central. Indeed these ties of geography, where it makes sense to draw comparative lessons and parallels between countries around the world, allow India to avail itself of contemporary instruments and expertise from across the world. Not privileging local histories allows India to avoid the problems of translating its local set of experiences into a language that has no ready categories for those experiences. The politics of AIDS, and indeed the politics of globalization, reveal that it is easier to privilege ties of geography over those of local history.

Chapter 3. Governing Through the Non-Governmental: NGOs in India's Shifting Terrains of Public Health

Introduction

The Indian government's response to the AIDS epidemic is marked by a significant departure from past public health initiatives in the country: the national government has relied heavily on non-governmental organizations (NGOs) for the delivery of AIDS-related health services. Such a strategy stands out as a stark anomaly in the history of India's public health. In tackling other epidemics and in other nationwide public health programs, such as for malaria, polio, tuberculosis, or "family-planning," the government and its agencies were and continue to be the principal pivot for providing information, services, and treatment. However, in the case of AIDS, there has been a decisive turn to NGOs.

What explains this trend of "outsourcing" public health services? And what are the political and epistemic consequences of the growing prominence of NGOs in India's AIDS terrain? To examine these questions, this chapter analyses the politics between AIDS NGOs, the national government, and international funding agencies. It shows how AIDS NGOs, bolstered by international donors, have become significant in determining the relevant risk categories, social identities, and ethical norms for epidemic management. These increasingly powerful civil society groups shape the public repertoires that frame the epidemic and that undergird public programs and policies.

The particular way in which AIDS NGOs configure social categories, identities and interests, and incorporate them into health policies, provides a window to how public

health, especially related to AIDS, is being transformed in India. The terrain of AIDS NGOs in India illuminates how public health policy is no longer solely in the domain of the national and local government, but is increasingly in the purview of international technocratic organizations and civil society organizations. Implicit in this emerging conception of public health is an entire image of the nature of the state and its relationship to its citizenry.

Service Over Representation

In the last ten or fifteen years, hundreds of AIDS-related NGOs have mushroomed all over the country in response to both international and national attention and funding. These groups are not necessarily linked to each other, and do not typically coordinate their activities through any established institutional mechanism. Some groups are supported by churches, gay activist networks, lawyer associations, and medical charities from outside of India. Others don't take any international funding and support their activities through local fundraising. There are family charities, and NGOs associated with hospitals, temples and colleges. Some NGOs have over one hundred employees, while others are one-person outfits operating with personal computers from home. Some work in rural India, while others are more prominent in the high society circles of Mumbai and Delhi, where fashion shows, cocktail parties and star-studded performances provide the stage for AIDS homilies. In its plurality, India's AIDS terrain is distinct from what is found in some other countries such as South Africa and Brazil where AIDS movements are characterized by relatively cohesive social movements organized around a few leading activist groups and charismatic leaders (Biehl, 2007; Robins, 2005). As a leader of a three-year old group that works with HIV positive people in Mumbai wryly admitted, "In India's NGO world, AIDS is the most fashionable cause, and the money and the cocktails bring us

together” (interview S, May 2006).

Indian AIDS NGOs are not only less cohesive but also their politics of “representation” is distinct from what is found in many health-based movements in other countries. In India, there is no shared collective identity which serves as the singular mobilizing force for AIDS NGOs, as found for instance in the AIDS activist groups dominated by gay men in the United States (Epstein, 1996). Moreover, few NGOs in India claim directly to “represent” people living with HIV. They typically do not claim that their members possess embodied experiences of AIDS, experiences that often serve as a unique source of authority in other health movements. Instead, most civil society groups in the country claim to *work for* people living with HIV. They typically code themselves and are understood as “service” organizations that provide important amenities to affected individuals (Misra, 2006). These organizations seldom draw their credibility from claiming to be the voices of the affected or from foregrounding the embodied experiences of illness. As such, the civil society response to AIDS in India is strikingly different from AIDS movements, and health-based movements in general, in some other countries where NGOs have convincingly presented themselves as the direct *representatives* of a large body of people living with AIDS or HIV. These health based movements, which some sociologists have referred to as “embodied health movements”, tend to be highly focused on personal understandings and experiences of illness (Morello-Frosch, 2006). In contrast, the dominant orientation of most NGOs in India is towards service rather than direct representation. One effect of this particular kind of politics of representation is that even while working for HIV positive people, the Indian NGOs’ general absence of claims of direct representation allows for an “othering” of HIV positive people. Because AIDS is not “our” disease, it could still be talked about as

“their” disease, that is, of marginal groups at the fringes of society.

The Policy Turn to NGOs

The first case of AIDS in India was detected in 1986 in the southern city of Madras (now called Chennai) (Misra, 1998). It was a few years later, in the nineties, when international technocratic agencies such as the World Health Organization (WHO) and UNAIDS began to point to India as the “new epicenter of the global AIDS pandemic” (see, for instance, 12th World AIDS Conference, 1998). The increasing attention, expertise and funding, from the national government and international agencies, was accompanied by a proliferation of nongovernmental organizations that addressed the epidemic.

Within the national government, there was increasing talk about a role for NGOs. Officials at the National AIDS Control Organization (NACO), which was the government’s nodal AIDS policymaking agency, repeatedly, and somewhat unusually for the Indian bureaucracy, noted that, “NGOs are crucial alliance partners of the government” (interview A, 2005, interview B, 2006). Each successive phase of India’s national AIDS policy had a steadily increasing role for civil society groups. The role and responsibility attributed to the NGOs was most prominent in the most recent iteration of the national AIDS policy, National AIDS Control Policy 3 (NACP 3), which was released in 2007. Officials at NACO, and at the World Bank and UNAIDS which were additional key players in drafting the AIDS policy, took pains to point out that they had consulted several NGOs while preparing the policy document. NGO representatives were included in most of the fourteen working groups, and many of the research reports commissioned for the policy were prepared by NGOs. One of the working groups was led and coordinated by a prominent NGO based in Delhi.

Moreover, NGOs were involved not only in the making of the policy. Within the policy documents, they were given a range of roles that included education and awareness campaigns, voluntary counseling and testing, condom distribution, care and support of HIV-positive people, and a host of targeted interventions within high-risk communities (See for instance, NACO, 2005; NACO, 2006).

There is some irony in the fact that the government's AIDS policies delegate their responsibilities to organizations that are specifically proclaimed to be *non-governmental*. As the state is receding from some of its traditional roles, it is contracting its governing responsibilities to a range of civil society organizations. To explain this shift in public health administration, state officials pointed out that the government was particularly unsuited for reaching out to groups that were seen as most vulnerable to AIDS. "These groups are not even recognized by the law. Prostitution is illegal. We still have old laws from the British era, Section 377 of the Indian Penal Code, that criminalize sodomy. Drug users, who are the main carriers of the infection in the northeastern states, see the state as a penalizer rather than as a provider of useful services and information," explained a former director of NACO in an interview. "How are we in NACO going to be effective in conducting outreach and educational programs for homosexuals, sex workers and drug users when another arm of the government, the police, is hunting and penalizing these very groups?" (Interview D, 2006. Also see NACO, 2005, p.19)

Non-governmental groups working on AIDS generally agreed that the state was unlikely to be effective in efforts to reach out to high-risk groups. An official with an NGO that works with prostitutes in Mumbai explained, "Most sex workers don't live in brothels. They are on the streets, or in homes. How would a government reach out

to these women and men? There is no official champion in the government for these groups. There is no official site where these groups can be reached” (interview T, 2006). Another group, based in Delhi, that worked with issues of sexuality similarly saw the government as being particularly maladroit in reaching out to men who have sex with men (MSM). “The government has very little to offer in this field. So it is passing the buck so that we can deal with sensitivities such as the issue of MSM. Even though it is skeptical of NGOs, it has become dependent on NGOs to do the work,” stressed one of their leaders (interview U, 2005). In order to underline the government’s inefficacy with risk populations, and its dependence on civil society groups, both the government and NGOs have devised arguments to justify the retreat of the state from what earlier would have been considered to be its crucial public health mandate.

The limited reach of the state with marginalized groups, however, is not the only explanation for the central role of NGOs. As mentioned earlier, the AIDS policy orientation denotes a big paradigm shift in public health practice as the state is displaced, or displaces itself, to put NGOs at the center. It is unlikely that this significant shift took place because the health ministry bureaucracy suddenly became reflexively aware of its limitations. Both the government and members of various NGOs admit that pressures from international donors were an important driver behind this paradigm shift. “The World Bank, when it pushed for the formation of a separate AIDS policy unit, was insistent that it wanted the government to involve civil society groups. Participation was a key word,” said a retired Ministry of Health bureaucrat to explain why AIDS policy was distinct from other portfolios in health (interview F, 2006). Members of NGOs concurred. As the head of one of the oldest groups that works on reproductive health, and now AIDS, explained, “The World Bank, DFID,

USAID and big donors such as Gates and Clinton are very important stakeholders in HIV/AIDS. This is not like reproductive health where the government owns everything. The government doesn't even respect NGOs most of the time. To understand why nonetheless NGOs are central to AIDS policy in India, you have to look at the international bodies" (interview R, 2005).

The strong inclination of most international donors to involve NGOs is reflected in their funding patterns. Most of the larger donors, with the prominent exception of the Gates Foundation, tend to funnel their funds to the government. However, funds donated to the government are often earmarked for civil society organizations. For instance, the United States Agency for International Development (USAID) works with a combination of different non-governmental groups and technical agencies in the states of Tamil Nadu, Maharashtra, Pondicherry and twelve port towns. The World Bank's funds often carry clear stipulations about disbursement to civil society groups, as does aid from the United Kingdom's Department for International Development (DFID). Typically funds from these donors such as UNAIDS, the World Bank, the Global Fund, USAID and DFID are transferred to the national-level NACO which in turn disburses them to various state-level AIDS control societies. Then, the state-level societies disburse the grants to various NGOs.

World Bank officials justified the strategy of supporting policy implementation by nongovernmental groups by pointing to their disillusionment with older programs run by the Indian government. They stressed that the urgency of AIDS demanded a different approach. As a program manager at the World Bank's New Delhi office explained, "We were worried about funds and initiatives being lost in labyrinthine state bureaucracy. It would be much more effective to have this money go to NGOs

which are on the ground” (interview J, 2006). In this, the official was echoing perennial concerns of grant money being misused or being badly managed. Other international organizations were skeptical of the government’s initial resolve to deal with the epidemic. “People at NACO would go through the motions, but where was the urgency, where was the resolve?” asked a WHO representative, echoing a common cynicism about the state’s seriousness, which was regularly called into question, especially in the early years of the epidemic, despite the progressive language of policy documents (interview K, 2006).

An Emerging Model of Contractual Accountability

The centrality of NGOs is raising vital questions about accountability in public health. Who is responsible for public health services, for whom, and how? Public health, after all, has been primarily the domain of the government. The government in India was the purveyor of basic public health services in much the same way that it provided primary education and public infrastructure. In the AIDS sphere, however, public health and its accountability are no longer strictly in the domain of the government. They are, instead, increasingly intertwined with global developmental capital.

In the last decade, the international attention to India’s AIDS epidemic resulted in enormous amounts of development capital being pumped into the country.

International donors have provided the Indian government with funds that have resulted in the budget for AIDS exceeding the entire remaining national health budget (NACO, 2006, Baria, 2005). Much of this international money has been explicitly routed to NGOs. “We have been zombied by dollars,” admitted the president of one of India’s most prominent NGOs working on AIDS. He described how his group, which had historically focused on youth and reproductive health, had now become a

significant AIDS organization. “Fifty percent of our budget in 2006 comes from AIDS. In 2000, less than 10 percent used to be from AIDS” (interview R, 2006). Several other NGOs that used to work on rural health, reproductive health, women’s issues, child health, etc. have transferred their resources to AIDS because of both the quantity of funds and the ease of accessing them. “AIDS has depleted funds, interest, and trained people from all other social and especially health problems. It has always been the case that social sector funding had its cycles, like designer fashions. International treaties very often set these fashions. Right now, family planning is down, AIDS is up. We have seen other trends before, but none which has brought in as much money as AIDS” (interview R, 2005).

Not only have existing NGOs shifted priorities, several hundreds of new NGOs have sprung up in response to the new funding. While there are many groups with proven track records of working on AIDS, there is an increasingly cynical acknowledgment among international donors, the state and within the NGO community about fraudulent outfits that have mushroomed overnight in order share in the glut of international money. An audit conducted in the state of Maharashtra revealed that half of the 157 NGOs that had received funds from the state’s AIDS control society proved to be bogus and didn’t have the established programs they had described in their funding proposals. In addition, there were charges that officials in the state AIDS control society were asking for commissions to sanction grants (Baria, 2001). The founder of a NGO in Delhi which works with AIDS orphans voiced an oft-heard complaint: “The relationship between many NGOs and the state governments is often corrupt. The governments need to disburse the funds, the NGOs give them kickbacks in return for receiving funds. ... Look at the parking lots of these NGOs. There used to be a time when you might find a small Maruti 800 without AC. Now you will see

only international sedans like Ford and Honda” (interview L, 2006). [Maruti 800 is an Indian-made compact car.] A recent World Bank report, released in January 2008, discussed massive corruption in NGOs involved in AIDS health projects (Padma, 2008).²⁹

Complaints about NGOs siphoning off development money flowing in for AIDS has brought to the foreground the broader issue of accountability in the realm of public health. In light of frequent media reports and concerns from donors, the government and international agencies frequently discuss the need for distinguishing between “good” NGOs and “bad” NGOs. What is emerging is a new model of accountability in public health that is based on contracts. In this model of *contractual accountability*, NGOs are accountable to the state government (or occasionally, directly to NACO or international donors). The state government in turn is accountable to the national government, which is accountable to international donors. The chain of accountability closely follows the transfer of developmental capital.

The focus in this model of accountability is prudent and prescribed use of funds. In other words, NGOs are accountable to the government not necessarily for delivering a particular health outcome, but for showing that they have used their grants in a judicious and honest manner. Similarly, the government is accountable to international donors not for reducing the prevalence of HIV but for ensuring that it and its contracted NGOs prudently manage financial resources. Indeed, it is the demands of such accountability to international donors that led to the creation of NACO as a stand-alone program, relatively autonomous from the ministry of health. As I have

²⁹ Of course, as many commentators have pointed out, the irony is that it was the World Bank that had initially pushed for the involvement of NGOs, calling them the “engine of a decentralized national AIDS program” (Padma, 2008).

argued elsewhere, NACO was designed to be somewhat separate from the ministry of health in large part because of World Bank concerns. The Bank was worried that it would not be able to monitor and track its several million dollars of AIDS-related loans if the money was given to the Ministry of Health at large. The accounting requirement of World Bank funds resulted in a particular institutional architecture in the Indian government (Mahajan, forthcoming). In this emerging contractual model of accountability, “transparency,” good “systems,” and well-maintained accounting “books” are the recurrent buzzwords.

In the emphasis on good books and audits, what sometimes gets pushed in the background are the intended subjects, that is, the vulnerable populations and patients, and the complexity of public health processes and outcomes. In many interviews, representatives of NGOs clearly acknowledged the problem of corruption and the ensuing need for regulation. However, they also complained that the consequent focus on strict processes often came in the way of delivering good services. Many complained about being “straitjacketed” by the rules of donors. “This is the money for 10 beds. This is the money for antibiotics to deal with opportunistic infections. But what about other forms of care? Other forms of testing? What if we can’t always show where every paisa is going? What if there are unanticipated events? What if things take much longer, much longer, than we had originally thought? All of that can get categorized as misuse,” remarked an NGO official, echoing frustrations expressed by many groups (interview U, 2005). Another NGO worker described her group’s health program for prostitutes that was funded by an international aid agency. “We could do Pap smears, and give the sex workers many medicines for STDs [sexually transmitted diseases] but we could not use our funds for providing health facilities to these women’s children.” She remarked how the boundaries imposed by such funding

rules affected the credibility of her organization with the prostitutes they were hoping to help (interview T, 2006). Many other NGOs reiterated how the accounting requirements by donors did not always map onto how social work is done “on the ground.” Thus, one consequence of contractual accountability is that NGOs increasingly structure their work around the constraints of their contracts and the attendant evaluations.

What is also emerging is how the rules of contractual accountability – of transparency, auditing, financial evaluations – are creating new definitions of “misuse” and “corruption.” As the national government and international donors try to deal with problems of bogus NGOs by creating new systems and audits, they simultaneously define new forms of fraud. Some of these newly classified acts of corruption – such as providing healthcare for children of prostitutes, planting trees, promoting handicrafts as a source of livelihood for indigent women – may not have been specified in the contracts as being AIDS-health related activities. But nor were these activities always deemed corrupt in NGOs’ work with communities. Definitions of misuse here turn out to be a complex north-south collaboration.

While NGOs find themselves increasingly dependent on funders, the government too finds its autonomy braided to its commitments to international donors. No more is it directly responsible only to its citizens for the day-to-day delivery of health services. Rather, the government increasingly is accountable to the donors who provide more than half the national budget for AIDS. No more is the government directly in charge of health delivery. Rather, it outsources its conventional functions of public health to NGOs. The resultant “private indirect government,” at an obvious level, attenuates the state’s role in providing basic public services (Mbembe, 2000). But it also raises

questions about how the state can enforce regulation. If the state *itself* is no more running health programs, then how can it guarantee to international donors that their monies are being wisely utilized? I argue that the retreat of the state from its traditional political functions creates a special importance for contracts. It is through contracts, which are underwritten by transfer of global capital, that the state attempts to retain order in the face of its own retreat.

The anthropologists Jean Comaroff and John Comaroff have argued in *Law and Disorder in the Postcolony* (2006) that the retreat of the state has led to a “fetishism” of the courts. According to them, in light of the increasing withdrawal of the state, it is the courts that become the “utopic institutional site” to which all turn for maintenance of order (Comaroff and Comaroff, 2006, p. 33). However, in India’s AIDS terrain, I argue that it is not the court but the contract that serves as the regulating, ordering device. And the contract here is not backed up by the courts, or by national law in general. After all, despite many complaints about corruption, donors have seldom, if ever, taken the government or any NGO to court.³⁰ If funds are misused, the international donor (or the government) seldom makes threats of litigation. Rather, the national government or the donors simply abandon or change the terms of the contract.³¹ “There is a constant worry that the contract will be cancelled,” admitted an NGO official, echoing a common anxiety among the NGO community (interview U, 2005). In other words, even though breach of contract is

³⁰ The court cases related to AIDS in India are typically about violation of individual rights, such as the right to privacy. There have few, if any, cases over programmatic, policy or funding disagreements between donors and NGOs.

³¹ The most recent and a dramatic example of this took place in late 2007 when NACO cancelled its contracts with almost 350 NGOs. According to NACO, the contracts were terminated because of worries about corruption, and because the NGOs were involved with issues that did not match the new program focus. “Migrants and street children, for example, are no longer the primary focus of targeted interventions” (Padma, 2008). The media has suggested that the crackdown by NACO was at least in part the result of a World Bank review that pointed to massive corruption in health projects in India.

often called corruption – an *illegal* act, the breach is seldom sorted out in the larger purview of national law and the courts. Rather the breach is dealt with within the terms specified in the contract, by the contract holders. Contractual accountability in public health, which tethers together NGOs, the government and international agencies, is not dependent on a national legal framework; it is an internally self-sufficient ordering mechanism.³²

Paradigm of Targeted Interventions

The dependence, perhaps better described as co-dependence, between the government, the international donors, and the NGOs, has had significant consequences on how public health interventions are designed and administered. Elsewhere, I have discussed how international technocratic agencies come with a foreknowledge, or a prior template, through which to understand and manage the AIDS epidemic (Mahajan, forthcoming). As per these plans, they, and increasingly the government, have pushed for AIDS policy to be implemented through a stand-alone ‘vertical program’ that has considerable financial and administrative autonomy from the routine workings of the health ministry. Moreover, the government and international agencies have emphasized the importance of ‘targeted interventions’ - focused, group-specific responses rather than broader structural socio-economic response (See for instance, NACO, 2005, USAID, 2005). While targeted interventions have proliferated over the years and taken on many forms, the main pillars still consist of condom distribution,

³² This model of contractual accountability that I describe is somewhat different from a “liability model of accountability” that Adriana Petryna discusses in the context of international clinical trials (Petryna, 2007). According to Petryna, a liability model of accountability involves determining responsible local parties and holding them accountable for acting legally should anything go wrong in a trial (p. 11). This model presumes, Petryna argues, a working national legal system that will deal with the local parties’ inappropriate research practices. In contrast, I argue that the contractual model of accountability does not presume, nor *need* to presume, a working national legal system. The two models of accountability, nonetheless, are related in that both of them describe emerging norms of accountability in public health in the global South in the context of globalization.

focused education programs, and counseling and care in high-risk groups. Attentive to the policy prescriptions of the government and international agencies, many civil society groups have accordingly adopted programs dominated by targeted interventions. Keen to design their projects along the lines prioritized by donors, the NGOs focus on one or another risk group, rather than adopt for instance integrated family-based, or general primary health focused programs. They tend to focus their efforts on how to reach the risk groups, count them, saturate them with information, and distribute condoms to them.

A representative of an NGO that had worked on primary health in western India explained how the group changed its emphasis to focus on specific risk groups. He explained that his organization shifted its strategy fairly recently to focus on the high risk population of truck drivers:

The Gates Foundation decided to put 40 crores [about 10 million dollars] for truckers' projects. The CEO who would coordinate this project was going to be given a salary of over 30 lakhs annually [approximately 75,000 dollars]. We have never seen this kind of money in the social sector. The interviews were being conducted in Oberoi hotel [this is one of Mumbai's fanciest five star hotels]. There were some people even from McKinsey who were interviewing for the CEO post. We got into line. Our group used to work on primary health issues . . . Now much of our work is with truckers (interview W, 2006).

Many of the NGOs admitted to discomfort with the targeted interventions that they were implementing, and complained that this style of intervening was being “thrust down their throats so that donors could see the best spending of their dollars” (interview S, 2006). Many admitted to realizing that this was part of a public health

model that had proven to be counterproductive in the realm of family-planning. As one of the NGO workers whose group focused on male sexuality commented, “These are shortcuts. These are about labeling people, and moving away from the general population. But we know that reproductive behavior doesn’t change that easily, that it requires a far more holistic, social and cultural approach” (interview U, 2005). Many groups claimed that there were dangers of keeping AIDS work distinct from larger primary health programs. However, the architecture of the health ministry and the priorities of the funders made it difficult to integrate AIDS into a broader health agenda. “There is talk of integration and convergence. But it is very difficult to implement, because AIDS is funded by donors through a vertical program, and reproductive and family health is funded entirely by the government in a distinct program in the ministry,” explained a former bureaucrat at the ministry of health and a current official in a population health NGO (interview X, 2005).

How donors are directly shaping NGO programs is vividly illustrated through the work of the Gates Foundation. The Gates Foundation is very much the new dominant player in India’s AIDS sector. With its initial 200 million dollar grant, followed by an additional grant of over 100 million dollars, its contributions have dwarfed those of the World Bank, USAID and other donors. The foundation is distinct from other large international donors like the World Bank and USAID in that it does not go through National AIDS Control Organization and the government. Citing reasons of efficiency, it completely circumvents the government and provides the funds directly to NGOs. Its programs are focused in six states –Karnataka, Maharashtra, Tamil Nadu, Andhra Pradesh, Nagaland and Manipur - that have the highest HIV prevalence (Avahan, 2005). Its projects are all targeted at high-risk groups such as prostitutes, homosexuals, drug users, and truck drivers. According to some NGOs, because of the

disproportionately large funds that Gates brings in, other philanthropic organizations such as Ford and McArthur have demurred at providing AIDS-related grants to projects in those six high-prevalence states.

The Gates Foundation is quite distinct in its approach to the social sector in India. It has adopted a corporate model of management to deal with NGOs. As the president of the India's Gates Foundation, Ashok Alexander, described:

We are unique because of the tremendous execution pace that we have here. Our benchmarks are of the private sector. In the first year, we established our presence in 550 towns, with doctors, peer workers (sex workers) and nurses. If we were a business organization, we would have been very proud of such rapid growth. We follow a business model with segmentation of the problem. Where in the social sector do you find such execution focus? Where do you find such structures of monitoring and evaluation? (interview, Ashok Alexander, 2006)

The foundation tried to ensure its rapid pace of execution by having a highly visible presence on the ground. Alexander explained that they had chosen to be on the ground because of the scale and complexity of the epidemic in India. Outside India, the only other foundation offices were in Seattle and in Washington DC.

In other countries, we invite proposals, and then give grants based on the proposals. We give a check, and require an annual report of activities in return. Our strategy in India is entirely different. Here, we have a physical presence on the ground. Many of the grants we give out are conceived by us – they are developed in consultation with the grantee. Then 6 months into the project, we assess it, see how the project is evolving, and change the

parameters of the grant accordingly. The grantee generally can't come in and drive the strategy – we are very much involved and in the driving seat.

The foundation provides short-term conditional grants to NGOs, and the contracts can be yanked at any time. “If a NGO becomes a barrier between providing a service to society, then we will get another NGO, we will short circuit the power structure to get the service to the people. We focus on speed, on scale and sustainability.” He was insistent that “the community” was at the centre of each Gates project. He saw no problems in adopting a corporate model for dealing with the community, nor with adopting targeted interventions. Indeed, the intervention design was integral to ensuring both efficiency and accountability from NGOs.

At one level, targeted interventions focused on high-risk populations seem like an obvious and sensible course of action, especially if the epidemic is understood as being concentrated in a few discrete groups within the general population. But advocacy of this mode of intervention takes place against a backdrop of a debate within public health about what constitutes as appropriate public health policy. AIDS program designs have been typically guided by a behavior change model. This model presumes that armed with adequate information, individuals will adopt more risk-averse behavior. But there is another paradigm which draws attention not to cognitive processes but rather to social and political contexts that put individuals in the position of vulnerability (for instance, see Farmer 1998, 2003; Pigg, 2001; Halfon, 2007). According to this paradigm, public health programs should attend to how economic and social conditions lead to illness. It calls attention to socio-economic orders reflected in relationships, sexual behavior, and decisions pertaining to health more broadly. According to this model, it is not just a deficiency in information that leads

to risk-prone behavior, but rather absence of access to alternative paths of economic and social viability and power. In more concrete terms, this would mean that effective public health policy should not be about merely distributing condoms and airing advertisements about the dangers of unprotected sex and sharing needles. Rather, public health policy should involve designing AIDS programs that are integrated with primary health and social infrastructure.

This debate between targeted intervention versus an integrated health approach has played out in India's public health history prior to the AIDS epidemic. India's long-standing Population Control Program (later called the Family Planning Program, and currently termed as the Reproductive Health and Family Welfare Program) was the site of a similar debate for several years. One of the lessons that older bureaucrats and experts derived from India's long experiences with population control was to get rid of "targets" and vertical programs (various interviews). In multiple interviews, retired bureaucrats from the ministry of health described how targets for condom use, and for fertility control in general had led many agencies "to cook up" the numbers. More seriously, targets were partly responsible for egregious violence in states such as Andhra Pradesh where forced female sterilizations were conducted in large numbers. This violent and painful history that is an integral part of India's population control program had led to a change in focus away from targets. Targets didn't seem to change reproductive behavior on a sustainable basis. Holistic programs focused on women's literacy and economic well-being seemed to be more effective routes rather than target-based fertility reduction (see Jeffrey and Basu, 1996; Mamdani, 1972).

Alexander acknowledged this public health debate, but defended the Gates Foundation's approach by saying that some vertical programs, such as those for small

pox, had had a more successful history in India. Moreover, the urgency of the AIDS epidemic didn't leave time for long-term structural programs; it required a sharper, more rapid response whose success could be closely monitored and measured. Moreover, the Gates Foundation sought to ameliorate the problem of NGOs' accountability by having a tight monitoring system, clear measurable targets, short-term contracts, and a close watch on the work being done on the ground.

Like the Gates Foundation, many others actors in public health policy forums cite the smallpox program's success as a reason to adopt vertical public health programs (for instance, see Magnussen, 2004; Cueto, 2004). The smallpox program relied on large-scale administration of an easily transportable vaccine to newborn children. It had an easily identifiable target population. It involved the one-time administration of the vaccine. That this might not be the appropriate analogical intervention model for AIDS, especially in the absence of any AIDS vaccine, is seldom acknowledged. AIDS prevention programs require the more complicated task of changing sexual behavior which might find a better analogy in the family health/population control programs in which India has a long history; however, the AIDS establishment in the government, international donor community and NGOs seldom draws this analogy. Instead, the development capital that is gushing into the social sector drives NGOs to pursue tightly circumscribed projects with high-risk groups in the hope of yielding easily measurable results.

Rights, Testing, and Vital Statistics

The previous section described how the vulnerability of NGOs to funding resulted in a preponderance of targeted interventions focused on discrete high-risk communities. This section further describes how the dominant role played by NGOs has also

resulted in particular ways that epidemiological data are collected and understood.

Despite the diversity of NGOs in the field, it is striking how homogenous and familiar their emergent discourse is. The categories and rhetoric the NGOs use to understand and describe the epidemic in India seem remarkably similar to those that are employed in other developing countries such as South Africa, Thailand, or Brazil. The similarity between Indian NGOs and AIDS groups in other countries is perhaps not surprising given how embedded many Indian NGOs are in transnational advocacy networks. These activist networks, as Margaret Keck and Kathryn Sikkink describe, are “bound together by shared values, a common discourse and dense exchanges of information and services” (Keck & Sikkink, 1998, pp. 27). A large number of Indian AIDS NGOs are globally mobile, highly cosmopolitan and very visible in international conference circuits, web-based news groups, and chat rooms. In this section, I will attempt to show how the homogeneity of discourse adopted by the Indian NGOs has direct consequences for how the AIDS epidemic is understood and addressed in India.

The emergent civil society discourse in India is marked foremost by a commitment to individual human rights and empowerment. Various groups struggle for rights to privacy, livelihood, and sexual freedom, and against early marriage, mandatory testing, displacement, and various other forms of discrimination. For instance, many groups in Mumbai have campaigned against crackdowns on brothels which would hurt prostitutes’ right to livelihood and right not to be displaced. Others have fought against sodomy laws on the grounds of protecting rights to sexual freedom. Attempts to enforce mandatory HIV testing have been criticized for violating the right to privacy. Anthropologist Kavita Misra describes in her work how “the emphasis on confidentiality and professional ethics around the maintenance of privacy and personal

information is one of the most urgent and robust expressions of the language of rights that permeates AIDS service networks in India” (Misra, 2006, p. 49). Much of this discourse of rights is drawn from global sources, and has helped put into place new forms of epistemic and political categories, classifications and interventions that are increasingly recognizable throughout the global South. These new forms of governance are not just political arrangements, but also are reflected in how public health knowledge is developed, understood and implemented.

The emphasis on rights has profoundly molded how public health data are collected. For instance, the states of Goa, Kerala, Andhra Pradesh tried to pass laws in 2006 that would require all couples to take HIV tests before marriage. Maharashtra is attempting to pass a similar legislation in 2008. In all cases, there have been strong protests against this proposed legislation on the grounds that it violated the right to confidentiality, and the right to consent to testing. Eventually, the bills were withdrawn from most state legislatures. (The Maharashtra bill is still under discussion.) In this instance, the politics of rights – in this case against mandatory testing – directly influenced the type and quality of seroprevalence data. State government officials stressed that they too were invested in rights, but not only in the individual’s right to confidentiality. As a high-ranking bureaucrat in one of the state’s AIDS Control Societies explained: “The AIDS epidemic is becoming increasingly feminized. Women are being infected in marriages. By mandating compulsory testing, we hoped to give women some strength through information. We hoped to provide protection to women in marriages” (interview E, 2006).

Other officials commented on how mandatory pre-marital testing was a non-discriminatory way of collecting important seroprevalence data. Public health experts

have historically paid great emphasis on building up reliable public health statistics as necessary – though not sufficient – criteria for addressing epidemiological problems. For instance, historians of public health have extensively discussed how comprehensive testing policies and public health intelligence systems, whether in relation to contemporary Cuba’s AIDS epidemic, China’s “internal passport system,” or in early modern England and France, have been instrumental for controlling epidemics and leading to dramatic improvements in public health (see for instance, Szreter, 2005). In contrast, a public health information system is a relatively low priority for India. Moreover, efforts to create one are occasionally thwarted by activists who see the extant modes of testing and surveillance as being egregiously in violation of individual rights and as leading to stigmatization of particular groups.

The activism against mandatory testing takes place against a complicated backdrop. The earliest examples of mandatory testing for HIV were far from benign and universal, and were specifically targeted at vulnerable groups. For instance, starting in late 1987 in Madras, prostitutes were frequently tested, along with foreign students who came primarily from Africa. Several prostitutes tested positive for antibodies to HIV and this contributed to the establishment of the oldest profession as the dominant high-risk category in India (Cohen, 2005). Similarly, in 1998 the state of Maharashtra tried to enforce mandatory HIV testing for all prostitutes in Mumbai. Many of those who tested HIV positive were removed to an institution outside of Mumbai. The compulsory testing and quarantining was strongly opposed by various non-governmental groups, and eventually it was these protests and the subsequent litigation that forced the government to change its policy (Chhabra, 2007).

Similarly, activists who rally for the right to confidentiality point to how patients have

been kicked out of hospitals after being diagnosed HIV positive. Others point to how confidentiality and privacy are not guaranteed precisely to those groups and sections of the population that are likely to be most vulnerable to social ostracization and stigma. “These are not benign public health surveys. These are tools that the establishment uses to stigmatize the very people it should be protecting,” stressed a worker with a NGO that tried to define its ethics through a primary commitment to confidentiality (interview Q, 2006). However, just as the right to consent has been challenged by state bills, the right to confidentiality has also been contested, often from within the medical establishment. “Indian hospitals don’t always have sterile hygienic work conditions for doctors and nurses. We don’t necessarily use disposable needles. So we are constantly undertaking risk in working with patients. Shouldn’t we be told about the HIV status of the patient?” asked a doctor at Delhi’s premier public hospital, expressing her discomfort with the confidentiality guidelines that the institutional ethics board of her public hospital in Delhi had recently introduced. She described how under current guidelines, HIV status was privileged information that affected persons could choose to withhold from their doctors. She argued that this information was “obviously” important for ensuring better care. “Family members, especially wives, look after the sick. Shouldn’t they know? Shouldn’t the nurses who provide IV and the ward boys who help bathe and clean the patients know? The ward helpers, who deal with sharp objects and bodily fluids, are constantly vulnerable. Why are the rights only with the sick individual? Why not with others who care for the sick?” (interview G, 2005)

This tension, between individual rights to consent and confidentiality, and larger public health goals of obtaining information and evaluating whether remedial measures are truly taking effect, continues to be a febrile source of conflict within the

medical and public health circles in India. NGOs typically position themselves as the bearers of service for the sick and protectors of their rights. Their lobbying, litigation and public campaigns have proved to be effective in that the national policy establishment increasingly agrees with them and espouses similar norms of confidentiality and consent. The national policy documents underline “voluntary” testing, and NACO has come down against hospitals, and state governments that have pushed for mandatory testing. The norms of confidentiality and consent that now pervade the policy establishment resemble those in the United States, and in many other parts of the west. Arguments made in favor of universal testing or comprehensive data collection are increasingly falling to the wayside as policymakers emphasize the ethical costs of such approaches.

However, these new regimes of ethical norms, often translated through a global language of rights, did not impact only the realm of morality. As I have tried to show above, these norms also directly shaped which epidemiological data were collected, and how they were obtained. They determined which interventions were considered acceptable, and which were ruled out. In other words, NGOs’ adopting a cosmopolitan discourse of rights resulted in collective measures, such as universal testing, as being discredited in favor of voluntary testing and privacy.

Men Who Have Sex With Men

NGOs in India are shaping how epidemiological data are collected and understood not only through their rights-discourse. They also shape the understanding of the epidemic by determining which risk categories are relevant to AIDS. By adopting, studying and working with particular risk categories, civil society groups have facilitated the emergence of new social identities in India. Nowhere is the emergence

of such identities more prominent than in the realm of sexuality.

The large amounts of developmental capital and the many social groups that have been associated with the AIDS epidemic have brought to the fore new debates and labels for sexuality and gender in India. NGOs working on AIDS epidemic are often involved in debates and discussions about sexuality and its role in the epidemic. Often, the projects for combating AIDS are simultaneously projects that create new sexual identities. For instance, Bombay Dost, one of the country's most prominent groups that works with gays uses its funds to throw large gay parties and support gay publications. According to Bombay Dost leaders, throwing these parties was no different from doing other forms of AIDS work. In fact, by consolidating and building a gay community, Bombay Dost saw itself as creating a platform for dispersing AIDS awareness and prevention messages.

The political scientist Dennis Altman has commented on how the cosmopolitan category of "gay" has spread across the world along with the capital, institutions, norms and viruses associated with the global AIDS epidemic (Altman, 1996, 1997, 2001). In contrast with the story of a seamless global spread of a sexual identity, the anthropologist Lawrence Cohen provides a more complicated narrative of same-sex politics in India and how it is changing in conjunction with the mobilization around the AIDS epidemic (Cohen 2005). Cohen describes the struggles between two competing NGO networks over whether to legitimize the category of "gay" or the "*kothi*" concept. *Kothi* was a name for a particular family of NGOs "an indigenous gender category for a 'feminized' identification within nonelite (and thus nongay) networks . . ." (pp 269-270). According to this group of NGOs, *kothi* refers to men who act or identify in some way as women. *Kothi* (along with *panthi*, "the real man,"

counterpart to the *kothi*) embodied “gendered” as opposed to “sexual” norms, especially among the non-English speaking, non-elite groups. This gendered identity was presented as more appropriately reflecting Indian “reality” than sexual identities as represented by the terms homosexual or gay. In contrast, the NGO network that pushed for “gay” identities refused gender as the relevant defining axis. This network was instead keen to push a gay identity, that it viewed as much more empowering than a glorification of traditional concepts such as *kothi*. According to this network, the *kothi* concept was a being pushed by Western-style activists in search of the “exotic other” in India. In the vivid and dramatic story that Cohen tells, both categories, of the *kothi* and the gay, get reified and materialized in the debates and conferences related to AIDS. Both networks clashed over the authenticity and historicity of the identities gay and *kothi*. Each accused the other of being driven by an AIDS cosmopolitanism, a foreign other, either in the form of Western-style activists looking to “discover” a unique exotic culture in India, or by English-speaking elite minorities who related more easily to the gay communities of the west than to local realities and lived worlds of India.

What is at stake in many of these debates is not only the power to represent sexuality in India, but also to determine the meaningful terms and categories to be used in the economically fortified enterprise of AIDS policy. These debates spilled into the more rarified policymaking realms of New Delhi. In the formulation of the national policy on AIDS, there was a charged discussion on how to describe ‘homosexuality’ and design interventions for this social category. A group of NGOs argued against the use of the term ‘homosexual.’ As one of the members who was involved in this debate explained to me, “We were pushing for the more capacious term of MSM [men who have sex with men].” This group argued that many men who have sex with men in

India also have sex with women. Many are married and have families. Many ascribe to gendered categories of *kothi* or *panthi* or use terms such as *jankha* or *saheli*. This panoply of identities and social conditions did not necessarily map onto the word homosexuality, which had a specific cultural social and political identity of its own. Other experts retorted that these men, who were sometimes married, were just men in denial, men who were fearful of being socially ostracized. They argued that adopting the category of gay or homosexual would not only be a more honest description of their sexuality, it would eventually empower these men. Instead, MSM was not an identity, as it would not give these men any “group advantage.” The first group, in favor of MSM, came back with the retort that one could not presume that Indian men were seeking to realize the same social “gay” identity that was common in the west. One could not presume, in other words, that Indian conceptions and subjectivities of male sexuality and masculinity were in what Dipesh Chakrabarty has called “the waiting room of history” (Chakrabarty 2000, p. 8).

Eventually, policy documents, and powerful international agencies such as UNAIDS took on the term MSM. While there were some pressures to use categories that conform to an international taxonomy, the MSM-homosexual debate revealed how the pressure of global norms was negotiated with local contingencies. In my interviews with various officials at NACO and at organizations such as UNAIDS and WHO, MSM as a category was considered to be both politically and epidemiologically more viable. It did not tightly circumscribe a cultural identity or a behavioral identity in the way “gay” or “homosexual” tended to. For many at NACO, MSM also did not automatically rule out all other positions and categories in the way that “homosexuality” seemed to. The category-brokering around male sexuality in India’s AIDS policymaking realm seemed to facilitate a more capacious, though problematic,

realm of MSM that then became the matrix for AIDS prevention and education interventions.

Access to Treatment

Indian AIDS NGOs, while attentive to global discourses, have not adopted all aspects of the rights-talk that pervades transnational social movements. Most strikingly, NGOs in India have seldom demanded “a right” to antiretroviral drugs. This goes against the prevailing trend in many other developing countries such as South Africa and Brazil where civil society groups have made “rights to treatment” a foundational platform for their activism. Anthropologist Joao Biehl has referred to this trend in his work on the “pharmaceuticalization of public health” (Biehl, 2006, pp. 222); similarly, anthropologist Steven Robins has discussed this movement of rights to treatment as undergirding new forms of “health citizenship” (Robins, 2005).

The absence of a prominent demand from NGOs for rights to antiretrovirals dovetails with the Indian national government’s policy. Although the Indian AIDS policy comports with many global trends, it has never offered treatment through antiretrovirals. The latest iteration of the national AIDS policy, NACP 3, has a small pilot project that seeks to provide antiretrovirals to 20,000 AIDS patients over the course of the next 5 years (NACO, 2006). Even this relatively modest inclusion within the policy was controversial and met with resistance from within the ministry of health and NACO (interviews B and C, 2006).

The abstinence from antiretroviral drugs is ironic given the fact that Indian pharmaceutical companies are the world’s largest manufacturers of generic versions of the drugs. While antiretroviral drugs are under patents in most countries, India’s

intellectual property laws, until 2006, allowed for these drugs to be manufactured and sold in generic form. As a result, Indian pharmaceutical companies such as CIPLA and Ranbaxy have provided generic and much cheaper forms of antiretrovirals to governments of developing countries such as South Africa, and to organizations such as Doctors Without Borders. In a 2005 report, Doctors Without Borders estimated that over 80 percent of generic ARVs used in the developing world came from India (Doctors Without Borders, 2005). “I provide heavily discounted drugs to NGOs and governments all around the world, but my own country, the epicenter of AIDS, will not buy these drugs from me,” complained Dr. Yusuf Hameid, the chairman of CIPLA, which is India’s largest pharmaceutical company (interview, 2005).

NACO has always maintained that it does not make economic sense to concentrate meager financial resources in buying expensive drugs for a few, when the same amount of money could be used in large-scale prevention programs (interview D, 2006, interview A, 2005). The silence of the NGOs on the issue of treatment is more puzzling, as they are not necessarily heavily invested in public resource triage.

An important part of the explanation perhaps lies in the politics of representation. As discussed earlier, Indian NGOs are not mainly formed by people affected by AIDS. Rather, the NGOs code themselves as “service” organizations. They understand the epidemic to be concentrated in high-risk populations such as of truck-drivers, prostitutes, homosexuals and drug users. While AIDS NGOs provide services for these vulnerable populations, they don’t necessarily claim to politically or socially represent these marginalized groups. The marginalized populations, ostracized by both law and culture, have not created strong political or social pressures on the national government and civil society for antiretroviral therapy.

Other explanations are provided by NGO leaders. “We are fund-dependent,” explained a NGO worker. “In HIV, the funds are not in buying ARVs [antiretrovirals]. The funds are in rehab, drug reduction, hospice care, support, and literacy. But not in ARVs.” Most other groups concurred and pointed to donor contingencies and pressures. Multilateral donors and foundations such as the World Bank, DFID, the Gates Foundation and the Clinton Foundation, have not allowed their funds to be used for purchasing generic forms of antiretrovirals. A typical example is the Clinton Foundation, which offers to negotiate with multinational pharmaceutical companies on behalf of the Indian government or other interested parties to obtain lower prices for the drugs. However, it refuses to fund the purchase of generic versions of the same drugs in India. While access to AIDS drugs is a big goal for the Clinton Foundation, it doesn’t support any means of access that could potentially violate drug patent privileges. The Clinton Foundation did not fund purchase of generic drugs even when it was legal under Indian national laws to manufacture and sell generics of drugs that might be patented in other countries (interview L, 2006). The World Bank, USAID, DFID and the Gates Foundation are similarly reluctant to support any policy or NGO project that could potentially violate patent privileges of multinational pharmaceutical companies.

The refusal of international donors to support generics is coupled with the Indian government’s own newly strained position on the issue. The growth of the AIDS epidemic in India is coincident with a dramatic transition in its domestic intellectual property regime. In 1995, the country signed onto the TRIPS (Trade Related Intellectual Property Issues), which is the WTO section that deals with intellectual property rights. India was granted a 10-year transition period within which to bring its

national laws in accordance with TRIPS. The new national laws, passed in 2005, provide product and process patent protection to pharmaceuticals in order to comply with TRIPS requirements. These new laws force the government to respect patents on antiretrovirals and require it not to export or import generic versions of the ARVs unless sanctioned by the original patentee. The combination of the international funders' reticence and the national government's freighted stand on international intellectual property rights perhaps explain why NGOs in India seldom demand the rights to drugs. As in the case of emphasizing targeted interventions and adopting a discourse of individualized human rights, civil society groups' politics of access to treatment turns out to be strikingly aligned with the policies of international donors and the national government.

Conclusion

In a marked shift in India's public health history, nongovernmental organizations have been brought to the centre of policy execution in the AIDS epidemic. In this chapter, I have examined the politics between NGOs, the national government, and international donors that has facilitated this dramatic policy shift wherein the government increasingly "outsources" its public health functions to NGOs. I analyze how the recent prominence of civil society groups has had profound political and epistemic consequences.

I argue that the huge amounts of global development capital that NGOs' have received is leading to a new model of contractual accountability in public health. This model of accountability is focused on prudent financial management. Increasingly, NGOs structure their work according to the constraints embedded in this model of contractual accountability. Responding to the incentives and priorities of donors and their

contracts, NGOs shape their public health programs in favor of targeted interventions over more integrated approaches. They increasingly advocate a globalized discourse of ethics which adumbrates the values of privacy, confidentiality, and more generally, individual rights. This advocacy of individual rights shapes the moral landscape of AIDS and public health, but also profoundly determines what count as legitimate public health interventions. However, this embrace of a rights discourse has not resulted in Indian NGOs typically demanding rights to antiretroviral treatment. This reluctance to demand rights to drugs, like the embrace of targeted interventions, reflects the vulnerability of NGOs' to their international donors.

Even though many NGOs voice misgivings about some of the funders' priorities, they also face irrevocable pressures to conform to fund-driven plans. Their vulnerability to circulations of global development capital reveals how even though formal policy documents discuss "participation" by NGOs, this participation by no means results in benign relations of power between civil society actors, the government and international donors. Even though NGOs have been involved in some of the highest levels of policy-making, this hasn't necessarily given them autonomy from structural pressures of funding. The burgeoning literature on participation often emphasizes the importance of civil society groups' "upstream involvement" in policymaking so that local actors have the opportunity to define terms of the debate (Reardon, 2006, Clark and Murdoch, 1997, Wynne 1996). The AIDS story in India points to how the outcomes of civil society participation even at high levels of policymaking can be overdetermined by structures and norms of funding.

In her work on "denationalization," Saskia Sassen argues that the state is assuming a new role in an era of globalization. While discussing the increasing role of foreign

business firms in national economies, Sassen states that the embeddedness of globalization in national territory is facilitated by the state's own withdrawal from regulating the economy (Sassen, 2002). In many ways, India's AIDS policy provides an example of a similar denationalization in the realm of public health. In AIDS policy, the state withdraws and disperses its authority and administrative duties to a whole host of non-governmental organizations. In doing so, the state further enables the embedding of global norms and categories in the political, epistemic and normative landscape of AIDS, and more broadly in public health. It is not that the state is wholly absent from this landscape; indeed it is often an important obligatory passage point for many NGOs that want to obtain development capital. However, the state's role comes in the form of its 'outsourcing' its functions in the arena of public health, an arena that has traditionally been viewed as the direct purview of government. Instead of being directly responsible for public health, it becomes party to an emerging model of contractual accountability wherein its responsibilities are increasingly tethered to those of NGOs and international organizations. The story of AIDS in India provides a window into emerging logics of globalization wherein public health, a traditionally sovereign realm of the state, is increasingly within the purview of international organizations and civil society groups.

Chapter 4. AIDS Policymaking in Post-Apartheid South Africa: Redefining Expertise, Science, and Politics

Introduction

In late 1999, Thabo Mbeki, the president of South Africa, made what are now infamous comments that questioned the causal link between HIV and AIDS. The president's skepticism about mainstream science provoked outrage and derision both within the country and abroad. Since then, both popular media and academic scholarship on AIDS policy in South Africa have overwhelmingly focused on the seemingly heretical statements made by the South African premier. Numerous analyses have been offered to explain why an otherwise technocratic, "science-friendly" government adopted such a bizarre stand vis-à-vis AIDS.³³

In this chapter, I am less concerned with the Mbeki government's underlying motives. Instead, I hope to examine how AIDS became a terrain in which the relationship between expertise and political power was molded in post-apartheid South Africa. The debates and controversies over AIDS shaped, and sought to shape, the relationship between the government, institutions of scientific research, and civil society. Sheila Jasanoff has used the term "civic epistemology" to describe the social norms, institutional arrangements, and policy orientations that determine authoritative knowledge in a society (Jasanoff, 2005). In this chapter, I hope to show how the politics related to the AIDS epidemic shaped post-apartheid South Africa's civic epistemology in new and unexpected ways.

Moving the focus away a bit from some of its more outrageous statements, I

³³ For instance, see Butler (2005), Nattrass (2005), Sitze (2004), and Richey (2006).

investigate the paradigm of public health that the Mbeki government proposed in its policies. I ask how this paradigm of public health was different from what the government's critics were proposing. What did this paradigm take into account and what did it render irrelevant? What evidence and expertise were considered important?

I will argue that in its policies, the Mbeki government proposed a paradigm of public health that was explicitly concerned with social and economic factors that influenced the AIDS epidemic. I have referred to this paradigm as a "structural socio-economic" paradigm, versus the "biomedical" paradigm proposed by the government's critics. In the structural socio-economic paradigm, analyses of poverty *and* virological studies were equally important; traditional healers and molecular biologists were both considered relevant experts on how to understand illness and disease; history was deemed a relevant lens through which to understand expertise and health. In such a paradigm of public health, traditional boundaries between "science" and "politics" were redrawn to make more room for non-scientists and unorthodox scientists in science policy. Understandings of expertise shifted. There were challenges to established relationships between the local and the global, the national and the international, the centre and the periphery. New conceptions of the role of history and imagined futures in public health policymaking were brought to the fore. In other words, a much broader range and variety of stakeholders and abstractions were deemed relevant in formulating AIDS policy. In proposing such a structural paradigm of public health, the Mbeki government was also implicitly and often explicitly challenging various aspects of the larger global socio-technical machinery of AIDS.

I will examine how, in the end, the Mbeki government substantially failed to shift the paradigm of public health to a more holistic approach that emphasized social and

economic features integral to epidemic management. This is a government that is likely to be remembered for its unconventional, and for many, very offensive, statements about HIV-causation, toxicity of antiretroviral drugs, and the role for garlic and olive oil. It seems unlikely that this period in South Africa's young democratic history will be associated with ushering in new holistic paradigms of public health and policy, despite what the government tried to do through its policies and bureaucracies. The government, very self-consciously, sought to change how credibility should be accorded to public knowledge. However, the rules for determining scientific credibility did not shift all that easily. Their intransigence provide insights into how certain types of scientific order sustain their authority in the context of a postcolonial nation that is inextricably connected to global circulations of knowledge, people and materials.

I first describe some of the politics around AIDS during the apartheid years. While I sketch this history very briefly and with only the most cursory strokes, it is an essential background to contemporary debates. The next section provides a sketch of the national AIDS policies in the post-apartheid period from 1994 to 2007. Following this, I turn attention to some of the incidents wherein the government attempted to redraw boundaries between politics and science. At the center of this boundary work were questions of expertise. Who were the relevant experts in addressing AIDS, and what role should they have in policymaking? What especially should be the role of experts in policymaking when the science was new, relatively uncertain, and often contested? These questions about expertise, technical decision-making, and representation are core topics within science studies and democratic theory.³⁴ In South

³⁴ For a sample of such scholarship in science studies, see Ezrahi (1990), Jasanoff (1990), Epstein (1996), Fuller (2000), Hilgartner (2000), Collin and Evans (2002), and Lynch and Cole (2005). In political theory, see Habermas (1971) and Oakeshott ([1962]1991).

Africa, these were not academic subjects. Instead, they were highly contentious debates that were fought out in public arenas of the popular media, courtrooms, the parliament, street protests, and international conferences. In the final section, I move away from the government's statements and instead focus on how scientists who work on AIDS in South Africa responded to the state's actions. The conclusion explains why the debates about science and AIDS in South Africa were also simultaneously about national sovereignty as South Africa contends with increasingly globalized epistemic and economic systems. The inability to change the terms of the debate over AIDS in South Africa underlined the limitations of extant national sovereignties.

The Apartheid Legacy: Contested Understandings of AIDS

The history of AIDS in the apartheid era serves as an important background to understand the contemporary contested terrain of the epidemic. This history reveals that various actors in South Africa viewed the disease, its definition, epidemiology, and knowledge about prevention and treatment through a heavily tinted lens of race. The apartheid government used, and was perceived to use, the fault line of race to construct definitions of AIDS and the reasons for its spread. This history reveals that from the outset, AIDS was embedded in a deeply politicized, febrile and racially divided debate. Different groups used the disease as a platform for their rhetoric of hate and blame, credibility and authority. During this period, the majority black population heavily distrusted and contested the information about AIDS provided by and associated with the apartheid government.³⁵ The Mbeki government's

³⁵ South Africa has a complicated, and highly political taxonomy of labels for racial groups. Black, white, colored, Cape colored, Malay, African, Afrikaaner, Indian – all jostle for space and meaning, and indicate different things in different contexts. There are multiple museums in South Africa devoted to the politics of these categories and labels, how they were constructed, and how they have shifted. Within Science Studies, Geoffrey Bowker and Susan Leigh Star (1999) have discussed the racial classification under apartheid in South Africa. Jenny Reardon (2004) has similarly discussed the politics of classification of racial groups in the context of the Human Genome Diversity Project. For the purposes of this dissertation, I will use “black” to mean all “non-white” people. Thus, black here

controversy, in some ways, is only the latest in what has long been an unusually contentious history.

AIDS was first detected in South Africa in 1982 when the country was still under the apartheid regime. The first cases of AIDS were detected among white gay men (Epidemiological Comments, 1993, p.3). This was around the time when the male homosexual community in the United States was active in a vocal social movement that was constructing AIDS as a human rights and gay rights issue (Epstein, 1996). Likely influenced by the social movement in the United States, the initial writings on AIDS in South Africa discussed patient rights and easy access to experimental drugs (Brandt, 1998). This was an early example of a transnational social movement where contact between AIDS activists resulted in a common discourse about disease in very different parts of the world (Hess et al., 2008).

By the end of the 1980s, it became increasingly clear that AIDS in sub Saharan Africa, including South Africa, was different from the epidemic in the United States and Europe. Emerging epidemiological data from the World Health Organization (WHO) showed that the infected population in the epidemic in Africa was overwhelmingly heterosexual and that it disproportionately affected the black population (Epidemiological Comments, 1993). The particular demographic structure and urban-rural divide of the South African population, high labor mobility, the apartheid

includes South African people of Indian or Malay origin, of indigenous African origin, in addition to South African people who have a mixed racial background (often referred to as colored in South Africa). I will use “white” to refer to South African people of exclusive European descent. This style of classification is often associated with the Black Consciousness Movement which was spearheaded by the South African leader Steve Biko who was invested in uniting the various stratified and oppressed racial groups in apartheid era South Africa (Biko, 2000). At particular points in the dissertation, I will disaggregate the category of “black” to highlight the break-up between Indian, colored and African persons.

government's segregatory policies, and the skepticism of the black population seemed to make the country especially vulnerable to the disease. In 1991, the medical sociologists Zwi and Cabral argued that there was need for "a new term – high risk situation – to describe the range of social, economic and political forces that place groups at particularly high risks of HIV infection" (Zwi and Cabral, 1994). South Africa seemed to possess almost all the factors that Zwi and Cabral listed as high-risk situations. The disease's spread was assisted by the systemic disruption to stable, settled sexual relationships, disruptions that were wreaked over a century by the migrant labor system created by the British in the early 1900s to serve the gold-mining industry, and policed by the pass laws (also a British creation) in the unified South African state set up after the Anglo-Boer War (Burnett and Whiteside, 2002). The high migration rates and population mobility were assisted by what was in South Africa a well developed transport infrastructure. Not only the mining industry but all of South African industrialization had been made possible by the constant movement of big numbers of black men from the countryside to town, and back. Labor migration meant that large groups of men, but also some women, lived in hostels and townships away from their conjugal partners.³⁶ Women were not allowed to stay with their husbands in the city hostels and dormitories. Men were seldom allowed to return home to visit their families (South African Race Relations Survey, 1988/1989). A variety of apartheid laws for zoning, homeland creation and labor management had ruptured communities, and uprooted over three million people. South Africa was the site of the most massive population movements in peacetime outside of the Soviet

³⁶ "Township" is a term that refers to large settlements in which black people live at the periphery of big cities such as Cape Town and Johannesburg. Every morning, black workers were expected to travel into the city centers where the jobs were, and leave every night to return and sleep in the townships. While attenuated and obviously not legally mandated, much of this racially segregated residential pattern persists today in post-apartheid South Africa as the majority population of blacks still lives in townships while the city centers and more affluent suburbs are occupied by whites and a small, emerging black middle class.

Union (Surplus People's Project, 1983).

The epidemic spread in South Africa in the years immediately preceding the end of apartheid, years that were marked by tremendous political unrest. Riots, routine urban violence, and military and police violence shredded normalcy in the townships. Where daily life and work was volatile, there seemed little concern about health. Social concern about casual sex was minimal (H. Epstein, 2000).

The migration of men into urban areas meant rural households were increasingly headed by women whose survival often depended on subsistence agriculture. Poverty coupled with low levels of female literacy meant increased vulnerability. Transactional sex was common, as it captured aspects of unequal gender relations in the region (H. Epstein, 2005). Thus, even though political unrest was most acute in urban townships, labor migration patterns ensured that rural areas also were socially destabilized and consequently vulnerable to the AIDS epidemic.

As international and national health agencies began to identify the epidemic as largely affecting largely heterosexual and black people, there was a shift in the discourse around the disease. The racially differentiated nature of the disease in a racially divided country led to racist stereotypes and much talk of "Afro pessimism." As the magnitude of the epidemic in South Africa grew, AIDS became a topic of debate in the parliament, where some of the more disturbed statements of the extreme right wing were documented. For instance, in one of the parliamentary debates in 1991, a member of the ruling National Party was accused of stating in his election campaigns that majority rule posed no problems because AIDS would decimate blacks into a minority in five years (Debates of Parliament, 18 May, 1990, Cape Town. Col. 9761).

In another debate, a Conservative Party member of parliament was quoted as having said that if AIDS stopped black population growth, “it would be like Father Christmas” (ibid. Col. 9797). Other members of the parliament condemned such statements, and warned that the epidemic could spread to the white population. However, the dominant discussion held black promiscuity as the primary risk factor. Outside the parliament, newspapers talked about HIV being transmitted by casual contact in pools, hospitals and schools. Such commentary provided scientific and medically ratified ammunition to those who opposed desegregation. It claimed the authority of science to defend political boundaries.³⁷

The apartheid regime’s racial characterization of AIDS met a predictable backlash from the black population. What the apartheid government claimed as being authorized by science, the majority population dismissed as politics. Many of the initial public health efforts of the apartheid regime were dismissed by the majority population for being politically malicious. Their dismissal of public health warnings about AIDS was facilitated by the fact that many people affected with the disease were not easily identified as being AIDS patients. The absence of clear identification allowed many to talk about the disease as a government fabrication (Everett and Sisulu, 1992). When the government claimed that the disease was spread through sexual contact and promoted the use of condoms, black community activists were suspicious that it was a “genocidal” policy to reduce the number of black babies (Everett and Sisulu, 1992). Educational programs were criticized as “racist propaganda.” A common epithet in the Soweto township (which lies outside of Johannesburg) dubbed AIDS as the “Afrikaner Invention to Deprive us of Sex” (van

³⁷ See van der Vliet, 1994, de Waal, 2006 and Epstein 1998, 2005 for history of AIDS in apartheid South Africa.

der Vliet, 2001). Some black publications, like *Sechaba*, the official publication of the African National Congress (ANC) in exile, accepted that there was a disease ravaging the black population, but they suggested a conspiracy on the part of the apartheid government to deliberately spread germs to decimate black people (Mzala, 1998). *Sechaba* echoed an oft-voiced fear that the virus was being used as a weapon against the black people.³⁸

The politics of AIDS in schools, which were a nerve center for anti-apartheid action, illustrated how the official scientific information about the definition, spread and prevention of the disease carried little credibility. In the 1980s, schools were a central site of black resistance, with boycotts and marches accompanied by more militant protests. Adults in townships felt that they had lost control of their children (Everett and Sisulu, 1992). The children ridiculed the adults for their political timidity, and became among the most radical fighters in the country, especially after the Soweto uprising. ‘Liberation before Education’ was their call as they remained out of school for years at stretch. Between 1984 and 1986, it was estimated that three hundred children had been killed, one thousand wounded, eleven thousand detained, and eighteen thousand arrested (Everett and Sisulu, 1992). The students had the explicit

³⁸ While seemingly farfetched, such fears had their roots in a history of public health and medicine where “scientific” policies were used for racial segregation. Historians of public health in Africa have recorded how from the passage of the first public health legislation in the late nineteenth century to the forced removals of 1960s and 1970s, public health was frequently used by the government as a justification for segregating the population. They have documented how the anthropologies of high apartheid and its health systems used the social sciences and the medical sciences as instruments of racial oppression (Swanson, 1977, Kaufman, 1977, Chimere-Dan, 1993). Since the end of apartheid, hearings by the Truth and Reconciliation Commission have further documented how the apartheid government had supported research on biological weapons, some of which were meant to be selectively used against the black population. The Truth and Reconciliation hearings also documented testimony on how the secret right wing organization, Broederbond, had emphasized that AIDS could become a vehicle for the restoration of white supremacy in South Africa. There are, however, no records of HIV ever having been deliberately spread through the population. See TRC reports at <http://news.bbc.co.uk/1/hi/world/africa/110947.stm>. Also see Fassin and Schneider (2003) and Butler (2006).

agenda of being ungovernable (Mokwena, 1992). There was little normality in the lives of these children, with family relationships, schools, and an integrated social experience brutalized by the long struggle. The black youth, who were at the frontlines of opposing the police and the state, were not going to take an invisible epidemic seriously. They rejected the definitions of the disease provided by the government, just as they rejected the methods to test, identify and prevent the disease. A 1990 survey amongst the students of KwaZulu Natal by the department of health found that a third of the respondents thought that AIDS was “a joke.” Ninety percent said that they would never use a condom. An equal number suspected the government of spreading misinformation and lies. For them, AIDS was “almost a laughing matter. It is a case of eat, drink and be merry, for tomorrow we die” (Hamilton, 1991).

Mineworkers were another prominent group who rejected the government’s public health measures on AIDS. Migrant mineworkers from Malawi had been among the first groups in which AIDS was detected. The government came up with legislation to quarantine them and other mineworkers who tested positive. This was part of a broader move by the government to monitor and control the spread of the disease by curtailing the movement of laborers. The legislation was met with opposition from the National Union of Mineworkers and the Congress of South African Trade Unions (COSATU). The unions pointed out that the government’s desire to quarantine migrant workers was ironic in light of its long standing policy of relying on migrant labor. The unions pointed out that if the government seriously considered labor mobility to be an overriding risk factor, then it should overhaul its entire industrial and political infrastructure which relied on moving large populations around the country. Rejecting the government’s methods of testing and quarantine, the unions pointed out that the government was being extremely selective about when and how to curtail the

movement of labor (AIDS Bulletin, 1997; Hamilton 1991).

In their work on the early modern period in Europe, Steven Shapin and Simon Schaffer argued that the credibility of science was inextricably bound up with trust in *who* conveys the information (Shapin and Schaffer, 1989). The messenger is as important as the message. Apartheid's legacy has been that many South Africans mistrusted, and had grounds for mistrusting science, medicine and public health writ large because it was purveyed by the government. For many blacks in apartheid-era South Africa, the information that white politicians, government hospitals, scientists, and doctors provided about medical science was intrinsically dubious as they understood science to be part of a larger malignant political agenda. What could have been dismissed as "irrational" fears in other places, were in South Africa, not entirely far-fetched. The final years of the apartheid government, which were also the years when the epidemic took hold in South Africa, have now been documented to coincide with the times when government laboratories were conducting research into the development of chemical and biological weapons, some of which were meant to be specifically targeted at African people; methods of contraception that would allegedly sterilize the black population; and alleged deliberate attempts to spread HIV.³⁹ It is then perhaps unsurprising that the majority presumed that the government attached the label of sickness to the black population because of prior social and racial conceptions. Science, here, was understood as a foil for a larger malignant political agenda. While the majority's distrust and skepticism extended to medicine, public health and science writ large, it was especially accentuated in the case of AIDS because of the disease's racially differentiated epidemiology and the subsequent racially charged discourse around it.

³⁹ For instance, see Gould (2000), Schneider (2002).

This brief and all too abbreviated history is intended to indicate that the debate about contemporary AIDS policy in South Africa in many ways manifests the politics of the past. This past helps frame the Mbeki government's controversial statements, without necessarily justifying them. It also helps illuminate why the government's controversial policies have had some valence in a democratic polity, and why the discourse of mistrusting "western" science resonates with so many South Africans. The history of AIDS in apartheid era South Africa brings to the fore that authority of medical science has been held suspect in the country long before the Mbeki government came to power.

The Epidemic and Attendant Policies in Post-Apartheid South Africa

Epidemiology

International organizations and the national government understand South Africa as having a "generalized" AIDS epidemic. In the category system that they apply to countries across the world, the World Bank and the World Health Organization define an epidemic as being generalized if HIV prevalence among pregnant women who attend antenatal clinics is consistently greater than 5 percent. In non-numerical terms, a generalized epidemic is typically understood as being firmly established in the general population, and sexual networking in the population is sufficient to sustain the epidemic independent of "high risk" sub-groups.

The size of the epidemic in South Africa has been disputed, with divergent estimates being produced by different agencies. In 2006, Statistics South Africa (a government agency that produces a range of national statistics) and the health department gave estimates that differed by 20%. The statistics agency said 4.5 million South Africans

had HIV, while the health department put the figure at more than 6.3 million. UNAIDS estimated that between 4.9 to 6.1 million people lived with HIV in South Africa.⁴⁰ The government and international agencies had often presumed that prevalence rates would be significantly higher in urban areas, but recent surveys indicate that rural areas are also heavily and often equally affected (HSRC 2006). The epidemic continues to affect a much larger percentage of black people than white people. Prevalence rates among African people are estimated to be over 13 percent. The corresponding rate in whites is 0.6 percent, and 1.6 percent among Indians and 1.9 percent among the colored population. Women increasingly carry a disproportionate burden of disease in South Africa. The gender differences are most stark among young adults, with women aged 15-24 estimated to be three times more likely to be infected with HIV than their male counterparts (UNAIDS, 2006).

Policies

During the transition period from apartheid, the African National Congress (ANC) convened conferences on health in 1990 and 1992 (Van der Vliet, 2001; Schneider and Stein, 2001). These conferences specifically discussed AIDS, and included members of the ANC, its allies in other parties, the apartheid government's ministry of health, health professionals and activists. The meetings led to the formation of the National AIDS Committee of South Africa, which in turn produced the "AIDS Plan" in 1993. When the ANC came to power in 1994 as the country's first democratic government, it adopted this AIDS Plan which was widely considered progressive in its embrace of women's rights and activists (Van der Vliet, 2001).

⁴⁰ See the South African Department of Health Study (2006); Human Sciences Research Council HSRC Press Release (2005), the UNAIDS website page on South Africa at www.unaids.org which has estimates from 2007-2008.

Despite this strong beginning, and some scandals and intermittent debates, AIDS policy in general didn't receive much emphasis in the early years of democracy when Nelson Mandela was the president of the country⁴¹. Various scholars have attempted to explain this absence of attention to AIDS by pointing out that the newly democratic country faced far more visible and urgent problems of political reconciliation and national unity; that Mandela belonged to a more conservative generation which was not comfortable publicly discussing issues of sex and sexuality; that it was important that the early years of new South Africa be associated with positive programs of reconstruction rather than with programs that addressed a massive epidemic (Crewe, 1992; Marais, 2000; Van Der Vliet, 2001).

AIDS became much more prominent on the national policy agenda when Thabo Mbeki became the president in 1999. In 2000, the new health minister, Manto Tshabalala-Msimang, launched the "HIV/AIDS/STD Strategic Plan for South Africa 2000-2005" (Department of Health, 2000). This plan, like its predecessors, emphasized that AIDS was not just a health problem, and that it required resources and initiatives from various different sectors of the government. While this plan was largely in line with guidelines provided by UNAIDS, it lacked concrete commitments to providing antiretroviral drugs (UNAIDS, 1998). The period of this policy was marked by debates about affordability of drugs, and growing criticism and activism by the prominent NGO Treatment Action Campaign (discussed in greater detail in Chapter 5). What was a much bigger watershed event was the 2004 policy,

⁴¹ The two scandals that are regularly mentioned include the government's commissioning of a musical *Sarafina II* which was meant to provide a popular anti-AIDS message. The contract, however, was mired with financial problems, and the play was panned as being irrelevant and poorly executed. The second scandal erupted in 1997 when the cabinet announced its support for the a new drug, Virodene, which was going to serve as a South African contribution to AIDS treatment. The government's support of the drug, despite its being rejected as toxic by the regulatory agency of the Medicines Control Council, resulted in widespread outcry about the government's interference in regulatory affairs.

“Comprehensive HIV/AIDS Care, Management and Treatment Plan.” This policy included four principal components: prevention; treatment; care and support; and research, monitoring and surveillance. Most significantly, the plan called for the country’s first major “rollout” of antiretroviral drugs in the public health sector. This rollout involved large-scale provision of antiretroviral drugs and constitutes the world’s largest program for treatment with antiretroviral drugs through the public sector. The Plan aimed to put 53,000 people on treatment in the public sector by March 2005. By January 2006, 111,827 people were estimated to be accessing free antiretroviral treatment in the 200 public health sector facilities across 53 districts and an additional 60,000 people were believed to be accessing treatment through the private sector (Comprehensive Plan Summary Report, 2006).

The pace with which this treatment plan has been implemented is a key source of tension between the government and civil society groups such as the Treatment Action Campaign (TAC) (Nattrass, 2007). TAC has pointed to unspent funds designated for the plan in each annual budget, and argues that the slow pace leaves more than 90% of the HIV infected population without treatment. As a middle income, industrialized country with a relatively well developed public health sector, TAC argues, South Africa should be able to do better. The government, in response, has pointed to its severe capacity constraints. It claims that there are insufficient numbers of doctors, nurses, and health workers, and a lack of physical infrastructure, especially at the rural level, that would enable a rollout at the scale and pace demanded by its critics.

For the government, it was important that the distribution of antiretroviral drugs and AIDS policy in general be integrated with the larger infrastructure of public health in the country. Health ministry officials and various policy documents consistently

emphasized that AIDS treatment has to be associated with efforts to “strengthen the national health system in general” (interview 23, MRC Public Health System, November 2005). They pointed to the dramatic shortfall of trained doctors and health workers in the public health sector. For instance, around the years of the end of apartheid, between 1989 and 1997, 80,000 health professionals emigrated out of the country. While the rate of emigration of trained doctors and nurses has declined, it still continues to be a cause for concern for the government. In addition to emigrating out of the country, many health workers have left the public sector to work in private practices, and migrated from rural to urban areas. At the end of 2000, only one quarter of the doctors in rural parts of the country were South African citizens; the remaining were recent migrants from other southern African countries (Padarth, et al, 2003, Department of Health, 2003, Butler, 2005). South Africa’s “brain drain” is somewhat compensated by a “brain gain” because many professionals from other African countries migrate to South Africa for jobs. Despite this compensation, there is an ubiquitous discourse of “capacity shortage” in the health sector (Kober and Van Damme, 2004).

National health ministry officials feared that this weakness in the health system would be exacerbated or at least further skewed by AIDS programs which, being better economically fortified, would further draw away doctors, nurses, and other health workers from the general primary health infrastructure. In interviews, many health officials offered anecdotes of how trained health workers, especially in rural areas, would leave public health clinics to work in AIDS programs, typically funded by international NGOs.

Economists and policy analysts have often observed this trend of resources being

drawn away from general infrastructure towards problems marked as emergencies. For instance, economists Amartya Sen and Jean Dreze have written about how the overwhelming international focus on responding to famines in Africa in the 1970s and 1980s resulted in the development of a parallel food distribution system that was hinged on supplies and aid from international donors. This parallel system eventually undermined national systems for more routine food distribution. In the context of health, they have argued that the Indian government's overwhelming focus on "population control" in the first three decades of its independent history systematically took away both resources and political attention from building a primary health care infrastructure, with profound detrimental impact on overall morbidity and mortality (Dreze and Sen, 1989, 1995). These critiques pointed to how the urgent displaced a consideration of the mundane. In South Africa, there's an explicit attempt to prevent the AIDS emergency from depleting funds, doctors, and political attention away from other health priorities. As an example, the latest national AIDS plan explicitly states two interrelated goals: "To provide comprehensive care and treatment for people living with HIV and AIDS; and to facilitate the strengthening of the national health system in South Africa" (Comprehensive Plan, 2005). At the level of institutional architecture, AIDS-related policymaking has been firmly integrated within the ministry of health. The government has resisted creating a stand-alone AIDS implementation body. Instead, there is recurrent emphasis on dealing with AIDS through a "multisectoral" approach, that is, an approach that acknowledged that AIDS was a social and economic problem, and not only a health issues, and therefore correspondingly integrated AIDS programs with the work of various ministries. This institutional architecture and the policy approach stand in contrast with India's vertical, stand-alone National AIDS Control Organization which circumvents the primary health infrastructure (Chapter 2).

Outside the ministry of health, the national government constituted the South African National AIDS Council (SANAC) in 2000. SANAC is headed by the deputy president of the country and was to be a forum for the voices of representatives from educational institutions, business organizations, various NGOs, and ministries. Even though it has been reconstituted a couple of times in response to criticisms from scientists and NGO workers, by most accounts, SANAC remains an ineffectual body and carries little weight in policymaking matters (interviews; Butler, 2005; Natrass, 2004).

Funds

International donors provide the majority of AIDS spending through development assistance in low and middle income countries (IDASA, 2006). As stated in Chapter 2, more than half of India's spending on AIDS in 2007-2008 comes from international donors and the proportion of international to national contribution used to be much larger in earlier years. In comparison, government officials and most analysts claim that the South African government provides a much larger percentage of funds for its AIDS budget (IDASA, 2006). Having said that, it is actually difficult to ascertain the relative outlays of the national government versus international donors for the public AIDS program. The government has treated AIDS as a "multisectoral" problem as a result of which projects and funds are distributed in multiple departments, and are split between provincial and national budgets. International assistance similarly seldom comes in a block grant to the national health ministry. It is distributed mainly through non-governmental organizations, universities and hospitals, many of which are international, and which work with local partners and occasionally the government. As a result, it is difficult to disentangle the relative contribution of the government and international donors to extant public AIDS programs.

The government's AIDS budget for 2005-2006 was 2.6 billion South African rands, which comes to about US \$428 billion. The AIDS plan for 2007 was increased and budgeted to US\$600 million. The AIDS budget accounted for approximately 20 percent of the total health budget. (In India, the budget for AIDS exceeded the entire remaining health budget.) The biggest cost within the AIDS budget was to purchase antiretroviral drugs, and accounts for over 40 percent of the total expenses.

International donors ramped up their contributions to South Africa when the national government launched the Comprehensive Plan which sought to provide antiretroviral drugs. The biggest international donor to South Africa's Comprehensive Plan is the United States' President's Emergency Plan for AIDS Relief (PEPFAR), started under George W. Bush in 2003. PEPFAR's main goal is to increase access to antiretroviral treatment. It attaches several conditions including the use of United States FDA approved drugs, a signed declaration that the recipient organization will not promote "sex work," and a promotion of abstinence and "faithfulness" programs. PEPFAR's current budget lapses in 2008, though the United States government has claimed that funding for PEPFAR will be sustained in the future. PEPFAR provided \$148 million in 2005, \$221 million in 2006, and \$397 million in 2007 to South Africa. It distributed these funds through over 300 partners, 80 percent of which were NGOs, faith-based organizations, academic institutions, and some South African government departments. Two thirds of the funds go to South African organizations, while a third go to international and American organizations. Some of the largest recipients of its South Africa funds include institutions such as the Columbia University Mailman School of Public Health and the Elisabeth Glaser Pediatric Foundation, which in turn work with local partners (PEPFAR, 2008).

The Global Fund is another significant international donor to South Africa's current AIDS plan. The European Commission, the United Kingdom's Department of International Aid (DFID) and the Gates Foundation are other donors. The World Bank is prominent in its absence; it has no health sector projects in South Africa. In general, the contribution of the various international agencies is more modest when compared to their loans to other African countries, and to India where the epidemic is significantly less severe (as a percentage of the total population, and in absolute numbers) but has nonetheless attracted hundreds of millions of dollars from the World Bank and other multilateral agencies.⁴²

The University of Cape Town economist Nicoli Nattrass, in a critical appraisal of the national AIDS program, estimated that the government's rollout is "strongly underpinned" by international funding, with about half of the total number of public sector patients on antiretroviral treatment being supported by programs that were in part funded by external donors. However, Nattrass admits to the difficulty in precisely parsing the contribution of the international donors to the current public rollout since "the contribution that donors make to public-sector patients varies between donors, across projects, and over time" (Nattrass, 2007, p. 620). Bureaucrats within the ministry of health claimed that there wasn't systematic data on all the different contributions of international donors but estimated that the government was responsible for more than 70 percent of the funding. Commentators such as Nattrass in general have criticized the government for not lobbying for greater international funds. For instance, Nattrass, in her *Moral Economy of AIDS in South Africa* (2004) compares South African government's inertia to Botswana where the government has

⁴² See UNAIDS website on South Africa; South Africa UNGASS report 2006.

successfully lobbied for and received funds from the Gates Foundation and the Global Fund. Government health officials, in contrast, have emphasized the importance of sustaining the AIDS programs with domestic resources, and not through donor grants. Thus, the government states in the Executive Summary of its latest national policy:

*There is currently no cure for AIDS. The best that an AIDS management programme can achieve is to prolong the lives of people living with HIV and AIDS, so that they can remain productive members of society. *Undertaking a programme like this therefore means committing to providing care and treatment for people over a long period. Once people enter into a comprehensive treatment and care programme, treatment must be sustained. *The drugs and tests required to treat an AIDS patient can run to several thousand rands per person per year, and the human and physical infrastructure necessary to sustain treatment is costly. Other nations that have undertaken comprehensive HIV and AIDS care and treatment programmes have typically had to treat and care for fewer people than is the challenge for South Africa. *To make this programme sustainable, it must be cost-effective and efficient, without compromising quality. Within the overall stewardship role of government, it is recommended that in order to ensure the sustainability of the programme, the biggest slice of the budget for this care and treatment programme should ideally come from the fiscus. Where appropriate the financing of the programme may be supplemented using donor resources.

(National Strategic Plan, 2007)

Of course, the government's desire for sustaining the AIDS plan through domestic resources has to be considered alongside the fact that many international donor agencies such as the World Bank have been reluctant to channel resources in AIDS in South Africa, fearing an ineffectual and on occasion "outlandish" policy (interview

WB1, November 2005).

The above is a rather rudimentary sketch of South Africa's policy terrain that has been marked by several upheavals, scandals and much drama. In the following two sections, I will focus on some of the more controversial incidents, which also provide illustrative sites where the government seeks to shift the rules for determining expertise, credibility and knowledge-making.

Experts, Dissidents, Denialists

In 1999, in what was to become one of the most controversial episodes in South Africa's AIDS crisis, President Mbeki expressed his doubts about the theory that the virus HIV caused AIDS. He stated that his "own reading" had indicated that the cause of AIDS had not been conclusively determined and that there were still big uncertainties in the science. He pointed out that while many scientists thought HIV to cause AIDS, there were "dissident" scientists with alternate theories that had never been fully disproved. One such alternate theory suggested that AIDS was a "syndrome," that is, not any one virus but a series of infections of tuberculosis, pneumonia, etc. which broke down the immune system and caused the disease. Other theories attributed the breakdown of the immune system to chronic malnutrition, chemotherapy, recreational drug use, or a combination thereof. In these alternate theories, HIV was either a passenger virus, or one of the many causative factors, and not the only or principal causative agent (Independent, 2000).

A few months after making these controversial statements, in April 2000, Mbeki sent a hand-addressed letter to the UN Secretary General Kofi Annan, Bill Clinton, Tony Blair and other world leaders, setting out his position on the epidemic. He stated that:

Not long ago, in our own country, people were killed, tortured, imprisoned and prohibited from being quoted in private and public because the established authority believed that their views were dangerous and discredited. We are now being asked to do precisely the same thing that the racist apartheid tyranny we opposed did, because it is said, there exists a scientific view that is supported by the majority, against which dissent is prohibited.

Excerpted from “Mbeki Sends His AIDS Argument to Clinton,”

http://www.healtoronto.com/mbeki_press.html

Mbeki went on to compare AIDS in the West – a declining epidemic and largely homosexually transmitted, to AIDS in Africa – a rapidly growing, heterosexually transmitted epidemic killing tens of millions of people. Given these stark differences, Mbeki pointed out that superimposing Western experience on African reality would be “absurd and illogical.” The “uniquely African catastrophe” demanded “specific and targeted responses to the specifically African incidence of HIV/AIDS.” The idea that AIDS in South Africa was profoundly different from AIDS in the west is partly supported by Annemarie Mol’s work on how disease is seldom singular. Rather, it is always “multiple” in the way that various actors differently “enact” the disease through various material and social practices (Mol, 2002). Thus, according to Mbeki, AIDS in South Africa, as understood and enacted by people there, was a different disease than what was conceptualized in say, the United States or in the UNAIDS machinery.

Mbeki’s letter also expressed concern with the way dissident opinions had been excluded from the scientific debate. It argued that to further exclude these opinions would be to “freeze scientific discourse on HIV/AIDS at the specific point this

discourse had reached in 1984.”⁴³

This skepticism about AIDS-related science reopened a debate that many scientists had thought had long been put to rest (Epstein, 1998). This controversy was triggered by around the University of California, Berkeley scientists Peter Duesberg who questioned whether HIV could ever cause the disease that was called AIDS. Duesberg pointed to multiple paradoxes associated with HIV. For instance, he conducted a review of scientific literature that revealed 4000 cases formally listed as AIDS where there was no trace of HIV or HIV antibodies. He pointed to the puzzle that HIV was biochemically most active in the first few weeks of infection in a new body, but caused symptoms of AIDS only after a long latency period of several years. He asked why there had been so little demonstration of the cellular level mechanisms through which HIV was supposed to cause not only the symptoms of AIDS, but also of over two dozen other diseases that are included in the larger syndrome that AIDS is defined by. Duesberg asserted that it was presumed that where we have AIDS, we have HIV. But that followed from the definition of AIDS, it was based on a correlation and not on causation. He argued that the disease called AIDS was likely caused by drug toxicity and malnutrition, and HIV was likely just a passenger virus. This debate between Duesberg and other scientists has been written about extensively, and was generally considered closed in mainstream AIDS research, especially after the relative success of antiretroviral drugs in making AIDS a chronic disease.⁴⁴

⁴³ For instance, see “Mbeki Sends his AIDS Argument to Clinton,” 19 April 2000, www.iol.co.za, “Skeptic Mbeki Fiddles While Rome Burns,” *Washington Post*, 20 April 2000, “South African President Escalates AIDS Feud,” *Washington Post*, 19 April 2000.

⁴⁴ For instance, see Epstein (1996) for an account of how the controversy emerged in AIDS science and later tamped down. Also, see Fujimura and Chou (1994) on how the same data were interpreted very differently by Duesberg and more mainstream scientists to support opposing views on AIDS etiology. Fujimura and Chou argue that the “epidemiological style of practice” used by Duesberg created a narrative that was incommensurable and difficult to compare with a style of practice that focused on viral pathogenesis.

But more broadly in South Africa, the government's skepticism also called into question who were the relevant experts and what counted as expertise in the immediate policy context, especially when addressing uncertain or controversial science. Mbeki was arguing that the dissidents needed to be taken seriously. But he was also arguing that the government had a role in determining who was brought to the table. The fact that these dissidents had already been dismissed by the mainstream scientific community was not sufficient reason to discredit them. For Mbeki, their dismissal reflected the politics embedded in medical establishments, both within South Africa and in the west. In light of this politics, according to him, the government was an appropriate party to intervene in scientific debates about the epidemic. In making these claims, the president was collapsing the authority of the expert into the authority of the state. "Political procedures often go into authorizing science. This was making it explicit, uncomfortably so," the head of a leading research organization in South Africa pointed out (interview KM, October 2005).

In this case, the fact that the dissidents were generally white, North American or Australian, scientists, didn't seem to be a reason to dismiss them. The government found the dissidents' theories compelling because they seemed explicitly to take into account distinctive features of the epidemics in Africa. The alternate theories proposed by scientists such as Peter Duesberg seemed to make room for a broader explanatory and causal context by emphasizing that AIDS in Africa was not the same disease as AIDS in North America. According to Duesberg, AIDS in Africa was best understood as an umbrella term for a host of old diseases that hadn't received attention from the international scientific community. The money spent on antiretroviral drugs, thus, was better spent on primary health care, clean water, nutrition and hygiene (Duesberg

1996, 1998). In these theories, the emphasis was not a single viral causative entity; rather the definition, cause and treatment of a disease were inextricably intertwined with social, behavioral and economic factors. As such, these theories seemed to speak more directly to South Africa's experience with AIDS.

The biomedical explanations that focused on a "reductionist" HIV-causation model tended to easily translate solutions that had worked in the west into problems encountered in poor countries in the south. Indeed, in order to transfer solutions and prescriptions from one country to another, it helped to conceptualize disease and treatment in discrete biomedical terms rather than in integrated historical and social frameworks. Too much historical and social baggage made travel cumbersome.

In light of these conflicting theories, Mbeki set up the "Presidential International Panel of Scientists on HIV/AIDS in Africa" in May 2000 to determine "the most appropriate expertise for addressing the AIDS epidemic." In addition to some mainstream scientists such as Robert Gallo and Luc Montaigner, the panel included dissident scientists like Peter Duesberg and David Rasnick. A pamphlet explained that the purpose of the presidential panel was to explore "all aspects of the challenge of developing prevention and treatment strategies that are appropriate to the African reality." The pamphlet acknowledged that the inclusion of dissidents had caused uproar among the scientific fraternity. But since orthodox treatments had met with little success against AIDS in Africa, "blind acceptance of conventional wisdom would be irresponsible." The pamphlet hoped that differing scientists would come to a consensus through discussion.⁴⁵

⁴⁵ "What Did You Hear About AIDS Today," Ministry of Health, Pretoria, April-May 2000. For a review of Mbeki's questions about the causation theory of AIDS, see van der Vliet (2001).

This panel only included scientists trained in western biomedicine. It did not include politicians, nor did it include practitioners of traditional medicine. While the government sought to open the debate by including dissenting scientists, it did not at this stage, make the debate capacious enough to include at the table *sangomas*, healers, anthropologists, or politicians. While the government did not invite any politicians to be members of the presidential panel, it nonetheless made it clear that the government had a role in the debate. After all, the panel was constituted by the president's office, and not by a scientific institution such as the country's Medical Research Council, nor through a process of say peer review. Thus, while on the one hand, the government upheld the autonomy of science by appointing only scientists to the panel, on the other hand, it granted itself an important role in framing the outline of the debate, and in choosing the relevant experts. At all stages of the AIDS epidemic, the Mbeki government would continue to perform this boundary work of demarcating science and politics.

The Mbeki government's approach to science advising stands in contrast to how advisory panels are typically constituted in countries such as India, or the United States or the European Union (Jasanoff, 1990, 2005; Hilgartner, 2000). Given the importance of negotiations and consensus-building, panels are seldom constructed in a "symmetrical" fashion where two opposing sides are represented in roughly equivalent numbers. The equal representation of two opposing sides is especially unusual when one of the sides has been discredited in mainstream science. Typically, technical agencies prefer to appoint scientists who "enjoy unquestioned standing among their peers" (Jasanoff, 1990, p. 243). The Mbeki presidential panel, in contrast, provided a forum for reviving a debate that one side had claimed had been closed. This style, of

bring differing experts to the table, was not unusual for the Mbeki government. However, in this instance, it didn't yield any constructive outcome.

As was perhaps predictable, the scientists on the Presidential AIDS panel did not come to any consensus. Instead, the panel resulted in a series of heated exchanges and face-offs (interview 24, NRF). The panel members could not agree on what counted as credible evidence; what counted as reliable experiments; what indeed the questions were. From the account of those who were present at the panel's proceedings, the divergent "priors" that the different parties brought to the table made conversation more or less impossible. Bringing warring sides to the table, at this late date, cemented oppositional stands that had become set in earlier phases of the controversy, and did little to build consensus.

Several scientists involved in AIDS research in South Africa underlined that this was no way to build consensus in science. They complained that the government was giving equivalent credibility to dissidents, mavericks and skeptical parties in arguably closed debates. While the government saw the absence of dissidents in mainstream science as a sign of politics, most scientists in South Africa that I interviewed saw the inclusion of dissidents as a sign of the government's political interference. A scientist who led a prominent program on clinical AIDS research in one of the country's largest hospital emphasized:

The president misunderstood science and how it works. He treated it akin to an ideology, where there can be a capitalist view and a socialist view, and one can give an equal seat at the table to both, and then choose one over the other, or come to some golden middle road. Science does not work that way. There are no such equal options. There are established mechanisms of peer review

and publication that determine what theories should be given importance.

Politicians don't decide this.

(Interview 25, November 2005)

While the government sought to have a legitimate role in the scientific debate, scientists in turn sought to “keep the politics out.”

Other AIDS researchers emphasized that the reason why the dissidents were not given attention was not because scientists were intent on “muzzling dissent.” “Duesberg has been making these claims for several years. The reason why his claims have been dismissed is because there is little evidence to prove his theories,” said a virologist at the University of Cape Town (interview 26, UCT). He and others summarily dismissed the claims made by Duesberg's supporters that it would be difficult to collect new evidence in the absence of funding and support for alternative research. These supporters have pointed to how Duesberg lost NIH funding following the 1987 article in which he questioned the HIV-causation theory. Graduate students slowly stopped working with him, he was “dis-invited” from conferences, journals such as *Nature* refused to publish his articles, and he lost most external funding at University of California, Berkeley where he is a tenured professor (Farber, 2006; Bialy, 2004; Epstein, 1996). Scientists invested in mainstream understandings of AIDS retorted that Duesberg's claims have been refuted point-by-point; that pointing to some uncertainties didn't necessarily invalidate the entire remaining body of knowledge about AIDS.⁴⁶ “That is akin to saying that because there are some gaps in the fossil record, that the entire theory of evolution is wrong,” remarked a scientist who has

⁴⁶ In 1998, the journal *Genetica* published an article by Duesberg and Rasnick, outlining their main claims (Duesberg and Rasnick, 1998). This was followed immediately by a point by point refutation (Galea and Chermann, 1998). Earlier, *Science* had published a long article in 1995 that reviewed Duesberg's claims, and concluded that none of them withstood scrutiny (Cohen, 1995).

been in the fray in South Africa (interview 27, MRC, December 2005). He further pointed out that interest in Duesberg's theories had declined after 1996 when more effective antiretroviral drugs became available and that Mbeki thus re-ignited a dead controversy. "These dissidents are really at the fringe, at the margins. Do we want to be wasting our time on this?" asked a scientist in a public research facility in Durban (interview 28, December 2005).

In response to Mbeki's questions and his appointment of the presidential panel, over 5000 scientists put their signatures on what is commonly called the "Durban Declaration" which spelt out the established views on AIDS. This declaration was subsequently published in *Nature* (Durban Declaration, 2000). The mainstream was offering a counter-panel, so to speak. The overwhelming consensus in support of the HIV-causation theory illustrated by the Durban Declaration did little to end the debate in South Africa. Government officials dismissed the report as being "elitist."

Filtering the Global Through the Local

The Mbeki government's approach to determining authoritative knowledge for policy purposes was not exclusive to AIDS. In other policy domains – trade policy, building innovation systems, and affirmative action - the government also has sought to bring together differing international experts to air their contrary views. The government has emphasized that South African scholars and practitioners ultimately must decide the interpretation and relevance of views expressed by cosmopolitan experts. This approach represented a highly self-conscious exercise in filtering "global" universal knowledge through local perspectives. One recent example that has received considerable attention was in economic policy. The national treasury ran a two-year project that brought together economists from around the world to provide advice

and analysis on how to deal with the country's stagnant economic growth and high rates of unemployment. Recently, the treasury put on its website all the papers that were completed during the two-year project. In a statement that accompanies these papers, the treasury notes:

The research papers do not necessarily reflect government's views, nor has government adopted or rejected any of the recommendations made by the Panel. Government also notes that there is no universal recipe or set of policies for a successful growth strategy. Whilst government has been debating, and will continue to debate the issues raised in the research, the process of responding to the papers and recommendations will benefit from a broader public debate. At their last meeting with members of Cabinet on 19 July 2007, the President requested that the papers should be made public to encourage a broader debate on shared growth. It is with this objective in mind that the papers are now being released for further dissemination by the public in general and the economic community in particular.

To facilitate the broader debate, Government is planning a major workshop on the report, between the international panel, government officials, local academics and economists, policy researchers and various stakeholders. It is hoped that this workshop will also encourage local economists and academics to prepare response papers in order to stimulate the broader public debate. In this respect, economic departments at SA universities and research institutions will be encouraged to convene workshops later in the year on various aspects raised in the research papers, where such local papers can be presented.

<http://www.treasury.gov.za/publications/other/growth/>

This effort, like the AIDS panel, attempted to distill the outsiders' views through the

experience and knowledge of locals. The government was demanding that science not be determined by a universal logic but that it make room for local knowledge and experience, or what James Scott calls *metis* (Scott, 1998, p. 67). Scott offers the concept of *metis* as a counter to the homogenizing and hegemonic impositions of the nation-state. In South Africa, local knowledge and expertise is offered as a counter to global schemes and knowledge.

The government often justified its skepticism of mainstream science by pointing to the history of racism that had been facilitated in the name of science. Especially in the context of AIDS, this sense of historical grievance was evoked by the president, his successive health ministers, and senior officials within the government. “Anybody can question science. In fact, it is important to be skeptical and hold science accountable. Scientific theories are only as good as they work in a particular context. They are always open to question. The problem is that the media and the general public are not educated about science. They see science as the new religion today. It is seen as dogma to be followed,” stressed Anthony Mbewu, a principal author of the national AIDS policy. Mbewu was also the recently appointed head of the Medical Research Council (MRC), which is a public research institute that funds and conducts medical research.

However, as the government rapidly discovered in the case of AIDS policy, instead of being hailed as good policymaking, the government’s actions were labeled outrageous. In its demand for the centrality of local perspectives and understandings, the South African government found itself at odds with an international and national scientific elite. When the government tried to redraw boundaries between what should count as expertise, and what the role of the state should be in determining authoritative

knowledge, it met with strong resistance. In other words, the government didn't succeed in shifting the terms of the civic epistemology of South Africa, namely, the different systemic, institutionalized, and informal ways in which knowledge claims were assessed.

Pharmaceutical Politics: Of Garlic, Olive Oil and AZT

The previous sections examined the government's attempts to contest boundaries around science and expertise. The state explicitly asserted its right to ask questions and to interrogate experts in the technical domain of AIDS research. The AIDS-causation debate eventually died down as the president withdrew from all public discussion of AIDS policy in 2001. However, a new battleground opened around issues of pharmaceuticals and treatment. Pharmaceutical drugs – especially antiretroviral drugs – became another specific site where the government contested ideas of expertise and science.

The government's policy in 2008 calls for an extensive rollout of antiretroviral drugs. Indeed, it is the world's largest rollout through the public sector of antiretroviral drugs. However, civil society groups such as the TAC have waged a pitched battle to get the government to this stage, and are still struggling to accelerate implementation. In this battle, the media has often focused on comments by the minister of health proclaiming that not only antiretroviral drugs but also traditional remedies and ingredients such as "garlic, olive oil and lemon juice" had a role in fighting AIDS. The media routinely focused on her statements warning about the toxicity of antiretroviral drugs, and bemoaning how South Africa has become a population of guinea pigs for pharmaceutical companies.

The health minister's statements had a precedent in the president's early skepticism of antiretroviral drugs. In 1999, in one of the first statements that got labeled as "denialist" President Mbeki addressed the issue of whether AZT should be offered in the public health sector:

. . . we are confronted with the scourge of HIV/AIDS against which we must leave no stone unturned . . . Concerned to respond appropriately to this threat, many in our country have called on the Government to make the drug AZT available in our public health system . . . Two matters in this regard have been brought to our attention. One of these is that there are legal cases pending in this country and the UK and the US against AZT on the basis that this drug is harmful to health. There also exists a large volume of scientific literature alleging that the toxicity of this drug is such that it is in fact a danger to health. . . I have therefore asked the Minister of Health, to go into all these matters so that to the extent that is possible, we ourselves, including our country's medical authorities, are certain of where truth lies.

(Cited in Richey, 2006)

In these statements, the president was calling into question what was by then widely regarded as mainstream and effective treatment for AIDS. To support its skepticism, the government cited economic and moral problems in providing AZT. The health minister pointed out that even at reduced prices, AZT was extremely expensive since its effective use required testing, counseling, formula feeding, technical support, and an infrastructure for drug dispensation. It could at best be accessed by a privileged few, leading to a skewed distribution system. The government thus melded the technical issue of toxicity with infrastructural issues of distribution and moral concerns about equity. Similarly, in the debate over providing nevirapine (discussed in Chapter 5), the government raised how its limited infrastructure for monitoring and

administration could lead to early problems of drug resistance. This was a move – of fusing technical issues about efficacy and toxicity of drugs with a host of other issues of poverty, access, literacy, gender and so on - through which the South African government tried to reframe the question of expertise. It consistently declared that dealing with AIDS required a much broader effort than getting the right drug at the right dosage to infected individuals.

The political scientist Anthony Butler at the University of Cape Town has characterized the government’s preferred public health paradigm as an “ameliorative or nationalist” paradigm. I have referred to this paradigm as a structural socio-economic paradigm. In this paradigm, there is a focus on issues such as poverty, nutrition, and structural determinants of disease. Prevention and palliative care, with nutrition, traditional medicine, a massive social grants rollout, and anti-poverty programs dominate the policy prescriptions. Thus, the government started a series of programs to improve nutrition and food fortification among people including those living with TB, HIV and AIDS and other chronic debilitating diseases. Poverty alleviation programs were similarly considered integral to AIDS management. Traditional leaders were given responsibility for reinforcing the cohesion of rural communities. Institutionally, the AIDS program was integrated with remaining public health systems. Elucidating this approach, the health minister, Manto Tshabalala-Msimang wrote:

Our challenge are compounded by conditions of poverty and underdevelopment that undermine the overall health status of our population . . . Hunger still discourages people from completing the six months’ treatment for tuberculosis – a disease that remains the biggest killer of people with AIDS despite being curable even in the presence of HIV . . . the fact that this

government places the challenge of poverty squarely on the AIDS agenda is not an indication that we are reluctant to tackle the issues of treatment. Quite the opposite: poverty eradication and medical interventions are mutually reinforcing and we would be selling our people short if we did not attend to both.

(Tshabalala-Msimang, *The State*, cited in Richey, 2006)

Antiretroviral treatment was largely absent from this model. The fact that much of the global machinery and activists in South Africa focused on expensive antiretrovirals put them at odds with the government. Given the international patent regimes and the skewed nature of a broader international economic order, the government asserted that those who demanded antiretroviral drugs were apologists for pharmaceutical companies, and were engaged in a different sort of denial – a denial that didn't take into account the difficulty of accessing and dispensing these drugs on a large scale.⁴⁷

The government saw antiretroviral drugs as the mainstay of the “biomedical” paradigm. This biomedical paradigm of public health emphasizes discrete causal mechanisms for diseases rather than broad socio-historical contexts. Individual behavior and rights to treatment are key features of the so-called biomedical paradigm in South Africa. This second set of policy prescriptions was associated with critics of the government such as the Treatment Action Campaign (TAC). TAC acknowledged the role of poverty; nonetheless, its main agenda has been dominated by issues of

⁴⁷ See Adam Sitze (2004) for an argument on how the international economic order “overdetermined” denialism in countries in African countries. Also relevant in this context is a powerful critique by Nicoli Nattrass, an economist at the University of Cape Town. In her book, *Moral Economy of AIDS* (2003), Nattrass has argued that buying antiretroviral drugs and supplying them in the public health sector actually is economically the most rational path for the government to follow. Providing these drugs, argues Nattrass, allays much greater, long-term, economic costs incurred through higher morbidity and mortality rates. Far from being the expensive option, providing treatment was the economically prudent option.

treatment and individual rights.

These two paradigms – the biomedical and the structural socio-economic model - are not necessarily contradictory nor incommensurable. For instance, it is possible to imagine public health frameworks which address the role of poverty and malnutrition but also at the same time include antiretroviral treatment as part of the arsenal to deal with AIDS.⁴⁸ However, the two sets of policy prescriptions have been underpinned by different sets of assumptions about the nature of HIV/AIDS epidemic and what constitutes an appropriate government response.

For instance, the two paradigms differently cast what constitutes relevant expertise and knowledge for dealing with AIDS. The biomedical paradigm emphasizes the role of scientists and doctors, and asserts their autonomy from political interference. The structural paradigm makes much more room for a diversity of different experts. It also provides a role for traditional healers and local remedies, and for employment generation programs that gave women more economic autonomy. It sets a place at the table for history in order to understand how demographic changes and moral norms had developed. Scientists who purveyed the latest drugs or vaccines no longer had the last word in discussions of and responses to AIDS. The relevant knowledge for addressing the epidemic had to be drawn from far more eclectic and diverse quarters.

Moreover, the biomedical paradigm, underpinned by the idea of a virus spreading rapidly through a population, has marshaled a sense of urgency. It has channeled funds, prompted research, and led to conferences and meetings. In contrast, talk about poverty hasn't instigated quite the same degree of urgency and action. For instance,

⁴⁸ Paul Farmer has argued for such a paradigm. For instance see, *Infections and Inequalities* (2001).

despite slogans about AIDS being a social phenomenon, most funds worldwide have focused on biomedical research (Farmer, 2001). A recent *Lancet* review revealed a huge number of projects on biological “cofactors” such as ulcerating lesions, efficacy of microbicides, and circumcision, that affected vulnerability to AIDS. In contrast, much less work was focused on social inequalities and poverty, which have perhaps been the most consistent “cofactor” that is correlated with vulnerability to HIV infection and the development of AIDS in countries such as South Africa (Barnett & Whiteside, 2006).

The government claimed that privileging socio-historical explanations and “ameliorative paradigms” did not mean that it was “against” science. Much the contrary. As the head of the Medical Research Council, Anthony Mbewu, vehemently asserted, this government was “extremely receptive to science and scientists,” and was willing to engage with them at many different levels.

The Republic of Science

Most of the scientists working on AIDS, however, could not have disagreed more with Anthony Mbewu. “Distrust” and “antagonism” were words they consistently used to describe the relationship between the government and the national scientific establishment. Scientists repeatedly described how the relationship between knowledge-generation institutions and the government had steadily deteriorated. Most biomedical and epidemiological experts were unable to command the attention of decision-makers, and the president became increasingly hostile to expert advice. A scientist who works on HIV pathogenesis described:

The relationship with the national government has been terrible. The relationship with the Department of Health has especially been very unhealthy.

There is a lot of distrust of scientists and doctors . . . coming from the time that dissidents' held sway. Consider the number of times that the minister of health has been taken to court by the TAC . . . which has been supported by scientists. There is little respect between the two parties. There have been mixed messages that have filtered down to the people, which has had a very large negative impact.

(Interview 30, August 2005)

Another scientist at the University of Cape Town who works on clinical pharmacology echoed this view: "It is very polarized. We were publicly accused by the Minister of Health of being in the pockets of pharmaceutical companies" (interview 31, September 2005). To emphasize the frayed relations between the national government and the AIDS scientific community, many scientists pointed to the fate of Anthony Mbewu's predecessor. Before Mbewu was appointed in 2005, the Medical Research Council (MRC) was headed by Professor M. Makgoba. Makgoba publicly disagreed with President Mbeki's stands on mainstream AIDS-related science. He complained that the pressure on the MRC to toe the government's line amounted to "undermining of scientists and the scientific method which was especially dangerous in a developing country still in the process of establishing a strong scientific research base" (Makgoba, 2000: 1171). Makgoba's approach was to tell Mbeki to 'leave science to the scientists.' Eventually, Makgoba left his post as head of the MRC. Many scientists claimed it was because he had crossed swords with the president. They describe this incident as an example of political interference. Although none of the over two dozen scientists I interviewed knew of any case where the government had withdrawn funding or closed down any person's research on HIV/AIDS, they pointed to the Makogba incident, and other related pressures on the Medical Research Council as examples of political interference.

Most scientists saw the government's policies not as providing a holistic approach for understanding health, but rather as bringing politics into the realm of science. Like the government, the scientists too invoked the boundary between politics and science as a resource for credibility. They saw the AIDS policy as being "confusing" in its multiple emphases on nutrition and poverty. "These multiple goals and 'choices' mentioned in the policy send very mixed messages. Patients are confused whether to take ARVs or not. Of course poverty is important, but solving the problem of poverty won't cure people with AIDS," stressed a doctor working on clinical trials for a AIDS vaccine (interview 32, November 2005). Many were sharply critical of the health minister and the president who they often described as "lunatic," "imbecile," "insane."

The criticisms were generally less sharp from black scientists, but then there were extremely few of those. Most scientists, especially senior scientists, in South Africa tend to be white. Some are Indian, but almost none are black African. While walking through various university and research institute laboratories, the occasional African postdoc or graduate student I would meet were more likely to be from Zimbabwe or Malawi than South Africa.⁴⁹ Some scientists admitted that the AIDS controversy had been aggravated because there had been no senior black scientists who could criticize the government's stand on HIV. The prominent exception had been William Makgoba, who didn't keep his job. "All the scientists are white. There is always a racial undercurrent. We are paying for the sins of our past. Given South Africa's history, the suspicion of white scientific advice was understandable," confessed a

⁴⁹ This, despite the aggressive affirmative action policies of the government to recruit black students into the sciences and engineering. Principal investigators in various laboratories said that the difficulty with recruiting black students lay in the relatively poor schooling infrastructure for the majority population. The apartheid educational system hadn't expected blacks to become doctors and scientists; it had designed curricula and schools to train blacks as mineworkers and laborers.

scientist at the University of Cape Town (Carolyn Williamson, SAAVI, November 2005). But she stressed that this historical grievance didn't justify the "loony" stand of the government. Science could not be held captive to the politics of the past; there were, after all, millions of lives at stake. Here "truth" mattered with a vengeance. There was no luxury to refract it through cultural or historical lenses.

Many scientists said that the interference from the government affected their funding, which to a significant extent came from international donors such as the Wellcome Trust, the National Institutes of Health in the United States, and some governments of northern European countries. As a scientist who works on South Africa's AIDS vaccine project explained, "The government policy threatens international funds to our scientific programs. The government has very small grants, through the MRC or the Department of Science and Technology, for biomedical research. So we need to fight it out for international funds. But international donors do not want to invest in a place where there is no sensible policy, no action. International donors can be very sensitive to policy. They need a solid health policy" (interview 33, September 2005).

In addition to funding, scientists were concerned that the government's policies were affecting their standing in international networks. "We draw our prestige through participation in international networks of science. We publish in American and British journals, go to conferences in the west. The government's wonky statements make us look bad," stressed a scientist at the University of Western Cape (interview 34, September 2005). Most scientists were acutely aware of how dependent they were on their western counterparts and networks for credibility and prestige. Often, these were unequal relationships. The government's policies, however, seemed to make the already unequal relationships even more skewed by portraying South Africa as a

“backward” and reactionary place.

In international funding, American donors often presume to know what you want and impose that on you. It is often with the best of intentions. But negotiating equal partnerships where financial clout is very different is not easy. In Africa, scientists are very conscious of power . . . exerted by international donors. The American researchers come in – they often know much more and are better; sometimes they are not but presume that they are better and know more. It is hard to be assertive in a position where you may not know as much as your partner. In Africa, some of the collaborations can be appalling where scientists treat Africa as a collection site. It is better in South Africa but atrocious north of the border. It is easier in other countries not to build capacity. It is not the NIH’s mission to build capacity in African countries, it is their mission to do research. But with all this controversy on AIDS in South Africa, people are reluctant to come and work with us. We are in the best position to do research in Africa, but the government’s statements are hurting us by alienating support.

(Interview 35, August 2005)

While the scientists repeatedly spoke of alienation and animosity with the national government⁵⁰, they underlined their close relationships with non-governmental organizations such as Doctors Without Borders and the Treatment Action Campaign (TAC). Robin Wood, the principal investigator at the Desmond Tutu HIV Centre at

⁵⁰ While scientists typically said that they had very bad relations with the national ministry of Health and the national government, they did also point out that relations with some provincial governments could be rather good. The government of the Western Cape province, especially, was praised for consulting scientists and having a very progressive AIDS policy. The Western Cape often has not had an African National Congress government, but has been led by the Democratic Alliance. For the purposes of this dissertation, I focus only on the policies of the national government, and disregard the variations at the level of provinces.

the Institute of Infectious Disease and Molecular Medicine echoed what was a common theme with other scientists:

Our relationship with the TAC is quite good. It is a mature relationship with Zackie [referring to Zackie Achmat, the chairman of TAC]. I was the medical advisor on their Constitutional Court case. Many of my colleagues have advised TAC on various other cases. Maybe the relationship between scientists and activists should not be so chummy. The chumminess is a side-effect of having the government so out-of-kilter . . . there is a common opponent.

(Interview 36, November 2005)

This link to international donors and to NGOs, and the estrangement from the government, hold some insight about the changing relationship between science and the state in an increasingly globalized world. Science studies scholars and political scientists such as David Guston (2000) and Yaron Ezrahi (1993) have discussed science's dependence on the state for resources and political clout. They discuss an implicit social contract where science provides legitimacy to the modern state in return for resources and autonomy. The AIDS controversy in South Africa reveals a different dynamic. For many South African scientists and doctors, the international community, in the form of scientific networks, research trusts and international donor organizations, is a more important source of funds and credibility than the national government. These scientists were eager to distance themselves from the government, not least because proximity could mean a corrosion of their credibility and their ability to attract resources from international donors. Their expertise needed to be validated, not by the state, but by their international professional networks and increasingly by non-governmental groups that worked to obtain rights to treatment for HIV-infected

people.

Conclusion

The story of South Africa's national AIDS policy holds several ironies. Here was a government that was vehemently skeptical of antiretroviral drugs and many other aspects of mainstream science around AIDS. This same government rolled out the world's largest program for antiretroviral treatment administered through the public sector. This was a government that consistently emphasized various social, historical determinants of the epidemic. However, the extreme polarization around AIDS policy in the country has meant that it is very difficult to discuss non-biomedical framings of the epidemic; such moves are quickly associated with denialism. This was a government that challenged various economic, scientific and social aspects of the global socio-technical machinery that prescribes best-practice solutions to the south. However, the government has had to conform to many of those prescriptions that it initially challenged.

How is one to explain these various ironies and the bizarre nature of the country's AIDS policy? In this chapter, I have tried to show that it is not possible to understand the policy without taking into account the historical memories and national aspirations that animate the policymaking apparatus. These abstractions are hard to pin down, but nonetheless essential for making sense of South Africa's politics around AIDS. Thus, one has to factor in historical memories and associations of medical science with racial discrimination. Similarly, the AIDS policy cannot be divorced from a discourse of nationalist aspiration that strives for a new post-apartheid identity. This discourse strives to forge connections with a larger Africa, and resists the international portrayal of the continent as the site of the "new Black Death" and a "resurgent plague."

The post-apartheid government resists universalistic claims made by biomedical experts. Instead, it seeks to shift the paradigm and rules, the civic epistemology, through which the disease is understood. In the process, what also gets pushed around are the rules for who counts as an expert. In the course of the conflict, the boundaries between science and politics shift. The public health model adopted by the South African state attempts to be critical about the dominant biomedical ways of conceptualizing the epidemic. It tries to bring into relief issues of poverty, inequity and historical factors that might determine the trajectory of the disease. In this framework, the relevant experts are not just scientists and doctors. Rather, relevant public knowledge is seen to be produced in a number of other spheres. The units of analysis are no more just “individuals” and “sexual behavior” but also broader issues of poverty, history and gender. Risk is understood not only in terms of inter-individual variations but also in terms of socio-historical influences on choices and health. Implicit in this reframing of disease were also new ideas of national identity. In its attempts to reframe AIDS, the government also articulated new post-apartheid national sovereignty where local constituencies could speak to the global establishment on their own terms, and without discounting their past.

The AIDS controversy in South Africa raises the question of why the end of apartheid didn't entail a new relationship between the government and institutions of science. After all, the new government was for the first time democratically elected. It had a new slate on which to write a future for the country. Why was the government so shackled by old concerns and fears about the misdeeds of science? Why didn't the relationship with science change? Part of the purpose of this chapter has been to attempt to describe how change does take place. Sometimes, change is necessarily

slow. The change in regime-type and change in laws don't necessarily imply an immediately change in the broader social and economic structures that animate people's lives. The change in legal status and constitutions does not necessarily entail an erasure of historical memories. Many aspects of life South Africa are still as they were in the apartheid era. The economic disparities in the population which had made it the most "unequal" country in the world have not disappeared; in fact, according to some economic measures, the income inequality has increased since the end of apartheid (Kanbur, 2006). The bureaucracy which ran the country has new leaders, but much of it is still staffed by professionals of an older apartheid era. The ranks of doctors and scientists have not overnight become dominated by black people. The highly racialized educational system, which is a vivid legacy of the apartheid era, persists in many parts of the country, and is difficult and expensive to transform quickly. A transition in these larger structures – of education, economics, government – will likely lay the foundations for new relationships between the government and institutions of science.

Chapter 5. Treatment Activism in South Africa: Contestations Over Science, Citizenship, and Public Health

Introduction

South Africa has a broad based social movement organized around the AIDS epidemic. The social movement includes lawyers, academics, doctors, and various activist organizations. At the centre of this movement is the Treatment Action Campaign (TAC). It is not possible to understand the landscape of the AIDS epidemic in South Africa without a serious consideration of this group. TAC is the most prominent non-governmental organization working on AIDS, but also probably the country's most prominent non-governmental organization writ large. TAC defines its goal as increasing access to AIDS treatment for South African people living with HIV.

TAC's activism centers around demanding *rights* to AIDS treatment. In this chapter, I argue that TAC's rights-agenda is accompanied by an explicit and implicit conception of what is science, what should be its boundaries, who should qualify as scientific experts, and what role scientific experts should have in democratic decision-making. In other words, TAC's politics exists in conjunction with certain epistemological claims and commitments. TAC's vision of the workings of science has heavily privileged the authority of experts, and the notion of an unassailable 'scientific method' that reveals unambiguous truths. I argue that TAC's particular 'positivist' model of science is not coincidental nor contradictory to its radical democratic ethos; on the contrary, TAC relies heavily on this particular vision of science to realize its liberal demands. In other words, TAC's liberal politics is strongly tethered to its conservative epistemological commitments.

Background

The economic and social devastation caused by South Africa's AIDS epidemic has been accompanied by an intensely confrontational politics that has pitched the national government under President Thabo Mbeki against NGOs, mainstream scientific and medical experts, and international organizations such as the World Health Organization. In this highly vitiated and polarized politics, no group has been more vocal and more forceful in denouncing the national government's AIDS policies than TAC. TAC was started in December 1998 in Cape Town, South Africa by about a dozen protestors who were demanding that the government provide comprehensive medical treatment for HIV-positive people.⁵¹ Since its inception, the group's membership has grown dramatically. It had over 12,000 members in 2005, and its officers estimate that the group's membership had grown to over 14,000 in 2006.⁵² Over 70 percent of its members are women, over 80 percent of members are unemployed or work in the informal sector in urban areas, and its members are overwhelmingly African. This demographic composition belies the national leadership of TAC, which till recently was largely non-African and male. Perhaps what is also not captured in the numbers is the prominence of the group in South Africa's public sphere. TAC's street protests, its media statements, its court cases and frequent challenges to the government have a near ubiquitous presence in South African newspapers, radio and television.

The most prominent face of TAC is that of its iconic founder and chairperson, Zackie Achmat. A charismatic and highly articulate leader, Achmat's fame extends far

⁵¹ For a history of the TAC, see "Treatment Action: An Overview, 1998–2001," on the TAC website, www.tac.org.za. Also see Friedman and Mottiar (2004) and Robins (2004).

⁵² These numbers are obtained from various interviews with TAC officers, and the 2005 and 2006 TAC Annual Reports. See *TAC National Congress Report*, September 2006.

beyond South Africa. He has been on the cover of *Time* magazine, has been profiled in the *New Yorker*, *Newsweek* and *PBS*, in addition to having been voted one of the ‘Top 100 Great South Africans’ in a poll conducted by South Africa’s *Mail & Guardian* newspaper. Equal parts public intellectual, rabble rousing mobilizer and messianic figure, Achmat has been nominated for the Nobel Peace Prize, has been feted by Nelson Mandela, Vaclav Havel and Bono, and has received numerous international awards.⁵³

Much of TAC’s early activism was targeted against multinational pharmaceutical companies that held patents to antiretroviral drugs that are the mainstream treatment for AIDS. These patents, TAC claimed, made the drugs extremely expensive and priced them out of reach of the average South African patient. TAC’s first major campaign, which vaulted it into international and national media spotlight, was against a consortium of 39 multinational pharmaceutical corporations that had brought a case against the South African national government in the Supreme Court (Butler, 2005; Schneider, 2002). In 1998, the national government had introduced a bill into the parliament that would have allowed the import of inexpensive generic versions of antiretroviral drugs into the country. The bill also provided for the ‘compulsory licensing’ of patented drugs to allow cheap manufacturing within South Africa. The multinational pharmaceutical consortium argued that if this bill was made into law, it would violate international intellectual property law encoded in the World Trade Organization’s TRIPS agreement of which South Africa was a signatory. Through its litigation, the pharmaceutical consortium hoped to force the government to withdraw this bill from the parliament.

⁵³ See for instance Hawthorne (2003) and Power (2003) for coverage in the international media on Achmat.

TAC and its small but committed cadre of activists launched an effective global campaign that decried the pharmaceutical consortium for valuing patent profits over lives. The group networked with other NGOs and with journalists from around the world, with pharmaceutical companies in India and Brazil that manufacture generic anti-AIDS drugs, and with academics within and outside of South Africa. Through a media onslaught, TAC brought the plight of South Africa's AIDS patients and the issue of drug patents to the global centre stage. The pharmaceutical consortium eventually withdrew its case and struck a compromise with the government, a compromise that was credited to TAC's campaign to a significant extent.

In response to accusations of the pharmaceutical consortium, TAC argued that in trying to change intellectual property protection for drugs, it and the government were not interfering with scientific research and technology development. Instead, they were working for the larger public good. The boundary that TAC drew between science and politics allowed the government and NGOs to challenge patents; this challenge was not seen to encroach on the domain of science. For the pharmaceutical companies, on the other hand, challenging drug patents affected the workings of scientific research. At this stage in TAC's trajectory, the group was "on the same side" as the national government. However, this was soon to change.

TAC became increasingly antagonistic to the national government when the president of the country and some of his advisors and ministers expressed skepticism about mainstream science around AIDS. As described in Chapter 4, in late 1999, South Africa's president Thabo Mbeki made his statements questioning whether the cause of AIDS had been conclusively determined. While not outright rejecting the HIV-

causation theory, Mbeki publicly wondered why alternate theories had been rejected. The national government's skepticism about causation extended to the efficacy and safety of antiretroviral drugs; the health minister questioned whether nutrition was not more or equally important than 'toxic' antiretroviral drugs in combating the disease; and the role of traditional medicine was often highlighted as a potential resource for understanding and fighting AIDS.

The national government's statements invited widespread ridicule from within and outside the country. At the home front, the most vociferous charge against the government was led by TAC. The NGO, which had been founded around issues of drug access, was now engaged in debates about the nature and role of scientific expertise. TAC never got involved with the content of AIDS science the way gay activist groups in San Francisco and New York did (Epstein 1996). However, in the process of countering the national government's statements, it did come up with its own representation of the sociology of science. For the group, it became very important to draw boundaries between the realm of "politics," and the realm of "science." As described in Chapter 4, the government tried to reinscribe politics-science boundaries to make more room for itself and for different types of experts. TAC, in many ways, mirrored this boundary drawing that sought to differentiate science and politics; in its case, it tried to reaffirm the autonomy of science from governmental interference.

Guarding the Republic of Science

When President Mbeki and his health ministers began to question the mainstream consensus around AIDS causation, Zackie Achmat, the leader of TAC, repeatedly underlined in speeches, editorials and interviews that, "Science is not in the arena of

democracy. The role of democracy is in the distribution and use of scientific knowledge, but not in its creation” (Interview Achmat 1, October 2005. See also TAC, 2006b). The production of scientific knowledge, according to Achmat and other TAC representatives, had to be left to credentialed scientific and medical experts. “Democracy” to them implied political interference in the sanctum of science. As politicians and non-experts, the president, his ministers and advisors “had no business” giving their opinions on AIDS science (Interview Achmat 1, October 2005). By interfering in the privileged arena of experts, the government’s “charlatans” and “pseudo-experts” jeopardized the quality and objectivity of scientific information (TAC, 2006a).

Within the sociology of science and science studies, there is a subset of scholarship that has examined how civil society groups and “new social movements” working on a range of issues such as the environment, biodiversity, gay rights, and patients’ welfare strive to influence the methods and agendas of scientific research. This scholarship frequently analyzes case studies wherein knowledge and knowledge-making are no more confined to scientific experts. Rather, “lay” people want to be included in various aspects and stages of technical decision-making.⁵⁴ In contrast to the cases in this literature, TAC provides an example of a NGO that did not challenge the authority of mainstream scientific expertise. On the contrary, the group worked hard to reaffirm the autonomy of scientific experts. It did not want to get involved in the processes and content of knowledge making, nor in the scientific debates about causation and treatment. Those were strictly “the realm of the expert.” Moreover, it strove to keep the government out of these debates.

⁵⁴ See for instance Biehl (2006), Morello-Frosch (2005), Clark and Murdoch (1997), Wynne (1996), and Epstein (1996).

It was, however, not the case that TAC wanted to exclude itself from all matters of AIDS policy. For instance, the group very clearly claimed a role in matters of access to treatment. But this way of weighing in on science policy was not deemed as interference. Rather, TAC categorized its own questions about access as legitimate ethical and political concerns. On the other hand, the government's interrogations about definitions of disease, etiology and treatment were classified as heretical and charlatan interference in science.

The AIDS debate in South Africa, and the government's and TAC's competing boundary work and claims for credibility, followed the contours of many other scientific controversies where one party often supports mainstream science while another supports more heterodox science.⁵⁵ As the works of Pinch (1986) and Collins (1985) have shown, opposing parties often attack the credibility of their opponent by labeling the opponents' claims to be political and unscientific while announcing their own assertions to be more objective and scientific. Moreover, credibility was often established and demolished through association. Thus, TAC always displayed its association with leading scientists and social scientists in the United States and South Africa. It highlighted the government's support of heterodox scientists, and used that association to discredit a range of different concerns that the government raised, even if the concerns were not often related to heterodox science.⁵⁶

⁵⁵ There's an extensive literature on scientific controversies. For a small sample, see Mazur (1981), Collins (1985), Pinch (1986), Engelhardt and Caplan (1987), Nelkin (1992), and Martin (2001).

⁵⁶ The AIDS debate in South Africa bears strong resemblance to many scientific controversies that the SSK literature has covered. Despite these similarities, I do not wish to treat the South African AIDS debate along the lines of most SSK controversies, for that would entail adopting a position of symmetry and according similar importance to the positions of the mainstream scientists and the more heterodox "dissident" scientists. I do not wish to take this position of symmetry given the heterodox scientists' extremely marginal position. More saliently, my interest in this research is less to determine how different theories of AIDS gained authority. I am more interested in the implications of these struggles for the larger civic epistemology in post-apartheid South Africa.

According to TAC, not only was science not in the realm of democracy, it was wrong to think that democratic precepts of diversity could be carried into science. There was a “scientific method” which had to be relied upon to create consensus. Therefore credentialed experts who did not agree with the mainstream consensus, the so-called dissident scientists, had little credence in TAC’s view. The activist group was angered when in 2000, President Mbeki instituted a scientific advisory panel that had equal number of mainstream scientists and then other scientists who held highly unorthodox views on AIDS etiology. “Science is not about pluralism and diversity, it is not the same as creating a rainbow nation,” stressed a TAC official, referring to the phrase coined by Desmond Tutu, the Anglican Archbishop of Cape Town, who used ‘rainbow nation’ to describe his hope for a united multiracial multicultural post-apartheid South Africa (TAC 36, September 2005). “There is a sophisticated scientific method, which yields right answers and eliminates wrong ones.”

The South African government’s support for highly marginal scientific viewpoints raises the question of how governments should factor expert dissent into democratic decision making processes. This issue is relevant not only in Mbeki’s South Africa but also in George W. Bush’s United States where the administration initially questioned the scientific credibility of global warming. For the purposes of this chapter, however, the relevant point is that TAC did not engage in any depth with the issue of how to negotiate between conflicting experts in policy-relevant science. Instead, it invoked an unproblematic boundary between mainstream experts, and “dissident” and “denialist” experts. The labeling of the marginalized experts as “dissidents” and “denialists” in itself proved to be an important strategy for discrediting scientists with unorthodox views.

In decrying the government's call for a diversity of experts and viewpoints, TAC consistently asserted that claims of scientific uncertainty were spurious. TAC's politics of emergency, where the need of the hour was to save lives, had little room for discussions of scientific uncertainty. An organization which saw its members afflicted by a painful and horrible disease, an organization where leaders commonly started public meetings with statements such as "Comrades, we are still dying," perhaps understandably found postcolonial, postmodern critiques of mainstream science abstruse. For TAC, science entered the political arena as a public good because it offered 'lifesaving' drugs. There was no need for scientists to offer justifications for their technologies nor to expose the internal processes of scientific research to public participation and accountability. The AIDS epidemic warranted a rapid response, and this urgency sat ill at ease with long debates and uncertainties. Indeed, for TAC, the relevant debate was not about the views of highly marginalized scientists who questioned whether HIV was the cause of AIDS. Nor was it about "an African disease versus a western disease." The pressing question for the TAC was about *access* to drugs.

Of Babies, Drugs and the Courts

TAC's impatience with arguments of scientific uncertainty and heterodoxy was vividly illustrated in the battle over nevirapine. Nevirapine is an antiretroviral drug that was shown to reduce the chances of mother-to-child transmission of HIV. In 2000, the South African national government was restricting the use of nevirapine in the public health sector to selected pilot sites in each province for two years. The government claimed that since nevirapine was a new drug, it would be prudent to restrict it to pilot sites to assess appropriate dosage and potential problems of

resistance and toxicity. TAC feared that the government, notorious for its sluggish response to the AIDS epidemic, would delay or deny access to the drug. This, after all, was a drug that could not only extend the lifespan of a patient, but could actually save lives (of newborn children).

To protest the government's restrictions, TAC undertook a grassroots mobilization campaign, demanding that the government provide nevirapine on a universal basis. There were public marches and demonstrations that resounded with songs, dances and slogans that were reappropriated from the anti-apartheid struggle. In the marches and meetings, TAC members wore bright red and purple t-shirts emblazoned with the phrase "HIV Positive," proudly announcing a normally stigmatized status. In fiery speeches punctuated with cries of 'Amandla', (a Xhosa and Zulu word meaning "power") a political rallying cry against apartheid, various TAC leaders denounced the health minister to be a "murderer," and claimed that the state, in its indifference to citizens' human rights, was behaving like the former apartheid regime. In ways discursive and political, TAC framed itself as the progeny of the anti-apartheid movement – an oppressed group struggling for human rights against an arrogant and recalcitrant state. That the government of the African National Congress (ANC) was being cast as the villain, was an irony not lost on the TAC leadership. After all, the ANC was the party which had won the struggle against apartheid and consequently enjoyed enormous credibility and loyalty. In a delicate balancing act, Zackie Achmat, in almost every speech, pointed out that he is a card-carrying member of the ANC and that he had fought against the apartheid regime alongside many of those who were now in the government. Such moves sought to counter the inevitable accusations that the TAC, through its highly confrontational and occasionally vitriolic activism, was being disloyal to the liberation party.

In addition to social mobilization, TAC also filed a case against the national government, accusing it of violating the fundamental rights of South African citizens. The case, initially filed in Pretoria's High Court, went on to the Constitutional Court, which is the highest judicial body in South Africa. In the case, TAC argued that the right to health was a fundamental right promised in the South African Constitution and the government's restrictions on nevirapine were unreasonable in light of constitutional provisions (Constitutional Court, 2002). Initial clinical trials had demonstrated that administering a large single dose of nevirapine to a pregnant woman when she went into labor could significantly reduce changes of HIV being transmitted to her child. TAC argued that the government was constitutionally obliged to provide this single dose nevirapine in public health clinics, and more generally, obliged to plan and implement an effective and progressive program throughout the country for prevention of mother to child transmission of HIV.

The government, in its defense, cited concerns about the safety of a relatively new drug. It pointed to reports of how the clinical trials, especially the HIVNET 012 trial in Uganda, used to ratify nevirapine had been riddled with problems and inconsistencies. To bolster its case, it pointed to the fact that the United States Food and Drug Administration had not approved single dose nevirapine and had in fact asked the company Boehringer-Ingelheim to withdraw its application for licensing such a regimen. The government further pointed to potential problems of drug-resistance due to administration of large single doses of nevirapine to women in labor. It argued that such problems of resistance were especially likely in South Africa because it as yet did not have the public health infrastructure of testing, screening and other ancillary services to accompany drug administration. The ensuring drug resistance would likely

immunologically compromise the newborn child. But the single dose treatment would more clearly compromise the mother as it would render most first-line treatment unsuitable for her. The government finally pointed out that nevirapine resistance was relevant not only to the mother and child in question. It was a much bigger problem relevant to public health writ large, and if not foreclosed carefully, would lead to far more complicated, intractable and expensive therapeutic interventions. Given the significant unknowns surrounding this new drug, it would be prudent to have further long term studies before providing the drug on a national scale. It asked the courts to view the administration of nevirapine not as a rights issue, but as a public policy and public health issue. Underlying the public policy was a body of scientific claims and evidence that needed to be examined and analyzed closely because they encompassed significant unknowns.

TAC lawyers saw these arguments as yet another example of the government's "quackery" and its denial of the urgency of the epidemic. They responded by pointing to the WHO's support of nevirapine, and the drug's widespread use in other 'resource-constrained' countries. They pointed to the large medical literature that weighs the relative benefits of antiretroviral drugs to be far greater than their risks. They agreed that a long term, multi-drug treatment would be better than a single large dose of nevirapine. However, they pointed out that most HIV-positive pregnant women in South Africa don't find out that they are HIV-positive till quite close to the time of delivery. Thus a long-term treatment was not always feasible, and a multi-drug treatment was likely to be much more expensive. Given these constraints, single dose nevirapine was the best and most humanitarian alternative that the government was obliged to provide. According to TAC's submissions, the uncertainties of scientific knowledge that the government was pointing to were bogus and excuses to keep the

drugs from needy patients. A discourse of uncertainty, according to TAC, was being wielded as a political tactic with little basis in “scientific fact” (TAC, 2002)⁵⁷. TAC used the government’s controversial skepticism to label it as a “denialist” state, and this denialist label was effectively wielded in discrediting its arguments.

TAC’s case was built around a claim for fundamental rights, whereas in its deposition, the government had focused on what it considered to be controversial and uncertain science underlying the new drug. In a reprimand to the government, the Constitutional Court ruled in favor of TAC and ordered the government to provide nevirapine in public health clinics to all HIV positive pregnant women who asked for the drug. The Court did one by one take up each of the government’s concerns and then seriatim dismissed them out of hand. In its dismissal, though, it did not engage in detail with the scientific nuts and bolts of the debate. Rather, it dismissed the government’s concerns in a relatively cursory fashion. Therefore, it dismissed concerns of safety and efficacy by saying that “the evidence shows that safety is no more than a hypothetical issue” (TAC v. Minister of Health, 2001). The court equally summarily dismissed the concern about resistance:

As far as resistance is concerned, the only relevance is the possible need to treat the mother and /or the child at some point in the future. Although resistant strains of HIV might exist after a single dose of nevirapine, this mutation is likely to be transient. At most there is a possibility of such resistance persisting. However, its weight is small in comparison with the potential benefit of providing a single tablet of nevirapine to the mother and a few drops

⁵⁷ See Pinch (1981) on how scientists in debates tend selectively to present their own arguments as certain and their opponents’ arguments as uncertain in order to defend their area. Also see Brian Campbell (1985) on how uncertainty is used as symbolic action among experts in a debate. According to Campbell, there is no intrinsic need for a discourse of certainty in order to establish authoritative scientific claims. Rather, the social context can create a situation where uncertainty can be managed and become the basis of an authoritative argument.

to her baby at the time of birth. The prospects of the child surviving if infected are so slim, and the nature of the suffering so grave that the risk of some resistance manifesting at some time in the future is well worth running.

(TAC v. Minister of Health, 2001)

According to the court, “the essential facts are not in dispute. Most if not all the disputation is besides the point.” Science studies scholars such as Michael Lynch (1998) and Sheila Jasanoff (1998) have pointed out that occasionally established scientific facts and technologies do not withstand the adversarial techniques of deconstruction wielded by skilled lawyers. The courtroom becomes a site where uncertainties in science are constructed and highlighted. In the nevirapine case, however, uncertainties that the government was trying to highlight were brushed aside or simply ignored. The court gave the uncertainty claims little credence, and clearly sided with TAC. Such closure of scientific debate was testament to TAC’s success in undermining the government’s credibility. Perhaps the closure was also inevitable given the imperative of urgent policy-making. Perhaps the court found it essential to draw stark lines so as to move ahead and force the government into taking action on the epidemic that it saw ravaging the country. However, in summarily closing the debate on nevirapine, the court also constrained the overall space for expert debates in the public arena. Moreover, by determining which experts, which evidence and which science will receive legitimation, the court itself took on the role of expert. It became the site where the safety and efficacy of AIDS drugs was ruled on, the site where public health policy was made. The court became the site for knowledge production (Jasanoff, 2005).

After summarily bracketing the scientific debates and deliberations of experts and

government technocrats, the court focused on matters of individual rights that were raised by TAC. Before the TAC case, the Constitutional Court had been approached twice for the enforcement of socioeconomic rights (Ray, 2007). On both occasions, it ruled that the state is under a constitutional duty to comply with positive obligations imposed upon it by the Constitution. In this case too, the Court held the state responsible for executing a reasonable plan for prevention of mother-to-child transmission of HIV by providing nevirapine in all public clinics and hospitals.

This case has been widely hailed as landmark jurisprudence not only in the context of the AIDS epidemic but more broadly in the young legislative history of South Africa's democratic republic. The legal drama allowed for a cementing of TAC's rights-based politics, and allowed the TAC to further discredit the government's debates on AIDS-related science. TAC's quashing of debate over what it considered closed scientific truths is perhaps most vividly illustrated in its litigious activism; while I have described only one case here, the group regularly turns to the courts to enforce a stringent understanding of treatment. The group's aversion to debate particular questions of science also extends more generally into the language and political action it adopts. I do not in this chapter want to get into what is a charged public debate in South Africa, about whether the government was right or wrong, nor whether TAC was right or wrong in their respective stands on drugs, causation and treatment.⁵⁸ The point I want to make is that TAC's representation of clear scientific consensus and of deferring to all-knowing scientific experts was - and continues to be - inhospitable to

⁵⁸ The government's initial support of the highly marginalized scientists who question the HIV-AIDS causation theory has little or no mainstream credibility, and it is easy to see why such claims would get dismissed. Somewhat more unfortunately, what also gets dismissed are the government's public health concerns of widespread drug resistance, the ethical and scientific variability employed in clinical trials to approve anti-AIDS drugs, and how a focus on pharmaceutical intervention takes away the focus from more intangible but equally important historical and social understandings of the disease and its causation.

any debate on scientific processes (such as clinical trials), on the guild-like solidarity of the scientific community in AIDS research, and on the broader questions of the role of science and scientific experts in democratic decision-making.

Who is a “good sangoma”?

TAC’s boundary drawing around science was also apparent in the debate on traditional medicine. In its activism and treatment literacy programs in the first few years, TAC had exclusively focused on antiretroviral drugs and other ‘western’ medicines in combating AIDS. Fairly recently, since 2005, TAC has begun to address the role of traditional medicine in combating the AIDS epidemic. Part of the impetus has come from the government’s attacks which accuse TAC of being solely interested in the products of western multinational corporations, and not being appreciative of indigenous African knowledge. The government has recently passed legislation to boost the role of traditional medicine, and rallied the support of traditional healers’ unions for its policies. In addition to wanting to counter the government’s moves, TAC addressed the issue of traditional medicine because its leadership realized that the majority of South Africans, including its own members, turn to traditional medicine as a matter of first resort, if not also last resort. In one of its monthly newsletters, TAC remarked how there were “200,000 traditional healers in South Africa, about 80,000 more than the number of public healthcare professionals” (Treatment Action Campaign, 2005b, p. 3). TAC realized it could ill afford to ignore how much more easily its constituency could and did access traditional healers, especially in rural areas and poor townships (interviews).

In its evolving stand on traditional medicine, TAC emphasized that traditional medicine had an important role in combating AIDS, but that all such medicine should

first be scientifically tested. As the monthly TAC magazine, *Equal Treatment*, explained in its editorial in a special issue devoted traditional medicine:

The labels traditional medicine and western medicine are not helpful. The real difference is between medicines that have been scientifically tested and found to be safe and effective, and those that have not. Scientific tests help us know which medicines are likely to work and are safe to put in our bodies. It is because of scientific tests that we know antiretrovirals are safe and effective. There is no reason why traditional medicines cannot also be scientific medicines.

Treatment Action Campaign, 2005b

Thus, the numerous traditional medicines hawked by various healers had to be consumed only after they had been tested in biomedical laboratories for their safety and efficacy. TAC judged the appropriateness of these herbal and other mixtures especially in terms of how the traditional medicines interacted with antiretroviral drugs. In its treatment literature, there are lists of common herbal medicines, alongside descriptions of what biomedical safety and efficacy tests had revealed, and what interactions these medicines were likely to have with antiretrovirals.

In a similar vein, TAC acknowledged that traditional healers, or sangomas, were important “alliance partners” in the fight against AIDS. It worked to organize an association of traditional healers, in part to counter the traditional healers’ association aligned with the government. In its public statements, TAC stated that traditional healers have been historically suppressed and neglected under colonial and then apartheid rule. But TAC was also clear about the appropriate role for traditional healers. It explicated that a good sangoma asked his client to go and get tested for HIV. A good sangoma asked his patient to take antiretroviral drugs faithfully. TAC

was explicit that “if your sangoma tells you to stop taking antiretrovirals, then he is not a good sangoma” (Treatment Action Campaign, 2006b).

For TAC, it had become important to include traditional medicine into its treatment portfolio – but it makes clear that traditional medicine has to follow standards and tests of a ‘universal’ biomedical knowledge system. TAC, at least in its official policy that is publicized by its top brass, had a clear hierarchy between the epistemic reliability of western biomedical knowledge versus traditional African medical systems. This epistemic hierarchy that the formal TAC policy represents does not necessarily reflect the behavior of all its members, many of whom go seamlessly between availing western and traditional remedies. Their medical practices are often determined by a complicated articulation of communal identities, economic realities, and local pharmaceutical access. TAC leadership is sensitive to the discrepancy between what it espouses and what many of its members practice, and tries to use its treatment literacy programs and services to ensure better adherence to antiretroviral drugs.

The group, however, did not represent its policy as representing a hierarchy of different knowledge systems. As Zackie Achmat explained in an interview, “There is one universal system of medicine, just as there is one universal system of science” (interview Achmat, October 2005). Since science and medicine were universal, there was no vexed question of hierarchy between different sciences. Similarly, a conception of a single universal knowledge system effaced problems of translation between what would otherwise be considered distinct knowledge systems with disparate logics and referential systems regarding how to understand the body, disease and illness. When asked whether subjecting age old remedies to controlled clinical

trials might result in the loss of certain essential elements of the remedy, Achmat responded that clinical trials were not meant to distort any element of traditional medicine, but rather capture it in a measurable reliable matrix. The problem was one of integration, not of conversion or incommensurability.

By describing some of the politics around traditional medicine, my point is not to argue for traditional knowledge as an important alternative for understanding and curing AIDS. Rather, my point is to show how the encounter with traditional medicine yet again reveals the clarity of TAC's epistemological commitments. As TAC remained focused on its support for antiretroviral drugs, it effaced what could be distinct logics, histories and political economies that underlay traditional medicine. For TAC, traditional medicine was useful because it could potentially serve as an ancillary instrument for augmenting adherence to biomedical treatment.

Epistemic Groundings to Liberal Demands

Since the nevirapine trial, TAC has pressured the government to provide antiretroviral treatment on a national-scale. The group spearheaded a high-profile civil disobedience campaign, and stepped up the pressure through protests, media reports, and threats of litigation every time the government seemed to be backing off from making a commitment to provide antiretroviral treatment through the public health sector. "This is our government. We have no qualms in demanding our rights from it," stressed a senior TAC leader in midst of these struggles (Interview TAC4, August 2005). As a result of the group's activism and litigation, the government announced a national plan to rollout antiretrovirals on a national basis.

Scholars such as Steven Robins have suggested that TAC, through its AIDS activism,

is creating a new model of “health citizenship” in South Africa – a citizenship that is based on rights and entitlements (Robins 2005). I have tried to show in this chapter that TAC’s model of rights-based citizenship exists in conjunction with a particular vision of science, a vision of science that has strict boundaries between seemingly autonomous realms of “science” and “politics,” which produces undisputed answers through a “scientific method,” and which emphasizes a universal biomedical rubric.

TAC downplayed uncertainty, plurality and incompleteness inherent to new scientific knowledge in order to claim its health-based rights. After all, it would have been more difficult to demand antiretroviral treatment from the government as a constitutional right if the validity of the treatment was open for questioning. It would have been difficult to drag the health minister to the Constitutional Court for not providing nevirapine on a national scale if TAC conceded that there might be uncertainties around problems of drug resistance and efficacy. Similarly, it would have been complicated to threaten civil disobedience campaigns and litigation against the government for delaying the roll out of the world’s largest antiretroviral program if traditional medicines are also seen as important components of treatment. TAC’s notion of rights-based citizenship tended to be inhospitable to critical analyses of science because it grounded its judicable claims to entitlement in certain knowledge.

What accentuated TAC’s intolerance for scientific plurality and uncertainty was the emergency-based politics it practiced. With people dying of a painful disease, there was a compulsion “to do something.” The imperative to act, and to act now, shrunk the space for debate and deliberation. TAC’s politics of emergency, with its clarion calls for quick action, was ill at ease with a framework of uncertain science that it saw a recalcitrant government conveniently promoting. To undermine the government’s

discourse of scientific uncertainty, TAC emphasized emancipatory solutions couched in a discourse of surety. In other words, TAC's rights based politics relied on making a positivist scientific epistemology sacrosanct. Rights here became the political equivalent of epistemic certainty.

While TAC's politics of rights seemed to demand a discourse of certainty, and an embrace of a progressive narrative of science, this has not always been the case for other NGOs. Steve Yearley, in his account of environmental movements in Europe, has described how these groups very often found science to be less good an ally than they would have wished. Yearley describes how the environmental activists often found that if they "relentlessly committed to scientific judgments, then they wouldn't be in a position to make instant and unequivocal judgments" which were often necessary in their politics. The activists' misgivings about science were accentuated because science did not always allow banishing uncertainty; it was too open to revision (Yearley, 1989, 1991, 1992). Similarly, Steve Epstein has described how some AIDS activists in the United States affirmed expert methods and knowledge, while others resisted an embrace of technical expertise (1996). These and other examples indicate that NGOs' rights based activism does not necessarily always embrace scientific certainty. The epistemological claims that go along with political rights vary, and depend on the specific contexts and contingencies. Some times, instead of detracting from proclaimers' credibility, uncertainty can often be invoked to legitimate credibility (Shackley and Wynne, 1986; Lynch, 1998). In the TAC story, however, the claim for rights is closely intertwined with a narrative of undisputed, expert-drive, scientific certainty.

Local Voices That Reaffirm Global Paradigms

TAC has represented South Africa's urban poor in some very rich and varied ways. Its membership had a large number of HIV positive black women from townships, and its mobilization and services were based in disenfranchised black neighborhoods. However, this intimate proximity to the local did not mean that TAC reaffirmed local traditions of knowledge. On the contrary, TAC actively affirmed the dominant global paradigms of biomedicine and embedded understandings of disease, testing and treatment. TAC saw the national government's emphases on traditional knowledge and questioning of the guild-like solidarity of AIDS scientific community as threatening its interests and its goals of distributive justice. The group worked hard to maintain a policy that was driven by mainstream scientific experts and that was consonant with the prescriptions of a larger global AIDS machinery. Thus, somewhat ironically, TAC, while in some ways most proximate to the local, was also the harbinger of global science and technology. It ushered in global political norms, epistemic frames, and disease categories into South Africa's AIDS epidemic. It provided a case where representation of local interests was coupled with an affirmation of global, expert driven biomedical knowledge. By so profoundly shaping AIDS policy in South Africa, the group provided a vivid example of "democratizing" science policy. But ironically, TAC's rhetorical means asserted the autonomy and superiority of biomedical experts, and the relative irrelevance of political and non-scientific stakeholders.

TAC had a clear prescription for policy makers, and these prescriptions were to follow the advice of mainstream biomedical experts. Its politics revealed that there can be no a priori presumption that citizens' or non-experts' involvement in public debates about science and science policy necessarily lead to framings that allow more diverse, open-

ended understandings of disease and medical science. TAC's politics revealed that, social movements, like technical experts, are vulnerable to framing imperatives and interests that can reduce the diversity of epistemological perspectives in policymaking.⁵⁹ This shuttering down of options, or what Andy Sterling has called "closing down," may not be necessarily normatively negative in its effect (Stirling, 2005). Indeed, TAC's restricted framing of the AIDS epidemic was key to creating legal and political pressure that ensured treatment for a larger number of South African people living with HIV.

Conclusion

TAC is an immensely important character in post-apartheid South Africa, not least because it provided, often self-consciously, a template for other NGOs and civil society actors in the country. Its activism, which spans the global, national and local levels, is helped create a new civic epistemology wherein new rules and norms were constructed to authorize knowledge and technology. It helped develop new norms of accountability in public health and public policy more broadly, where the government would be hauled to court if it did not deliver public goods. It has been instrumental in defining a new public sphere of a newly democratic South Africa where adversarial interactions between the government and members of civil society are a dominant trend. Given its foundational role in a young democracy, TAC demands critical analysis.

However, critical analysis such as offered in this chapter inevitably raises normative questions about the politics of the analysis and implications for policy. After all, TAC

⁵⁹ On how technical expertise is sensitive to framing effects, see Goffman (1974) and Wynne (1975, 1987).

fighters for the rights to treatment, to life, from a recalcitrant state and a health minister who has made seemingly bizarre statements about the value of garlic and olive oil in fighting AIDS. Might not a critical analysis undermine the humanitarian work that TAC is doing?

The goal of this chapter is not to condemn, nor praise, TAC's rights-based politics. Rather, I seek to analyze how TAC's politics around AIDS is tethered to and coproductive of particular epistemological commitments. I am interested in how particular discourses and politics about disease make space for some contingencies and some experiences, but not others. TAC's discourse, which focuses on rights to access drugs, is clearly effective in pressuring the government to provide AIDS treatment. Through its challenges of intellectual property regimes and drug pricing norms, it has also been successful in compelling multinational pharmaceutical companies to slash drug prices. The focus on antiretrovirals as a vital life-extending and life-saving technology has helped reduce the stigma associated with AIDS and many more South Africans have been willing to be tested and identified as having the disease. By focusing on the urban poor, TAC's campaigns have ensured that medical services don't circumvent those who are most vulnerable and most likely to be remaindered.

At the same time, TAC's rights-based politics results in "closing down" of the ways to frame the AIDS epidemic (Stirling 2005). TAC's almost exclusive focus on accessing drugs seems to push out other kinds of framings from the cultural toolkit in the public sphere. For instance, it is difficult to question the science behind antiretroviral drugs. The problem of resistance to single-dose nevirapine and other anti-AIDS drugs has not been much debated in the South African media that cover the

AIDS epidemic and TAC extensively. The ‘right to treatment’ focus has also eclipsed critical understandings about the disease that center on historical or racial experiences of knowledge production. TAC’s rhetorical success has been such that such framings are now associated with a Mbeki-style ‘denialist’ politics. In order to respond to Mbeki’s perceived denialism, TAC has developed an ‘us versus them’ credo which made it difficult to stray from the established line. This perhaps may be Mbeki’s most ironic legacy regarding the AIDS epidemic – in seeking to contextualize AIDS in more Africa-specific, social and historical terms, he provoked a politics that made such historical, contingent framings highly fraught and more or less impossible.

Chapter 6. Conclusion

This dissertation project asked how the AIDS epidemic was conceptualized in the national policy frameworks of India and South Africa. My research revealed that the Indian and South African states adopted contrasting approaches in imagining and responding to the epidemic. Therefore, this is a comparison of difference, of difference in how two democratic governments in the south forge relationships with global science and politics. But there were also similarities in the models of public health that get adopted. Many of these similarities emerged from the involvement of civil society organizations that similarly influenced public policies in both countries. In both South Africa and India, nongovernmental groups were central to the way the epidemic was understood and addressed. These NGOs could be both highly cosmopolitan and often close to the grassroots. They were often invested in a discourse of rights that is increasingly recognizable around the world. The story of AIDS policymaking is also a story of how public health policymaking shifts and moves into terrain where nongovernmental stakeholders become critical. Below, I summarize some of the key similarities and differences in how the two countries addressed AIDS.

The Indian State: A Case of Erasing the Past

India's national government embraced many aspects of the global machinery of AIDS. It was the beneficiary of hundreds of millions of dollars in global developmental capital from the World Bank, USAID and a range of other international institutions. The government allowed these funds and their purveyors to shape the architecture of its policymaking apparatus by establishing a stand-alone National AIDS Control Organization that enjoyed considerable autonomy from the remaining ministry of

health bureaucracy. It adopted the models of assessment and intervention brought in by global experts. Under advice from international technical agencies, it established a public health program of targeted interventions rather than a more holistic program that would have integrated AIDS management with other public health concerns and explicitly addressed the socioeconomic structures that shape the contours of the epidemic.

I describe in this dissertation that the Indian state embraced a “foreknowledge” brought in by international experts. This foreknowledge, purveyed by global machinery for epidemic management, was very seductive. After all, it provided international authorization for a public health framework for a new epidemic that otherwise seemed bewildering and incoherent. The foreknowledge provided pre-designed tools for counting the number of infected people. It beamed in scientists from the Centers of Disease Control who informed the government of generic schemes and categories for explaining the differential susceptibility of individuals and groups. It offered clear mechanisms for managing the spread of the epidemic. It offered control, based on an authorized biomedical understanding of the disease, and crucially, based on the comparative experience of other countries.

The historian of medicine, Charles Rosenberg, has argued in his book *Explaining Epidemics*, that like the citizens of Camus’s plague-stricken Oran, communities are typically slow to accept and acknowledge epidemics. After all, epidemics “threaten interests, and rattle the emotional complacency and accustomed ways of ordinary men and women” (Rosenberg, 1992, p.281). Rosenberg further states that the initial denial is due to a “failure of imagination” (Rosenberg, 1992, p.281). It is only when the bodies pile up, when the sick increase in larger and louder numbers, that

acknowledgement becomes unavoidable.

However, a “failure of imagination” is rendered moot in the context of foreknowledge purveyed by a global machinery of epidemic management. Whether in the case of AIDS in India or the avian flu in China, this machinery, armed with its prior templates and tools, assists national bureaucracies in anticipating and designing epidemics. There is little imagination required here; much about the contours of the epidemic has already been conceived of. As such, AIDS in India, as AIDS in Nepal and Botswana and Nigeria, have been experienced largely as “expected” epidemics (Pigg, 2001).

The foreknowledge that dominated the Indian policymaking process sat alongside a silencing of local experiences and history. While in South Africa, the government used history as a critical lens through which to assess new knowledge coming from outside, in India, history got remaindered. The vast lessons from India’s public health history were prominent in their absence. There was little mention about how targeted interventions had failed or worked in older disease programs; there was scarce debate about the mixed track record of condoms distributed through “family planning” programs. This almost voluntary denial of history came with some advantages. It allowed the Indian government to avoid translating its experiences and its past into a global language that had no ready categories for these experiences. The erasure of a messy past, moreover, allowed the Indian government to partake easily of global lessons and global technologies. Indeed, the country could become part of, and simultaneously make, the global project of combating AIDS.

The instruments of calculation and management that the international technocrats deployed privileged ties of geography over those of local history. So while India’s

history in family planning was rendered irrelevant for AIDS policymaking, Uganda and Thailand's experiences in combating AIDS were considered central. As India strove to be taken seriously as an emerging global player, these geographical connections and comparative lessons from other countries proved to be more attractive and relevant over ties to a mixed local past.

It was, however, not the case that the global foreknowledge came to dominate the policymaking process in a seamless way in India. National experts occasionally did resist particular categories and presumptions that the foreknowledge brings with it. As revealed by the story of how prevalence estimates in India shifted, changes did take place. However, in order to bring about these changes, the government had to undertake arduous amounts of work. Unlike the South African government, it didn't address the global machinery with direct confrontation and skepticism, but rather made its point through arduous negotiations. While successful in molding some globalized instruments to accommodate some local contours, the government nonetheless had to acknowledge the broader legitimacy of global knowledge.

The South African State: Using History As Resistance

Over the last decade, the South African government was marked by its consistent skepticism about various aspects of the global socio-technical machinery built around AIDS. It perceived these global schemes and discourses about the epidemic as being explicitly moral; vehicles where old stereotypes could be expressed and simultaneously legitimated. The government took umbrage at the international media's and world leaders' portrayal of the AIDS epidemic being the "African holocaust." It questioned the moral and political presumptions that underlie such fatalistic statements, perceiving the framing to be indelibly intertwined with the

blaming. It criticized the inequality and injustice embedded in the economic architecture that the global AIDS machinery took for granted. Here, it especially criticized patent laws that make anti-AIDS drugs extremely expensive. The government was skeptical of activists and NGO workers whose advocacy was dominated by a demand for rights from recalcitrant governments. It portrayed much of this activism, however well-meaning, as trafficking in alarmist discourses of emergency and disaster which reaffirmed age-old stereotypes of Africa as a crisis-ridden continent. But perhaps most radically, the South African government extended its skepticism to mainstream scientific theories associated with AIDS. On different occasions, it raised questions about whether AIDS is caused by HIV; about the toxicity and efficacy of anti-retroviral drugs that are regularly prescribed to fight the disease; and about the role of nutrition and traditional medicine in addressing the epidemic. It was these challenges to mainstream scientific views on technical aspects of AIDS that attracted much international attention. However, I have tried to argue that the government's challenges were part of a larger picture of skepticism and suspicion of the global AIDS machinery. The Mbeki government challenged the entire machinery, and not just theories about viruses and drugs.

The South African government pointed to the past as a reason for its skepticism of the present. This past included a history of medical science and public health that selectively stigmatized blacks during the apartheid era. The apartheid government promoted racialized theories of illness under the banner of an objective science, and used them to justify and implement policies of segregation and inequality. This was especially true when the AIDS epidemic was first detected in South Africa in the 1980s. The racially differentiated nature of the epidemic incited a highly racialized and racist response from the apartheid government. Given this history, the Mbeki

government openly wondered how could it be expected simply to trust institutions of medical science and the knowledge they purveyed? How could it be expected to accept the declarations of yet another emergency, yet another disaster that the black people of Africa were afflicted with and had to be saved from?

The discourse of disaster that accompanied the AIDS epidemic was especially galling for a young democracy that was seeking a new post-apartheid identity and an African renaissance. Even though riven by uncertainty and factionalism, there was to be a monumental foreground that was meant to surround the birth of “this most exceptional of nations.” But, the monumental foreground was not supposed to be the AIDS epidemic.

The government proposed a paradigm of public health that was sensitive to the social and economic structures that made people vulnerable to disease. Consequently, the government strove to address AIDS as part of larger systemic problems of poverty, malnutrition and poor medical access. Instead of building a vertical response machinery, it attempted to integrate AIDS into a larger public health system. This broader approach to the epidemic proposed new boundaries between “science” and “politics.” It changed and expanded the definition of who was deemed to be a relevant expert. It resulted in defining a more capacious material infrastructure to address the epidemic. In its challenges, the government tried to conceptualize the epidemic by refracting a “universal” scientific knowledge through the lens of local experiences. It demanded that epidemic management tools purveyed by international technocrats be adapted to local realities. It proclaimed, most controversially, that even “science” – its theories and technologies – should be held up to inspection against a local and historical register.

However, as we have seen, the government discovered that these shifts – in paradigms, laws, and infrastructures – while easy to proclaim, were not easy to install. The international and national scientific community firmly rejected the government’s skepticism of mainstream theories, and labeled them as quackery. The Constitutional Court forced the government to roll out a nation-wide program to provide nevirapine for pregnant women. Persistent litigation and activism by nongovernmental organizations pressured the government to undertake what is the world’s largest antiretroviral program through the public sector. The government’s attempts to include emphases on nutrition, poverty and employment in its AIDS policy were widely disparaged by critics as leading to confusion and obfuscation over antiretroviral drugs. Its failure to take action early were criticized as constituting violent action.

The South African government attempted to offer an alternative framework for understanding and addressing AIDS. It realized, however, that its sovereignty in this matter was severely limited. The scientists in its own country, by and large, desired the credibility, funds and approval of international peers and donors, and not the government. Social movements, spearheaded by the Treatment Action Campaign, could move the courts to demand sweeping changes in and new types of public policies. No more was the government independently determining public policy. Instead, the power of the executive was pathetically restricted to sending out “mixed” and “confusing” messages. Indeed, it was no longer clear who the sovereign was. Was it the global machinery and its “science”; was it nongovernmental organizations who with the help of the courts, transformed public policy; or was it an enfeebled state that in its outrage continued to make polemical pronouncements that, however, remained at the level of polemics?

Indian NGOs: Alignments With the Global and National

In both India and South Africa, non-governmental organizations had a large role in shaping AIDS policy and in conceptualizing public health more broadly. However, the Indian NGOs were distinct from the South African social movement in that they did not by and large claim to represent directly those infected with HIV. Rather, the NGOs in India claimed to provide services to the AIDS-afflicted. In India, like in South Africa, non-governmental groups embraced the language of rights. However, in India, as opposed to South Africa, NGOs largely demanded negative rights, that is, rights to be protected against various discriminations and incursions. Indian NGOs, strikingly, had not made a large scale demand for the positive right to health, and especially for the right to antiretroviral drugs. Part of the reason had to do with the politics of representation, and the vulnerability of the NGOs to their international donors, as discussed in Chapter 3. Moreover, unlike the South African Constitution, the Indian Constitution does not provide judiciable economic rights such as the right to health and housing. It enjoins the state, in its “Directive Principles,” to provide for the economic wellbeing of citizens, but does not hold the state *legally* responsible for this.

Many Indian NGOs were the beneficiaries of the large monies from international donors that entered India since 2000. As a result, many NGOs designed their programs and interventions to conform to the constraints specified by donors and their evaluative mechanisms. Responding to the incentives and priorities of donors and their contracts, NGOs shaped their public health programs in favor of targeted interventions over more integrated approaches. They increasingly advocated a globalized discourse of ethics which adumbrated the values of privacy, confidentiality,

and more generally, individual rights.

Chapter 3 illustrates how the NGOs' dependence upon global development capital resulted in a striking alignment between their work and the policies and priorities of international donors. Thus, even though formal policy documents discussed NGO "participation" in policymaking and execution, this participation by no means resulted in benign relations of power between civil society actors, the government, and international donors. Even though NGOs were involved in some of the highest levels of policy-making, this didn't necessarily give them autonomy from structural pressures from funding sources. The AIDS story in India points to how the outcomes of civil society participation even at high levels of policymaking can be overdetermined by structures and norms of funding.

The involvement of NGOs, alongside international donors, instituted new forms of accountability in India's public health sector. These norms of accountability were not hinged on the courts, as was the case in South Africa. Rather, the chain of accountability closely followed the transfer of developmental capital, and was regulated through contracts between the donors and the recipients. The resultant contractual accountability was central to managing the Indian state's "outsourcing" of public health functions to NGOs. The contracts were not dependent on a national legal framework; rather they were a self-sufficient ordering mechanism.

This model of contractual accountability, and the attendant prominence of NGOs and international donors, throws a spotlight on the retreat of the state. In India's AIDS policy, the state withdrew and dispersed its authority and administrative duties to a whole host of NGOs. In doing so, the state further enabled the embedding of global

norms and categories in the political, epistemic and normative landscape of AIDS, and more broadly in public health.

South African NGOs: An Adversarial Politics

South Africa had a broad based social movement organized around AIDS. As described in Chapter 5, this movement was responsible for dramatic shifts in national policy. The movement was led by a NGO called the Treatment Action Campaign. TAC and its allies often dragged a recalcitrant state to court over a range of policy issues. This litigation resulted in the Constitutional Court ordering the state to nationally distribute the drug nevirapine through the public health sector to pregnant women with HIV. Similarly TAC's activism pressured the government to launch a nationwide program of distributing antiretroviral drugs to those affected with AIDS. Its litigation, and its activism more generally, were couched in a language of rights – rights which were adumbrated by the South African Constitution. These rights include the right to health: a judiciable positive economic right that the radically liberal constitution of the country guaranteed.

Groups like TAC, and their highly litigious activism clearly shifted public health policy by compelling the government to provide antiretroviral treatment on a large scale. In addition, the groups' activism had epistemic consequences by determining in many ways how science should be understood in the public realm. They to a large extent adopted an emancipatory discourse, presenting science as a certain and progressive body of knowledge that was central to solving the problem of AIDS. As described in Chapter 5, TAC deftly drew boundaries around science to affirm its progressive qualities. Thus in its litigation over nevirapine, TAC brushed aside the government's cautionary concerns of potential drug resistance. It consistently

underlined the importance of antiretroviral drugs, and dismissed traditional medicine as having a subsidiary and occasionally harmful role in relation to biomedical remedies. Its demands for individual rights have gone hand in hand with its portrayal of science as an emancipatory force. Consequently, I argued that TAC “closed down” or narrowed the debate around AIDS by not engaging with some of the more problematic aspects and framings of new technologies and drugs (Stirling, 2005). Its focus on access to drugs pushed out other kinds of framings of the epidemic from the cultural toolkit in the public sphere.

Through its activism and persistent use of the courts, TAC shifted the accountability mechanisms for public health and public health policy. The group repeatedly took the government to court, where the government had to defend its policies. The courts became a site where major public health policies were determined. They were also a site where medical controversies were ruled on, such as of the toxicity of antiretroviral drugs, and their attendant resistance problems. Thus, TAC’s actions moved much of politics – of science, and of policymaking – to the realm of law. Conflicts that otherwise would have been debated within technical committees, in the parliament, by street demonstrations and other instruments of assertion and debate – found their way to the judiciary. Law became the means to adjudicate science, and the means to frame public health.

The turn to the courts and the language of legality and rights offered a new understanding of public health in South Africa. The courts, almost out of compulsion based on their own limitations, bracketed technical discussions and instead focused on matters of individual rights and liberties. This emphasis on individual rights reconfigured an older public health orientation which had always been towards

prevention, primary health services, and the wellbeing of people at large. In the politics of the AIDS epidemic, public health in South Africa moved away from this familiar conception which had been oriented towards the collective. It went from being about large-scale prevention, to being about individual-oriented, rights-based access to treatment. In his work on AIDS in Brazil, Joao Biehl has argued that the AIDS epidemic has been consonant with a “pharmaceuticalization of public health” with access to treatment has become a central pillar of AIDS programs (Biehl, 2006). In South Africa, I argue that the AIDS epidemic was consonant not only with a pharmaceuticalization of public health, it also moved public health from being about a state’s concern with the larger collective to being about a state’s ability to satisfy the rights of individual citizens. The older incarnation of public health was not necessarily always more effective in reaching marginalized groups or in responding to urgent needs of poor people. Indeed, activists’ rights discourse often forced the public health infrastructure to rapidly address the needs of patients who were represented by activists, and who otherwise might have been neglected by the public health system. However, the emerging individual rights–based model of public health meant that the state was more likely to address the needs of those who were vocally represented. The government’s concern with the public as a whole was rendered less important than its ability to respond to the active claimants of rights.

The turn to the language of legality, and the judicialization of politics and science, profoundly influenced South Africa’s post-apartheid public sphere. TAC offered a model of citizenship in which individuals are pitched against the government principally in an adversarial mode. This enabled marginal and stigmatized groups of society to be brought into the fold of public health. The same adversarial politics proved to be remarkably successful in forcing a recalcitrant government to launch

large programs of antiretroviral distribution. The adversarial politics between TAC and the government, however, also vitiated the debate around AIDS, creating an “us-versus-them” credo. Ironically, the tragedy of AIDS in South Africa, which is so closely intertwined with its history of apartheid, culminated in a view of citizenship in which the citizen and the state remained intractable adversaries.

Conclusion

In the global machinery built around the AIDS epidemic, there has been a consistent emphasis on a managerial vision enabled by different varieties of technologies. This managerial vision has constantly asked how the epidemic, infecting millions around the world, can be controlled. It has often been in search of incisive, powerful interventions that can halt the march of the epidemic. It has asked how we can control risk? Are there public health programs, such as the distribution of condoms, that can stop the rampaging virus? Does a message of abstinence and family values seem to be effective? Can we develop drugs and vaccines that can control the epidemic?

Not always accommodating to these managerial tactics, the epidemic has continued to wreak havoc. The intransigence of the epidemic has been matched with new control mechanisms and technologies. The global machinery has thus churned out a new set of questions. Can we develop new drugs that deal with resistance problems? Is male circumcision the new public health manna? Are microbicides for women the way of giving women more control?

In the midst of all the outcry, proclamations, determination, billions of dollars spent, new programs, new institutions, new discourses, in the last year or so there has been an emerging sense among epidemiologists that perhaps the existing tools for mapping

and understanding the epidemic are broken. Perhaps the epidemic is not marching in the directions and in the ways that had been commonly imagined and prescribed. Perhaps the scale and shape of the epidemic are different from what this managerial vision has proclaimed and tried to control. In response to this growing realization, some experts have called for better instruments and better technologies for counting. Some have called for a worldwide system of “rigorous registration” that would allow a closer tracking of the virus (Szreter, 2008). The findings of this dissertation suggest that the answer might lie elsewhere: not solely in developing better instruments and technologies, but also in changing relationships and social dynamics that underlie the technologies. It has tried to indicate that these relationships – between the north and south, the global and the local, the past and the future – are key to determining the conceptualization of the epidemic.

The dissertation also examines how the AIDS epidemic became the site for profound shifts in the conceptualization of public health in India and South Africa. Public health was transformed through a combination of transnational expertise and a democratic politics that focused on individual rights and legality. No longer is it solely in the domain of the national and local government, as it is increasingly in the purview of international technical and civil society organizations. No more is it associated with large-scale prevention and primary health care for the people at large. Instead, the emerging conception of public health focuses on individual-oriented, rights-based access to treatment. The emerging models of public health have new modes of accountability – hinged on courts and contracts.

Implicit in these emerging conceptions of public health are entire images of the nature of the state and its relationship to its citizenry. As such, public health becomes a

useful sampling device, because we can see in it some of the more extended forms of change that are underway in postcolonial nations in the south, which are increasingly associated with the emerging logics of globalization. Thus the AIDS epidemic throws into stark relief the recession of the managerial government into private indirect government; the migration of politics into realms of law; the prominence of civil society organizations, which are often highly cosmopolitan and aligned to international norms and institutions; ideas of local history that increasingly get superceded by comparative lessons and ties of geography.

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