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AIDS, surveillance and public policy: The politics of medical discourse

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University of Hawai‘i, 1989
AIDS, SURVEILLANCE AND PUBLIC POLICY:
THE POLITICS OF MEDICAL DISCOURSE

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ABSTRACT

This dissertation is a critical political reading of the AIDS epidemic, one which attempts to situate the epidemic within the surveilling practices of contemporary medical politics, as well as assess the impact of those practices on the formation of AIDS public policy. It is contended that medical authority engages in systematic surveillance practices which advance its authority over the epidemic in ways that satisfy its expanding and hegemonic professional and corporate interests. Surveillance is broadly conceived of here as a modern mechanism of disciplinary power which must be seen both as a set of institutional and individual behaviors, and as particular kinds of representational practices which naturalize authority and produce (and reproduce) what the author calls surveilling identities. Similarly, the AIDS epidemic is viewed not only as a tragic biological reality, but as a social and representational one as well. AIDS is argued to be the yield of a number of contending language and textual practices struggling to
establish the meaning of the epidemic, a location where power and knowledge are transformed into discourse.

These theoretical understandings emerged as part of a critical textual analysis of the Institute of Medicine, National Academy of Sciences' Report on AIDS, titled Confronting AIDS published in 1986. This report was one of the most important statements on the epidemic by American medicine up until that point in time, and consequently led to a number of policy actions including the creation of the Presidential Commission on the H.I.V. epidemic. The critique explores how medical authority is secured through the surveilling representational practices articulated in the report. These practices range from textual strategies which affiliate the National Academy with an idealistic historical gloss of medical progress, to those practices which serve to depoliticize the power aspirations of medical authority. The dissertation concludes with a discussion of the reciprocity of power relations between medical discourse and public policy on AIDS (seen here as a form of state and class discourse).
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CHAPTER I
AIDS, SURVEILLANCE AND MEDICINE

The plague is met by order; its function is to sort out every possible confusion: that of the disease, which is transmitted when bodies are mixed together; that of the evil, which is increased when fear and death overcome prohibitions. It lays down for each individual his place, his body, his disease and his death, his well being, by means of an omnipresent and omniscient power . . . Against the plague, which is a mixture, discipline brings into play its power, which is one of analysis.

Michel Foucault

In Daniel Defoe's classic fictional account of the bubonic plague in 17th century England, we are confronted, as Richard Goldstein observes, with "the 'plot' that we still impose on epidemics", a language of speaking plague that in some sense is foundational to the modern framing of our new experience with AIDS.¹ We read in his imaginary journal of the initial collective denial of the plague's death-reality, of the alert paranoia over this inexplicable and invisible enemy, of the physical and emotional suffering endured, of the surrender by many to feelings of terror, of the numbing
dissolution and then powerful resurrection of community, and of the stark and often absurd character of public measures to contain the epidemic. That great visitation of 1665, once narrative and fictive, now resonates as true; what was strange is tragically familiar. It is as if our AIDS experience, in humbling modern arrogance over 20th century technological superiority, has lessened somehow the historical distance between now and then.

Other familiarities strike us in Defoe's reading of plague especially that continuous fear, expressed by both the sick and healthy alike, of being watched. Official examiners, watchmen, searchers, not to mention the often innocent inquiries of good neighbors and friends, were all to be viewed with extreme suspicion during times of plague. For any visible sign of possible infection, real or imaginary, made one vulnerable to a number of devastating official impositions. In Defoe's time the "shutting up" of individuals and entire families in their houses was to be particularly feared. "Confining the sound in the same house with the sick counted very terrible, and complaints of people so confined were very grievous."2

Measures taken, embedded as they were in the motives and rhetoric of public good and safety, often led to the experiencing of private impoverishment, and horror. The prospects of physical suffering and social ostracism of
plague victims and for those still well, became inseparable from the fears and effects of public exposure, inspection, judgement, rejection, and confinement or exile. To be watched was the first encounter with this dread, an encounter to be avoided at all costs if possible, and if that was not to be, then one in which all personal resources had to be brought to bear against it and to render it harmless.

Surveillance was judged by the authorities to be necessitated by the nature of the disease. But, in a darker sense, it was also seen to be required by the changes that occurred in people once afflicted by the plague, or worse, by the character of those who brought the plague upon themselves and threatened to do so to others. Defoe observed that people suffered from "the rage of the distemper", "laying violent hands upon themselves" and others as well. Mothers murdered "their own children in their lunacy." And indeed there was great fear of those with plague in which "there was a seeming propensity or a wicked inclination . . . to infect others." It was not "distemper" that drove these people to acts of hatred, wrote Defoe, but a "malignity" in the "very nature of man". Rape, it was often understood, was the signature of this plague personality.

[S]he being so near, he caught hold of her and pulled her down also, and getting up first, mastered her and kissed her; and which was worst of all, when he had
done, told her that he had the plague, and why should not she have it as well as he?

Surveillance was believed to be society's protective response not only to the infectious nature of the disease, but also to what people thought to be the dangerous differences, psychological and moral, that the infection symbolized between those who were, and who were not, struck by the plague. But the protective response was itself a burden for all concerned.

Modern popular culture, as it informs the rationales for our present operations and policies of surveillance in relation to AIDS, appeals to this historic duality of fear, of infection and of infected persons. Yet while the fictional and non-fictional historical accounts that shape this plague narrative render a troubling air of legitimacy to contemporary surveillance, in the end they offer us little insight as to what political interests, actors or institutions are served through the proliferation of surveillance practices, or how surveillance in the contemporary context is substantially different from the past or, for our purposes, how surveillance has come to dominate the public response to the AIDS epidemic.

These are important questions in our view because of our strong belief that surveillance has become the political problematic of modernity. We agree with Anthony Giddens that the scope and sophistication of
modern surveillance practices, and the extent to which institutions and individuals engage in them, present us with a threat to human liberties unlike that of any time in history. And most of us are not unaware of this increasing foreclosure on our freedom. The recognition of surveillance as an increasingly dominant force in everyday life arises from a relatively recent legal and political history in both the East and West, one which reflects a pervasive public uneasiness and foreboding over the expanding governmental and non-governmental sector surveillance of ordinary citizens, and over what is seen to be a growing list of violations against rights of privacy. It is thus of the utmost importance that the AIDS epidemic be understood within a contemporary critical and political appreciation of the operations of what Robert Jungk calls the 'surveillance state' and its anonymous and unrelenting monitoring of the citizenry. Furthermore, we are concerned about AIDS in this context because it is our contention that the epidemic itself has the potential to provide a particularly powerful vehicle for the expansion of surveillance practices.

In addition, there is another sense, peculiar to our time in which we must see the connections between AIDS and surveillance. In our acutely postmodern concerns with language and image, and with the increasing recognition of how discourse structures power relations, we can now
understand that the language of AIDS has within it a political semiotics of plague that can either support, or resist, institutional surveillance. Within the language of AIDS we see the struggle of these forces. That is because surveillance is not just a neutral set of behaviors or actions, but a set of practices invested with contested political and moral meaning. As a practice which mediates relations of power, surveillance is thus constituted where textual and institutional power converge to produce certain kinds of constraints which we call 'surveillance'. To talk about surveillance as an act involves seeing the textual practices which shape, construct, and infuse institutional and individual behavior with this value, and how these practices provide legitimacy to the dominant interests of class, sex and race.

The purpose of this dissertation is to develop a richer and more comprehensive understanding of AIDS and surveillance, of the operations of medical authority and discourse in particular, and the consequences of those operations for AIDS policy-making. Certainly our concern with the practices of medical authority come from an awareness of the predominant role of medicine in directing both our social response to the epidemic and in the construction of our understanding of this disease. But our study is also motivated by a more general
appreciation, as Sylvia Tesh has argued, of how political ideology has historically invested itself into the medical discourse on disease, and disease causality. The effect of this subsuming of ideology within the language of medicine is to reflect domains of dominant interests both in terms of those social forces that are associated and represented by medical discourse, as well as in how this authority structures our knowledge of the body and the world. So we are interested in both what is authorized within medical discourse, and how it goes about actualizing these authorizations, which means, as we shall argue, that we are interested in a process which requires the use of surveilling practices.

In the rest of this chapter, we offer a brief summarization of the clinical aspects of HIV disease and then move to situate the AIDS epidemic within an historical reading of surveillance and the exercise of medical authority in the United States. In Chapter II we shift to examine some theoretical considerations about AIDS and surveillance within the context of medical discourse. Chapter II frames our theoretical approach, and acts as an introduction to a critical reading of the much heralded report of the Institute of Medicine, National Academy of Sciences (NAS) on AIDS.

This report, Confronting AIDS, was issued by the NAS in the fall of 1986 well over five years after the first
person diagnosed with AIDS was reported by the Centers for Disease Control (CDC). It was the product of an intense and wide-ranging seven month effort to assess the impact of the AIDS epidemic, to determine the research necessary for the prevention of the disease, and the treatment of persons afflicted, to judge the adequacy of provisions for care and the financing of that care, and to evaluate the public health measures being formulated to control the disease.

By the NAS's own description, the report was a "self-initiated" attempt to assert national leadership and offer recommendations "to the Executive Branch, the Congress, the research community, those who treat patients, the state and local governments, corporate leadership, and the public." The committees and panels that put together the report boast "an impressive breath of credentials" and included experts in the areas of "molecular biology, virology, immunology, epidemiology, neurology, psychiatry, infectious diseases, general medicine, health care, public health, economics, law, ethics, and other disciplines." Public and private meetings and workshops were held and a broad array of scientific background papers were commissioned by the Academy for its deliberations. The NAS statement on AIDS was thus a carefully constructed, authoritative, comprehensive, highly visible, and highly public
expression of modern American medicine from the very highest levels of that profession.

This NAS report will be summarized in Chapter III. Chapters IV, V and VI will present the body of our critical reading on the NAS report and its surveilling practices. Chapter IV examines how the NAS text inscribes medical authority into the epidemic through its articulation and appropriation of what we have called the nominating function of medicine and the emphasis that it places on credentialed and institutional science. Chapter V interrogates how the NAS text and its practices of depoliticization work to legitimate medical authority, and Chapter VI pursues the deployment by the text of what we describe as surveilling identities.

Following this critique our attention will move to the implications of our analysis for AIDS policy-making. We should note public policy is seen here as a site of political struggle. That struggle is constituted both in terms of the potential resistance policy making offers to the surveillance state, as well as to the deployment of a public political discourse (in this case on AIDS) which overtly or covertly makes acts of surveillance appear necessary, natural, or unavoidable. In Chapter VII we try to assess the operations of medical authority within AIDS policy-making, and how critical public policy assumptions are embedded within medical discourse.
Medical Portrait of a Disease

In its strict medical sense, AIDS is described as a newly recognized infectious disease which damages the body's immune system making the body vulnerable to a number of serious and often deadly "opportunistic" infections and cancers. The U.S. Centers for Disease Control, the federal agency within the U.S. Public Health Service responsible for disease control and prevention, define a case of acquired immunodeficiency syndrome as an illness characterized by one or more specifically designated opportunistic infections that arise in the absence of all known underlying causes of cellular immunodeficiency other than infection by the human immunodeficiency virus or HIV.¹³

These opportunistic infections include most prominently the rare protozoal infection Pneumocystis carinii pneumonia, or PCP, and an uncommon cancer called Kaposi's sarcoma or KS. People with PCP complain of fever, cough, shortness of breath, chest tightness, and labored breathing. It is this pneumonia that is now recognized as the most common AIDS-related "opportunistic" infection as well as the most frequent cause of death in U.S. victims. People with KS display mucocutaneous lesions on the skin with initial lesions common on the face or in the mouth. These lesions become
painful as the disease advances and it is not uncommon for them to spread to internal organs (visceral KS). Those patients with pulmonary KS have an extremely poor prognosis.

AIDS is thought by medical researchers to be caused by the human T-cell lymphotropic virus variant III (HTLV-III) or the generic designation now accepted, human immunodeficiency virus or HIV.\textsuperscript{14} HIV is part of a family of retroviruses which have been related to a number of diseases in a wide variety of animals. The pathogenic character of the virus lies in its capacity to destroy certain critically important white blood cells called T lymphocytes (T4 cells). These cells perform a number of functions essential to the immune system's task of identifying, isolating, and eliminating "foreign" microbial invaders of the body. The virus is predominantly introduced into the body through sexual intercourse with an infected partner, parenteral transmission via contaminated blood or contaminated needles used for the injection of drugs, and perinatal transmission from mother to child during pregnancy.

Persons infected with HIV, and who present clinical symptoms such as fevers, diarrhea, and swollen lymph nodes, but who do not meet present CDC criteria for AIDS diagnosis are termed as having AIDS-related complex or ARC. Consensus among researchers regarding the
definition and importance of ARC has been difficult since it captures a full range of conditions from the mild to the fatal. Whether these HIV infected individuals are on some irreversible course to what has been called frank AIDS is still open to question. HIV infection in specific individuals is ascertained through blood analysis that detects the presence of antibodies specific to the virus. Two widespread tests used include an enzyme-linked immunosorbent assay (known as the ELISA), and an immunofluorescent assay (known as the Western Blot). The ELISA is typically used as an initial screening mechanism, while the Western Blot acts as the confirmatory measure to determine infection.

One hundred and forty countries have reported AIDS victims as of August 1988. There may be at present as many as 10 million people in the world who have been infected by the AIDS virus. By 1990, according to the World Health Organization, there may be as many as 100 million. The spread of AIDS in the Third World portends, at this point in time at least, to become a major health catastrophe. The World Health Organization (W.H.O.) is now trying to raise the $1.5 billion it says is necessary to gear up worldwide efforts for AIDS prevention, and for services to the 100,000 people who already have full blown AIDS (according to its country-by-country reports and extrapolations which may be
grossly conservative, according to Jonathan Mann, who directs the efforts). 17

Underdevelopment is argued to be a significant factor in the spread of AIDS. Crowded conditions, poor sanitation, malnutrition and disease may contribute to not only the increased potential exposure to HIV, but increased likelihood of developing AIDS. High rates of untreated venereal disease may facilitate the spread of infection, as well as unscreened contaminated blood and unsterilized needles. The ability to protect the blood supply is affected by cost. The price of the ELISA is about $6 with the Western Blot costing much more. This is prohibitive for some countries given the number of tests needed for the harder hit areas. 18 There are further complications, however, given the recent revelation that these tests may not indicate infection by the newly discovered HIV-2. 19

The populations that live in the 11 nations that compose Central Africa include half of all those said to be infected worldwide with HIV, and it is there that 50,000 to several hundred thousand lives may have already been lost. 20 The African AIDS connection was first recognized in 1983 by physicians in Europe who reported AIDS-like illnesses among their African patients. 21 These incidences prompted clinical studies by Western researchers in Rwanda and Zaire where people with similar
illnesses and immunological problems were found. With the subsequent isolation of the human immunodeficiency virus (HIV), and the development of screening procedures to detect antibodies against HIV, further studies confirmed that African patients were suffering from the ill effects caused by the same virus. Further, in contrast to the United States, HIV infection equally affects both sexes.

The African nations of the hardest hit region, those countries of the Great Rift Valley -- Zambia, Uganda, Rwanda, Zaire, Burundi, Tanzania -- face a serious challenge that may, in some cases, threaten their already fragile political and economic stability. In Lusaka, for example, 15% of the adult population, and 30% of all its men may be infected. Serological testing of healthy adults in Kigali, Rwanda has shown 18% are positive to HIV. In Bujumbura, the capital of Burundi, it is estimated that one out of every 10 adults carries the AIDS virus; and in the Rakai area of southwest Uganda, one of the most heavily AIDS stricken areas in the world, an incredible 30% of the population are estimated to be infected.

Kenya has had, according to most accounts, an easier time of it. Although high rates of infection among prostitutes have been reported, overall prevalence of the
disease in Kenya has been quite a bit lower than its neighbors. 27

In South America, it is Brazil that appears most affected by the epidemic. According to the W.H.O., Brazil has the world’s third highest total of persons with AIDS -- 2,956 -- with another 350,000 persons suspected of already being infected. 28 Unlike Africa and more in line with the U.S., 92% of infected Brazilians are gay or bisexual men. 29 In the Caribbean, it is Haiti that is most affected with almost 900 persons already diagnosed. 30 And although all of Asia has reported only 277 persons with AIDS, the W.H.O. fears a catastrophe in the making. 31

The spread of AIDS in Europe is similar to the pattern experienced in the United States with a large proportion of those infected being gay men or IV drug users. The numbers of Europeans diagnosed with AIDS reported to the W.H.O. has been rising rapidly from 2,200 persons in September of 1985, to 14,610 in August of 1988. 32

As of January 23, 1989, some 84,133 persons with AIDS have been diagnosed in the United States. 33 All states and the District of Columbia have reported diagnosed persons with AIDS, although certain major cities such as New York, Miami, San Francisco, and Los Angeles report large numbers of AIDS victims. The National Academy of
Science/Institute of Medicine and the United States Public Health Service project a 10-fold increase in persons diagnosed with AIDS over the next five years. The severity of the epidemic in the United States is amply recognized in this quote from the National Academy of Sciences' report:

- By the end of 1991 there will have been a cumulative total of more than 270,000 cases of AIDS in the United States, with more than 74,000 occurring in 1991 alone.
- By the end of 1991 there will have been a cumulative total of more than 179,000 deaths from AIDS in the United States, with 54,000 of those occurring in 1991 alone.
- Because the typical time between infection with HIV and the development of clinical AIDS is four or more years, most of the persons who will develop AIDS between now and 1991 already are infected.
- New AIDS cases in men and women acquired through heterosexual contact will increase from 1,100 in 1986 to almost 7000 in 1991.
- Pediatric AIDS cases will increase almost 10-fold in the next five years, to more than 3,000 cumulative cases by the end of 1991.32

As seen from these projections, mortality for those diagnosed with AIDS is high. Fifty-five percent of all AIDS victims reported to the CDC have died. Most CDC-defined persons with AIDS die within two years of the onset of symptoms while 25 to 30% of all infected persons may die within 5 to 10 years.

Those most at risk for HIV infection included homosexual men and IV drug users. Some 70% of AIDS victims are homosexual or bisexual men, 17% are intravenous drug users, the rest being persons with hemophilia and others. About 7% of all victims are
women, and there are over 348 children (1.5%) nation-wide under age 13 with AIDS or preliminary symptoms. Ninety-three percent of persons with AIDS in the U.S. are men, with 90% of all adult AIDS patients being between the ages of 20 and 49, and almost 50% between 30 and 39 years old. Blacks and Hispanics, in relation to their relative numbers in the United States are over represented in the ranks of persons with AIDS: 25% are Black, with 14% being Hispanic.

It is estimated that there are between 50,000 to 125,000 persons in the U.S. with ARC depending on the definition adopted. Finally, about 1000 persons are exposed to the virus every day. According to some estimates, there may be 1 to 2 million of us who have seen the face of the virus already and are unknowing, asymptomatic yet infectious carriers of the disease.

AIDS and the Surveillance State:
The Hidden Politics of Medical Surveillance

To call to question the nature of surveillance as it operates within the course of the AIDS epidemic requires that we must first address the separation of the specialized professional understandings of epidemiological or medical surveillance from the more commonly understood idea of political surveillance which comes to mind when the concept is used in everyday
language. Epidemiological surveillance as described in the medical literature involves both passive reporting and active seeking of information, provides data on the prevalence, incidence, and distribution of disease or infection in the population. Such data can be used to monitor the spread of a disease, to shed light on the mechanisms of transmission of infectious agents, to help in designing public health measures to prevent the spread of the disease, to evaluate the effectiveness of interventions, and guide planning for the provision of facilities.35

The detailing of clinical diagnoses, laboratory test results, case histories, treatment plans and prognoses, may all be part of the reporting regimen. Typically, however, medical surveillance and aggregate research data of this kind deal heavily in the collection of statistical information in which identifying markers such as names and addresses of patients have been deleted or disguised. This is not true, of course, in the monitoring of specific 'recalcitrant' infectious individuals, or in sexual contact tracing. Even traditional public health measures as intrusive as quarantine (in the sense of sequestering a healthy person who may have been exposed to an infectious agent to see if illness develops) have come under the rubric of medical surveillance.36

When it comes to serious infectious diseases, medical surveillance historically has acted often as a front for the exercise of more extreme forms of medical policing such as detention and exile. Hawaii's experience with Hansen's disease makes clear that medical surveillance
has historically been far from a benign exercise.

We had no choice coming here, you know. They took us away to Kalaupapa fast. I was only seven, I did not know what was happening. They came to get me at school. I think the teacher reported me to the Board of Health. They use to get ten dollars for each leprosy person they reported. First I went to Kalihi, then they sent me here. Oh, I miss my mommy. She came a few times to see me, but then pau, no more. She had other kids. I think they kind of forgot about me... 37

While commonly expressed as public health research or as scientific measures consistent with the protection of public health (and thus non-political), the methods and effects of medical surveillance have in the past often contrasted little with contemporary political surveillance operations.

The distinction then between medical and political surveillance while important is at best only temporary and strategic, albeit instructive, when it comes to the AIDS epidemic. The difference, it should be admitted, is less one of method or mechanism, and more a difference of how these practices are framed within divergent declarations of intent or purpose. It should be said as well, and yet with some caution, that all public surveillance operations have been tucked, at one point or another, into some cushion of laudable motives.

The contestable nature of these intentions, as well as the effects of these practices, are particularly evident in the various recorded histories of the public health movement itself. As Daniel Fox observes, the
problems surrounding the medical reporting of infectious
diseases as well as other public health surveillance
efforts have frequently reflected the interest-politics
of the medical elite and public health leaders rather
than the requirements of disease prevention. He notes
that the relative success of epidemiological reporting
efforts for tuberculosis in New York City during the
1890s was less due to the commendable purpose of
preventing the spread of this disease than of the value
of such official operations to the power aspirations of a
medical hierarchy and its search for public legitimation
as a profession. Practitioners favored the extension of
state regulatory power over the reporting of infectious
diseases as one of several strategies to eventually gain
the status protection of licensure. These reporting
requirements helped to consolidate a profession
continually threatened with fragmentation by a number of
competing professional interests.

However, with the expansion of public health from the
domain of sanitation engineering into those areas of
disease prevention that had been traditionally under the
control of medical practitioners, the alliance that had
been forged between physicians and those calling for the
reporting of diseases abruptly dissolved. As medicine
began to become increasingly polarized between public
health professionals and medical clinicians, doctors
began to view reporting and surveillance measures, (and the associated public dispensaries and clinics) as competitive with their own efforts to secure patients. 39

By the 1920s, a series of developments furthered this political gap. The growing impact of the social hygiene movement, the explosive battles over the introduction of health insurance, and the increasing professionalization of public health, all but eliminated epidemiological surveillance as a viable strategy for professional unity. 40 Surveillance proposals now became a site for the expression of tensions between the forces of public health and private medicine, and reporting demands were re-envisioned by doctors as reformist attempts to establish socialized medicine, or, as invasions of the privileged relationship between physician and patient.

Physician resistance to surveillance has eroded substantially since the early 1900s as demands for patient information have increased. Yet these modern demands for information on patients are less linked to protecting the public from disease and more to the growing mobility of patients (and the frequency with which people change physicians), the need for coordinated care among multiple specialties, accountability reporting for regulated clinical and hospital protocols, legal procedures for gaining access to restricted medication, and most important, the dense requirements of public and
private financial reimbursement agencies that compare specific diagnoses to actual care and its cost. Indeed, far from being the repository of patient medical data that the physician once was, doctors are now merely the point of entry for this kind of information for larger health care organizations. Doctors working for Health Maintenance Organizations (HMOs), for example, are employees of large corporations and maintain now a corporate patient file. Physician dependence on Medicaid, Medicare, Champus, Blue Cross/Blue Shield, and other reimbursement agencies for significant sources of income, as well as their malpractice insurance requirements, has also made disclosure of patient information seem more necessary, and consequently more acceptable.

Yet, as we have seen within the AIDS epidemic, be it to protect their patients from the ramifications of disclosure, or for reasons having to do with the practice of defensive medicine, physicians are still reluctant to report patient information to officials despite professional censure or penalty. This has led some to speculate that this reluctance may account for a significant under-reporting of the incidence and prevalence of HIV infection.41

Thus even within the history of medicine, reporting and surveillance practices were by no means innocent of
political meaning. They reflected, and continue to reflect, both the internal politics of the profession, and the mediation of the external demands to which the profession is continually subjected, demands which have purposes often far from the protection of public health.

U.S. History and Medical Surveillance

One gains a better appreciation of this history of resistance to medical surveillance when it is viewed within the broader articulation of public concern over increased governmental intrusion into people's lives in the United States since the end of the 19th century. If anything, physicians' early resistance to public health measures seems less reactionary when compared to the general social antagonism, expressed in the early 1900s, toward the growing information demands and security anxieties of new and larger American bureaucratic institutions, as well as an increasingly inter-dependent and expanding domestic capitalist economy.

The political dynamic of that historical concern centers on the tension between emerging conceptions of privacy (increasingly envisioned as constitutional rights and legal protections from the intrusions of others), and new and pressing strategies for the expansion of government and corporate control. From the turn of the century to the present, one finds a well
documented history of enormous public hostility to attempts to secure information previously considered private. Continuous challenges have been made over eavesdropping -- "to hearken after discourse, and thereupon to frame slanderous and mischievous tales" -- to the unauthorized reading of mail, the increasingly detailed public census survey questions, to an overly inquisitive, expanding and sensationalist press, to improper accessing of telegraph and subsequently telephone communications, to the compilation, centralization, and transference of personal information via computer (data surveillance), as well as to a number of optical, electronic, and chemical technologies that are designed to access, record, or trace private actions. 42

The historical evolution of these concerns with privacy, and the consequent objections to governmental and corporate surveillance, as Richard Hixson observes, has shifted traditional notions of privacy from matters of honor and morality (where the sanctity of various privacy zones such as private property, the household, and one's personality are off-limits to official inspection), to the now firmly established conception that privacy is primarily a matter negotiated by law. 43 The constitutionalization and legalization of privacy reflected in the litigious "brush fire" which has swept
through most of the 20th century up until the present, is ample testimony to the fact that the perceived violations to that privacy, however thought of, have become more pronounced and more threatening. 44

A similar legal history reflecting these kinds of privacy and surveillance issues is also found in public resistance to attempts by health authorities to impose measures officially intended to curb the effects of infectious diseases. This history is filled with unsuccessful challenges to public health strategies. 45 At the turn of the century, U.S. courts usually endorsed even the most invasive efforts to contain diseases. The courts frequently deferred judgement about health matters to the experts and local officials if a danger to the public could be proven to exist. Most of these decisions were made within a quite limited framework of individual rights although such claims of privacy had been argued in opposition to public health measures as early as 1875. 46

As Deborah Merrit points out, up until 1940 the courts, in the name of science and public health, tolerated serious, and ironically often medically ineffective, invasions of personal liberty such as forced sterilization and quarantine. Individual rights were not always overlooked, but in cases where they were upheld, the impact tended to go against the protection of public
health. With few exceptions, the court often balked at
general mandatory examinations or testing for
communicable diseases as well as compulsory preventive
vaccinations since citizens were not demonstrably ill,
and consequently did not pose a danger to others. While the courts have retained their tendency to enforce
public health measures since 1940, a more positive view
of civil liberties as well as an increased wariness of
science in general has led to a more cautious
consideration of the impact of these measures on personal
privacy.

Gay History and Surveillance

All of these histories help us contextualize our
understanding of surveillance practices with the present
epidemic. Yet, one other important history must to be
recalled to complete our picture. There is little doubt
that the gay political experience since the end of the
19th century has had a compelling influence on how
persons with AIDS are both responding to present
surveillance attempts, and how others perceive the
political value of such attempts. The long tradition of
hostility toward homosexuality in the Christian west, and
the incessant efforts to regulate and outlaw homosexual
behavior have had their effects in the structuring of the
ongoing public response to AIDS and to private and
governmental medical reporting, research, and testing programs. How could it be otherwise? Homosexual behavior in England and Wales was legally punishable by death until 1885, and while it is readily admitted that in the succeeding 100 plus years legal sanctions against homosexuals have lessened, sexual practices between persons of the same sex are still strictly prohibited in many nations.  

In the United States during the mid-1950s homosexual behavior in New York state was punishable by as much as 20 years in prison. As historian Toby Marotta recounts, "People could be arrested simply for talking suggestively about homosexual sex and plainclothesmen were dispatched to entrap homosexuals by initiating such conversations." Until 1962 homosexual sexual practices (sodomy and various "indecencies") were criminal activities in all 50 states. By the official arrival of the AIDS epidemic in 1981, 29 states still had laws against homosexual sex.  

This widespread criminalization of homosexuality continues to manifest itself in the ongoing investigation, arrest, and prosecution of gay persons so much so that police surveillance remains a threatening fact of gay life. Moral and legal officialdom still trains its gaze upon gay bars, restaurants, conferences, demonstrations, and offices. The intimidation of persons
participating in gay functions, the recording of license plates, the checking of driver licenses and other acts of harassment continue. This regulatory obsession, and the consequent concern of gay persons over surveillance, is particularly evident in the struggles since World War II over the issue of police entrapment. Laws against loitering and lewd solicitation are argued to be deceptively and selectively enforced, and result in victimizing those who otherwise had no intention of breaking the law.

The criminalization of homosexual behavior has also legitimated discriminatory actions against gays in other areas of everyday life such as employment, housing, and the military. In what has been called the movement of gay persons from the status of deviant to that of minority, a constitutional history of resistance to these discriminatory actions and the surveillance practices that make them possible has emerged. These legal challenges have typically involved the struggle to establish the right to sexual privacy and preference through the constitutional protections of due process, equal protection, and the freedoms of speech and association. In many of these court cases on employment issues, for example, the mere admission of homosexuality, or legitimate political activities in support of gay rights, or the accusations of informants about homosexual behaviors...
practices was enough to warrant dismissal. In addition, the historical linking of gay political activities with Marxist politics and the New Left during the 1950s and 1960s created further justification in the minds of the security apparatus for governmental surveillance.

Not surprisingly, this legal and social antipathy toward homosexuality since the turn of the century has been, and to a certain extent still is, supported by the medical diagnostic classification of homosexuality as illness. If there ever was a prime example of the conflation of medical and political/criminal surveillance issues it surely is here. As Jeffrey Weeks observed, the legalization and criminalization of homosexuality has moved hand in hand with the medicalization of homosexual behavior. Through the medical model, the homosexual became a "new subject of social observation", and while this led to what Weeks says was the "individuation of the homosexual", it also was the critical link in the perverse logic which equated one's status as a homosexual (i.e. the problematic relationship of sickness to responsibility) to one's moral standing. In the case of employment, for example, this understanding led to the questioning of the homosexual's "fitness" for certain occupations such as teaching.

The power of the gay movement in recent American history has been directed in large part to combating this
punitive classification of homosexual behavior. One measure of the movement's success came with the official purging of homosexuality as a 'mental disorder' (that great destroyer of personal and political legitimacy) by the American Psychiatric Association and the American Psychological Association in 1973.58

AIDS and Surveillance

These chronologies act as a powerful political subtext to the relative short but deadly history of the AIDS epidemic. Yet while these collective memories account in part for surveillance becoming a powerful problematic in the politics of this disease, there is no denying that the intense social conflict acted out under the name of AIDS has acutely made the fear of surveillance quite palpable.

AIDS has been continually invoked in acts of discrimination and brutality against HIV infected persons and those suspected of being infected. Instances of such brutality are numerous and include everything from "gay bashing" and other forms of direct violence, to the loss of job or housing, termination of health insurance, financial impoverishment, discharge from the military, police harassment and incarceration, abandonment or neglect by family, refusal of treatment by health professionals, expulsion from school, denial of funeral
services, and a host of more personal indignities and emotional assaults born of public fear, paranoia, and stigma. 59

In addition, these persons, as well as the public at large, face a continuing onslaught of threatening legislative proposals, referenda, regulations and enforcement strategies meant to identify HIV infected persons. As a result, a number of large constituencies in the United States are already required to submit to testing as a condition of employment or entitlement including immigrants, ROTC and Job Corps students, military personnel and new recruits, Peace Corps workers, and Foreign Service personnel and dependents. 60 Other legislative and regulatory proposals too numerous to mention, both on the state and national level, seek to expand mandatory HIV antibody testing to those wishing to obtain marriage licenses, or admission to a hospital. 61

More worrisome are recent efforts to criminalize sexual behavior -- through new law, through renewed enforcement of prostitution or anti-gay statutes, or through the use of civil commitment procedures -- as a way to prevent HIV transmission. We have also seen right-wing proposals to quarantine, sequester in camps, segregate in prisons, or otherwise isolate HIV-infected persons, as well as calls to publicly identify them through published lists or the requiring of permanent
tattoos. Even the protection of silence may become prohibited through the enforcement of civil or criminal sanctions against any refusal to comply with the requirements of some states to identify sexual contacts, or to reveal one's positive HIV status on various applications or legal forms. Further, the AIDS epidemic as it embodies global conspiracy theories, quack remedies, illegal IV drug use, and underground networks for securing unapproved experimental drugs, heavily foregrounds surveillance so that even most benign official attempts to secure epidemiological and other personal information become immediately problematical for those who wish to avoid the very real personal and political risks of the disclosure of their health status.

The AIDS epidemic is invested with a politics of suspicion on all fronts. Yet, as we have demonstrated, it is a politics that is not without its present compelling reasons and a history of formative experience. It should be of little surprise then that in the U.S. the most hotly contested issues in this epidemic concern surveillance, namely, confidentiality and the use of HIV antibody testing. As early as 1983, beginning with the controversy over the possible transmission of AIDS through contaminated blood transfusions, serious questions have been raised over the typical practice of
maintaining lists of persons suspected of HIV infection. With regard to blood banks, these lists were established through questions designed to identify members of "high risk groups" and thus discourage potential infected donors. The persons on these lists, critics argued, were extremely vulnerable to political and social abuse since their names on such a list could act also as a surrogate marker for either homosexuality or illegal drug use. 65

With the isolation of the HTLV-III/LAV virus (now HIV) in 1984, and the subsequent development of antibody testing, as well as the increasing realization of the magnitude of the epidemic, specific concern began to focus on the confidentiality of test results. No longer did one have to cultivate an understanding of a complex, variable, and uncertain diagnosis in which to invest one's fear. Public attention could now be objectified and focused on an amazingly simple (or so it seemed) sign of infection: blood seropositivity.

The great fear expressed by gay persons and others affected by the epidemic is that testing results will be abused. As a consequence of external pressures (homophobic hostile public, press sensationalism, institution incompetence, etc.), lists collected with the "best of intentions" may become weapons of "social terrorism" and used against those who can least tolerate such harassment: the sick and the disenfranchised. 66 And
while a handful of court cases offered protection of epidemiological data, no national standards based on federal law dealt with the confidentiality of medical information since most responsibility for health care rests at the local and state level. 67

Numerous breaches of confidentiality in hospitals, prisons, the military, at the worksite, and as a result of press investigation, have already been documented. Early in the epidemic the CDC itself came under heavy criticism for its transferring of the names of AIDS patients to public health authorities and the New York Blood Center. In Seattle, a list of people undergoing treatment for AIDS was circulated among local policemen. 68 Epidemiological data gathered by military officials under strict assurances of confidentiality were later used as evidence in the separation of persons from military service. 69 And state officials in New York, in violation of the New York Public Health Law, used epidemiological research data in determining the "fitness" of children to attend public school. 70

More important than the illegal or unethical use of testing results or personal medical records, are the threats coming from a host of existing and potential legal intrusions into the privacy of this information. Six states already legally require that the names of people testing positive for HIV antibodies be reported to
state officials. 71 One of these states, Idaho, has also entertained legislation barring infected persons from certain types of employment, as well as preventing HIV infected children from attending daycare or public school. 72 There is, in addition to AIDS specific legislation, only limited assurance of the protection of such information from judicial subpoena. How this protection will stand up against the power of the courts to secure information that they may seek to obtain is open to question. With the growing demand for courts to adjudicate criminal and civil/tort actions related to AIDS, the confidentiality of testing results (or comparable medical information related to immune deficiency) may come under increasing scrutiny.

Further, the courts are also being required to review legislation that is designed to use previously procured epidemiological data for purposes other that those intended or stated at the time. All of these legal threats to confidentiality are reinforced by recent rulings of the U.S. Supreme Court which are highly unsympathetic to the privacy issues of gay persons. 73

The use of HIV antibody testing by the health and life insurance industry has also come under fierce criticism as advocates question the relevance and ethics of such testing. Beyond the questions over the exclusionary practices of HIV infected persons by
insurance companies, or the inherent limitations of HIV testing for the purposes proposed by these companies, are the problems of confidentiality that inevitably arise in the mass storage and transference of computerized antibody tests or comparable information. In addition to questions about the basic security of such information, there is the issue of the communication of sensitive information about applicants among insurance companies. In the United States, many insurance companies feed client records to the Medical Information Bureau, an industry funded organization that shares computerized information about applicants. The industry's model privacy act which the National Association of Insurance Commissioners has adopted, even permits insurers to exchange information in certain circumstance without the knowledge of the insureds. Given what was previously reported about the state of Idaho, this situation has led one writer to "envision a scenario in which an unsuspecting insurance applicant tests positive, has his or her test results reported to the state, and as a consequence, loses his or her job." Given what was previously reported about the state of Idaho, this situation has led one writer to "envision a scenario in which an unsuspecting insurance applicant tests positive, has his or her test results reported to the state, and as a consequence, loses his or her job." 

Some states such as California have legislated protections and sanctions regarding the use of antibody test results as a screening mechanism for employment or insurance purposes. Yet while these have been generally viewed as helpful, there remains a fundamental
question as to whether large governmental and private bureaucratic institutions that manage the collection, storage, and distribution of such information can in practice, insure confidentiality even under the most strict regulatory guidelines. As we have mentioned, there are enormous external legal and political pressures placed upon these bureaucracies to disclose this information either officially or unofficially. But in addition, institutions have a host of structural problems which can often compromise the security of information. These include the large numbers of personnel involved, decentralized access to centralized information, along with typical management problems such as staff shortage and turnover, insufficient training, and simple incompetence. Political problems afflict these institutions as well, such as cronyism, agency competition, and backroom deals, all of which force the issue of whether this sensitive information can ever be sufficiently protected. And, finally, as ever growing institutions, the systematic functions of these bureaucracies may be so loosely 'coupled' to each other (i.e. planning and evaluation) that accountability for insuring confidentiality may be impossible to maintain.77

This incredible onslaught by state, corporate, and medical authority upon HIV infected individuals -- the watching, identifying, and regulating -- has as much to
say about the nature of the modern surveillance state as it does about the nature of AIDS. But the institutional practices of surveillance that shape much of the political struggle surrounding AIDS are deeply rooted ones, not only in those institutions, but in our culture and language. It is to this aspect of the epidemic that we now turn our attention.
NOTES


2 Defoe, p. 169.

3 Ibid., p. 99.

4 Ibid., p. 167.

5 Ibid., p. 173.


8 See Michel Foucault, Discipline and Punish (New York: Vintage, 1979), p. 222: "Discipline creates between individuals a 'private link', which is a relation of constraints. . . ."


11 Ibid., p. vi.

12 Ibid., p. vii.

13 All technical and statistical information about AIDS unless otherwise noted is taken from Confronting AIDS.

14 Confronting AIDS, p.39.


16 Newsweek November 11, 1986; Time February 16, 1987;


20 Newsweek, November 11, 1986.


26 Newsweek November 24, 1986.

27 For study on transmission see J.K. Kreiss et al., "AIDS virus infection in Nairobi prostitutes, Spread of the epidemic to East Africa", New England Journal of Medicine (314) 1985, pp. 414-418.


32 Ibid.


34 Confronting AIDS, p.8.

35 Confronting AIDS, p.14

36 See Ruth Macklin, "Predicting Dangerousness and the Public Health Response to AIDS", Hastings Center Report, December 1986, pp. 16-20; and Larry Gostin and William J. Curran, "The Limits of Compulsion in Controlling AIDS" in the same report; See also Confronting AIDS, pp. 126-130.


38 Daniel M. Fox, "From TB to AIDS: Value Conflicts in Reporting Disease", Hastings Center Report, p. 12.


44 Ibid., pp. 15, 50.

46 Ibid., p. 3.

47 Ibid., p. 6-8.

48 Ibid., p. 8.


53 Marotta, p. 33.


55 Marotta, p. 143.

56 Weeks, p. 104.

57 Ibid., p. p. 105.


60 On testing of immigrants see New York Times, August


63 On current efforts in contact tracing see Illinois law, New York Times, July 1, 1987; in New York, see "Rise in AIDS sparks debate over testing and tracing of victims contacts", New York Times, January 27, 1987; in San Francisco, see "San Francisco AIDS Project tracing women", New York Times, January 14, 1987; see also Confronting AIDS, pp. 119-120. Even physicians can be subjected to criminal prosecution for their silence as in the case of U.S. Navy Lt. Cmdr. Thomas O'Rourke, a Navy physician stationed in Manila, who was court martialed for refusing to identify Filipino prostitutes who were infected with HIV. See Associated Press reports August 21 and September 15, 1987.

64 On global conspiracies see Altman, p.43; also Black American vol.27, no.27; For Soviet accusations about AIDS as American germ warfare see International Herald Tribune December 13, 1985; Time November 17,
1986; New York Times February 8, 1987; Associated Press report March 31, 1987. For U.S. response see remarks made by Robert E. Windom, Assistant Secretary for Health entitled "History of AIDS in the United States" given in Honolulu, September 1987. References have been made particularly to a text written before AIDS was recognized John Cookson and Judith Nottingham, A Survey of Chemical and Biological Warfare (New York: Monthly Review Press, 1969. On page 322 we read this: "The question of whether new diseases could be used (as a biological weapon -- author) is of considerable interest. Vervet monkey disease may well be an example of a whole new class of disease-causing organisms. Handling of blood and tissue without precautions causes infection. It is unaffected by any antibiotic substance so far tried and is unrelated to any other organism. It causes fatality in some cases and can be venereally transmitted in man." On "quacks" see " Authorities Act Against AIDS 'Cures'", New York Times, August 30, 1987, and "Preying on AIDS Patients", Newsweek, June 1, 1987. On underground networks for unlicensed drugs and treatment in Florida see Palm Beach Post, April 13, 1987; and generally, see United Press International report "Guerrilla clinics' treating AIDS in a network of secrecy", March 29, 1987.

65 Altman, AIDS in the Mind of America, p. 79.

66 See Cindy Patton, Sex and Germs: The Politics of AIDS (Boston: South End Press, 1985), p. 82. The term "social terrorism" is borrowed from Patton, p. 87.


68 Altman, AIDS in the Mind of America, p. 80.

69 Rhonda Rivera, "The Military" in Dalton and Burris et al., p. 229.

70 Frederic C. Kass, "School Children with AIDS" in Dalton and Burris et al., p. 78.

71 Newsweek, November 24, 1986.

73 See, for example, the recent U.S. Supreme Court decision on challenges to Georgia's anti-sodomy law in *Bowers v. Hardwick*, 106 S.Ct. 2841[, 2842-56] (1986). This decision led to mass protest demonstrations by Gays and others. See *New York Times*, October 12, 1987.

74 Schatz, p. 1801.

75 *Ibid.*.


77 This way of looking at organizational functions e.g. as either "tightly" or "loosely" coupled is borrowed from Charles Perrow, *Complex Organizations: A Critical Essay* (New York: Random House, 1979), second edition, pp. 209-213.
CHAPTER II

LANGUAGE OF AN EPIDEMIC

The doctors are not content with having control over sickness; they make health itself sick, in order to prevent people from being able at any time to escape their authority.

Michel de Montaigne

*Essays*

It should go without saying that there is a rich correspondence between the nature of surveilling practices and the social production of meaning. Surveillance cannot be seen as separate from the ways in which we infuse the AIDS epidemic with human meaning. Yet, the way we think about the social process through which we inscribe meaning on disease does have an effect on how we see surveillance. And as will be made clear in our subsequent arguments, surveilling practices are part of meaning making, putting some interpretations on the playing fields of discourse, while regulating others to the bench of silence. It is obvious that the meaning of AIDS is of major concern in the public and professional literature on the disease. The textual means by which we
Our understanding of the social meaning of AIDS has been shaped by our increasing awareness of how we have come to know AIDS — articles, news stories, journals, books, media — have been characterized by a rather nervous self-consciousness about what this unprecedented modern scourge portends for contemporary society.\(^1\) We witness in this literature-of-dread a hypersensitivity and competiveness about the correctness (truth) of various interpretations about AIDS in the sense of the epidemic's direct effects (death, costs, treatment, care and the like), and in relation to its effects on the social order in the long run (sexual counter-revolution, fiscal catastrophe, destabilization of the Third World etc.).

How can we account for this particular articulation of the social meaning of AIDS emerging as it has, as competing social overlays blanketing, and to a certain extent masking, a biologic essence? What traditions of thought specifically influence the current debates, discussions and writings about the AIDS epidemic that shape this modern understanding of meaning and disease? And finally, how do we assess both the epistemological and political standing of these forms of "social construction" and the meanings they are said to dispatch?

On the Social Construction of Disease

Our understanding of the social meaning of AIDS has been shaped by our increasing awareness of how we have
attributed meaning to past epidemics. Within the media, and academia's rush to say something about this disease, we have spawned the production of, and interest in, historical accounts of past scourges, plagues and epidemics. The medical and social history of disease, a subject often relegated to a lackluster existence in library stacks, and full of heroic albeit primitive clinical adventures, is now a familiar backdrop to discussions of social attitudes, prejudices, fears, and reactions to AIDS. A handful of now popular works by historians such as William McNeil, Allan Brandt, and Hans Zinsser, are continually called upon to give testimony to our collective historical understanding of where the AIDS epidemic fits in the ancient and ongoing war between microbes and human bodies. Since these histories do not always focus on AIDS specifically (given its recent introduction), they perform as useful historical analogues that set the mysterious (AIDS) within the familiar (the history of syphilis, for example).²

The effect of these frequently quoted histories is to dramatize the obvious contrast between the current medical knowledge of a particular disease or epidemic of the past, and the relevant historical public health measures, social explanations, and reactions articulated at that time. This often leads the modern reader to view the historical perception of diseases as absurd,
pathetic, wrongheaded, medically useless, anxious sublimations, ignorant, or simply dangerous. This consequent rejection of the social understanding of disease in the past, within the context of the present epidemic, has led to the popular suspicion that the social understanding of disease generally has little to do with disease pathology. But as Allan Brandt argues,

The pervasive fear of contagion; concerns about casual transmission; the stigmatization of victims; the conflicts between public health and assuring public liberties. How these issues will be resolved as the AIDS epidemic continues to unfold in the years ahead is far from certain, and we know history is not a predictive science. AIDS is not syphilis, and 1986 is not 1918. But one thing is certain: The response to AIDS, as already can be seen, will not be determined strictly by its biological character; rather, it will be deeply influenced by our social and cultural understanding of the disease and its victims. It is an understanding of this process which gives the historical record its meaning. 3

These accounts also typically reflect the problems associated with infusing disease with moral meaning. In his social history of sexually transmitted disease, Brandt describes how physicians in the early 1900s problematized venereal disease in terms of the dangers that it posed to the family, and subsequently, in relation to the perceived threats of racial degeneration, urban growth and decadence, and the anxieties over an expanding immigrant population. Of particular importance is Brandt's testimony to the effects of implanting worries about moral reform and social pathology into the social understanding of sexually transmitted diseases and
the public health measures these worries legitimated: surveillance, detention, and isolation. 4

The effect of these histories in particular, then, has been to foster a certain caution and separation, among the more thoughtful commentators at least, between the physical and the social. But there has been another effect as well: the social and moral interpretations of AIDS have to a certain extent been delegitimized. The meaning of AIDS, separated from the biological essence of AIDS, now becomes supplementary to the real (biological reality), affecting it certainly, but more as a distortion of truth than its explication. The representation of the 'anxieties of the times' in disease, seen as somewhat inevitable although preventable, are symbolized in these histories, as the invasion of the irrational into empirical and rational medical science. The dangers of that invasion are seen as critical lessons from the past that must be learned by those concerned with the present AIDS crisis.

Another literature in the social interpretation of disease comes from the investigations and studies of culture and its role in the determination of what constitutes health and sickness. In medical anthropology and medical sociology we witness less of a concern over how historical and modern anxieties are represented by conceptions of disease, and more interest in how the
social and cultural fabric writes itself into more fundamental understandings of health and illness. The critical difference between the historical studies mentioned above, and this body of thought, is the difference between asking, in the first case, how medical science is embedded in social relations, and, in the second, how social relations are embedded in medical science.

A rich resource of work lies in the area of medical anthropology with its focus on varying cultural understandings of the aetiology of sickness and its causation, the impact of which affects our understanding of AIDS. Here, medicine is seen as a "cultural system" that creates hierarchies of "health values" as well as provides cognitive, social, and historical explanations of specific illnesses. Anthropological investigations of cultural determinants in health and illness, according to one writer, seek to demonstrate how health understandings and practices elucidate the dominant values, beliefs, and normative expectations of a society and serve as a mirror of the affective qualities of social relationships.

For example, according to George Engel, the pain associated with sickness is conceived of as 'private data', the meaning of which is only made apparent when it is communicated with another. The significance of this 'data' both for the individual and the collective is witnessed in the behavioral, and self-interpreted,
meanings involved in the public presentation of that pain. Thus, the differing meanings of pain are mediated by self-interpretations that react to perceptions of public affirmation or disapproval. This affirmation or disapproval of pain can be dependent upon the illness to which it is attached, the particular displays of pain and the emotions that carry it, or the particular status of the individual expressing it. The social mediation of that pain affects, in the final analysis, the kind and quality of health care provided to the individual as well as the level of personal health achieved.

The nature of the physical and emotional pain of persons with AIDS and their loved ones has been of great interest to the public if one measures that interest by the continuous publication of interviews, diaries, autobiographies, and witnessed accounts of personal experiences with the effects of the disease. The strategies behind these accounts are often admittedly political, that is, they are produced with the intention of gaining support for persons with AIDS (services, research, funding etc) or are aimed at reducing the stigma associated with the disease through the compassion engendered when the human cost and suffering is made undeniably and dramatically evident. Yet there is also a process of social investigation going on that is intent on understanding the pain of AIDS as it is experienced
within the personal (and collective) mentalities of those who suffer it. The public seems to be asking: What is the nature of this pain that often disfigures, dments, and incapacitates, and how is it borne by the young and active, many of whom live in a subculture previously inaccessible to our inspection? In addition, since, as this literature suggests, that perceptions and expressions of pain, and consequently the medical attention brought to bear, are conditioned by the larger social order and values, the presentation of pain by the marginalized, as is the case with AIDS, has been rightly seen as being met with silence and reprobation consequently diminishing the quality of the health care response.11

All of this is to say that one's understanding of the social meaning of AIDS is often framed by the proximity to, and the reception, evaluation, and knowledge of this pain. This pain is more than a biologic event, it is also a social and political one, and this recognition is firmly a part of the contemporary western self-understanding of the AIDS epidemic.

There are also the perspectives generally derived from ethnographic interest about illnesses whose articulation and definition are at odds with modern medical understandings. These "folk illnesses" are seen as culturally specific "clusterings of symptoms and
physical signs" from which people "claim to suffer and
for which their culture provides an aetiology, a
diagnosis, preventive measures and regimens of
healing." In Arthur Rubel's study of susto among the
Mestizo, Zapotec, and Chinantec populations in Mexico, he
describes, for example, the indigenous explanation for
what appears to be a malady of fatigue, weight loss, and
despondency.

The communities' explanation is that a startling or
frightening experience leads to loss of vital
substance or force: "alma" among the Ladinos, "bi-4"
(a phonetic rendition of a Chinantec word) and "es
pir it" for and Chinantec and Zapotec, respectively.
In the first group, the substance is wandering, and a
cure requires that it be induced back into the
victim's body, whereas in the two Indian groups it
must be freed from its captors.

Susto presents problems for western medicine, as
Rubel acknowledges, in that its local construction, and
the taxonomic entities of modern medicine find very
little in common. Yet complaints of "susto" are likely to
represent physical and emotional conditions dangerous to
the individual and potentially life threatening. In the
end the problematic for Rubel is how can "cosmopolitan
medicine" equip itself with the necessary cultural
understanding of the disease to mount an adequate
treatment and prevention effort.

This example and resulting problematic typifies the
concerns and efforts surrounding the problem that AIDS in
the Third World poses for those in the West. The high
prevalence of HIV infection in places such as Central Africa, along with the heavy use of indigenous healers, as well as evidence of the local construction of the disease itself ("Slim" in Uganda, Misada in Kenya) add to the problems already faced in AIDS prevention by the West. Given that any education and prevention effort has to deal with intimacy and sexuality, sensitivity to the specific cultural expressions and authority structures involved seem necessary if that effort is to be maximally effective.

Our understanding of the meaning of disease is also influenced by notions that attest to the social causation of illness. There are a number of theoretical schemas or paradigms that attribute the meaning of AIDS in relation to the behaviors which are claimed to lead to infection or symptoms. One tradition offers a complex, theoretical trajectory that moves from a sociological analysis of an individual's social dysfunction and disorientation, to consequent problems in role performance and interpersonal conflict, to a psychological rendering of the somatization of those social problems, and ending with a biologic connection to, or at the very least creating the conditions for, disease and illness. For example, Richard Totman argues (in support of his structural theory of psychosomatic disease) for a 'psychological model' of people's encoding of the social world, one in
which the "likelihood of symptoms appearing is increased in the absence of frequent registrations of consistancy."¹⁷ What one must be consistant with, according to Totman, is a whole host of important social "rules" that give order and meaning to one's life.

Within the clinical debate over AIDS, speculations about the characterological traits of gay men, their so-called "deviant" sexual status, and behavior, are seen by some as sufficient grounds for judging them as "willing" hosts (biologically if not consciously) for disease. The 'genetic question', for example, related to AIDS concerns whether gay men are predisposed to certain diseases exacerbated by a lifestyle of 'immune overload' activities. This perspective neatly brings together notions of biological and moral deviancy as inevitably invitations to disease and punishment.¹⁸

Another related paradigm of social causation focuses on illness as the product of deception, ignorance or misinformation. Social or political conditioning and circumstances are understood to result in human behavior which demonstrably places the individual at risk for injury, infection, or chronic illness. For example, misinformation about the effects of cigarette smoking on health is manipulated by an aggressive and profit driven tobacco industry through seductive advertising, the effect of which is to addict individuals and make them
pulmonary cripples. The meaning of lung cancer, at least in contemporary America, is thus inseparable from the genealogy of deception and duplicity of this cultivated impairment and eventual death.¹⁹ This explanatory tradition serves as the basis for a whole range of health related thinking: from mainstream public health campaigns which base prevention strategies on models of health beliefs, to critical and Marxist analysis of the adverse health consequences rooted in the political economy of particular modes of production, to conspiratorial theories of deliberate intent to injure.²⁰

This range of meaning structures has been reproduced and seen by some as central in relation to the understanding of the AIDS epidemic. The health belief model, for example, has been a critical tool in the prevention programs against the spread of HIV infection. This model asserts that the behavioral change necessary to build good health habits (here seen as safer sex practices) can be actualized only if the individual learns and internalizes an enabling set of beliefs. Preventive education under this model consists of the constant articulation and reinforcement of these beliefs, and the evaluation of the level of internalization.²¹

There have also been the many critical voices coming from a number of different quarters complaining about the inadequate and self-serving nature of the social and
political response to the AIDS epidemic and its effect on the spread of the disease. These include a wide array of critiques about government and bureaucratic incompetency, professional apathy, and general mishandling by public officials, as well as condemnations from the Left concerning the role of class politics and structural problems of capitalism as it relates to the ability and motivations of western society to prevent the spread of HIV infection.22 There are also the accident and conspiracy theories which propose that the virus was mistakenly introduced into the environment as a result of the testing of biological weapons, or worse, that the virus was deliberately conceived as a genocidal weapon against gay or Third World people.23 Thus, all of these conceptions of the social causation of AIDS are perceived as inseparably set into the meaning of the epidemic, and result in a generalized understanding of its genesis or continuation in terms of social incompetency, outright exploitation, or even madness.

Finally, and in many ways the most contemporary, approach to the comprehension and articulation of the social construction of disease, comes from the more literary work of Susan Sontag.24 In Sontag's book, Illness as Metaphor, she argues that illness has been frequently seen as figure or metaphor, often resulting in negative consequences for those who suffer from it.
Sontag asserts that the healthiest way of conceiving illness is "one most purified of, most resistant to, metaphoric thinking." In pursuing this argument, she examines and compares the mythologies, metaphors and symbols that shape popular current and past conceptions of tuberculosis and cancer. Within the world of these mythologies, Sontag contends that TB was the disease of the passionate, reckless and sensual, and was quite often seen as the marker of the "gentile, delicate, and sensitive." This accounted in the 1800's for TB becoming, according to Sontag, a trope for new attitudes for the self for the "snobs, parvenus, and social climbers." 

The metaphorics and mythologies of cancer were (are) quite the opposite. Cancer is a disease of the withdrawn, passive and affectless, in short the repressed. Most cruelly of all, cancer was a disease seen as somehow deserved, as one of those illnesses in which the person, unconsciously, wants to be sick. Although Sontag wrote her book in 1977 prior to the recognition of AIDS, her words have been chilling in their seeming applicability to the current AIDS epidemic.

Any important disease whose causality is murky, and for which treatment is in-effectual tends to be awash in significance. First, the subjects of deepest dread (corruption, decay, pollution, anomie, weakness) are identified with the disease. Then, in the name of the disease (that is, using it as a metaphor), that horror is imposed on other things. The disease becomes adjectival. Something is said to be disease-like, meaning that it is disgusting or ugly . . . Feelings about the evil are projected onto
the disease. And the disease (so enriched with meanings) is projected onto the world."

Sontag's agenda for the eradication of metaphor from disease has been taken up in the debate surrounding the AIDS epidemic. For example, Dennis Altman concludes his powerful book, *AIDS in the Mind of America*, by observing that

Perhaps the most difficult thing to accept about AIDS is that it is, in human terms, without meaning; disasters occur for which there is no rational explanation or any meaning beyond the suffering itself. What Sontag calls "the trappings of metaphor" prevent us from seeing AIDS for what it is, a very nasty disease that all possible medical, political and social resources should be mobilized to conquer.29

Judith Wilson Ross, in an article entitled "Ethics and the Language of AIDS", sounds the theme again but in more detail. Ross identifies several "metaphors of AIDS" -- death, sin, punishment, crime war and otherness -- which she argues shape perceptions and which make the language of AIDS "so dangerous". She warns that

AIDS has been permitted and encouraged to carry a moral meaning, but that morality is in our minds, not in the disease. If our ethical judgments are not to be based on punitiveness and further divisiveness, it is time for us to confront the inner meanings our language betrays and then to rid not only our speaking and writing but also our thinking of these metaphors.30

**Social Meaning and the Language of AIDS**

The stakes in the meaning production business about AIDS are perceived as extraordinarily high, with serious
consequences riding on vast domains of unknowing and uncertainty, and bathing in a climate of fear and anxiety. Part of this problem is generated by the substantial technical issues and dilemmas with the model of growth used to project the numbers of people who will be infected. With the future being ever so much a part of our construction of the present, the image of AIDS as portending some Malthusian apocalpse has its effects.

Yet, there is also some sense that our ability to construct useful meaning is itself under fire as in Susan Sontag's complaint, and often picked up by AIDS commentators, that "nothing is more punitive than to give a disease a meaning." Certainly the various social, cultural, and religious meanings attributed to AIDS reflect the variety of human experience with the disease, and contrary to Sontag's sentiments there can be no "meaning-less" disease. However, the main criticism and dissatisfaction with the current wave of social interpretation of AIDS, as understood in this present inquiry, is not in the attribution of meaning to AIDS, but in the epistemologically reductionistic, and politically disabling role given to language in the understanding of the AIDS reality. Language is not simply a neutral reference tool to be seen as about social meaning and behavior, that is, within the dualism of subject and object where objects become containers of
meaning-to-be-discovered. Rather language must be viewed both as constitutive of the meaning of that life and behavior, and consequently central to an understanding of the effects of power.33

The popular and professional discourse on AIDS has included, in substantial ways, discussions and pronouncements that seek deliberately to build or combat social images of the disease. These images, in their construction, weave together in differing and complex ways political, moral, sexual, cultural, and scientific notions, ideas, vocabularies and perceptions. Along with the discourses in which they are contained, these images form the dimensions of the social "reality" of the disease and the context for both the public and private action in response to it. These varying ways of mobilizing, compiling, and articulating meaning, problematize the epidemic in ways that establish the political grounding that gives agency and power to some constituencies and not others, and that victimizes and dis-enables some and not others.

All of this is self evident, for example, in the confrontation over those images of persons with AIDS that are seen as negative, inaccurate, fear producing, and exploitive. Much of this discussion has centered around the critique of AIDS "as a gay disease" and the subsequent scapegoating of gay persons.34 The initial
perception of the disease as the "gay plague", the brief tenure of the clinical nomenclature "GRID" (Gay Related Immune Deficiency), along with the actual predominance of gay men affected by the disease in its early visitation, has according to this critique, not only led to a stigmatizing of both gay people and persons with AIDS, but also to a misunderstanding of the disease itself. This initial identification of the disease with gay men, has, according to writers like Dennis Altman, influenced the whole subsequent conceptualization of the disease with the effect of distorting the direction of clinical research into the disease. Rather than searching for specific pathogenic or cytotoxic micro-organisms that would explain the immune deficiency presented by the sick, valuable time was lost in the initial stages of research examining 'lifestyle' factors, creating taxonomies of gay sexual practices, and speculating over variations of a number of "immune overload" theories specific to gay men.

In addition, again according to Altman, this image has also contributed to a subsequent history of reluctance in the generation of financial support for research and treatment. Since the disease was thought to only affect gay men, a group traditionally viewed as marginal in western society, a sufficient and necessary effort on behalf of persons with AIDS was not forthcoming by public health and government officials. It
was only when the disease was perceived to also be infectious to heterosexuals that the alarm in America and consequently around the world was sounded.\textsuperscript{36}

These images, thematics, characterizations are human constructions, and producing them is the way we go about formulating social meaning. The AIDS epidemic is not merely a fact, or even a set of facts, possessing in themselves meaning that is somehow waiting in expectation to be discovered. The human meaning of AIDS comes to us not in the body's literal reaction to the HIV virus, but in how we have come to "see" the wasting and physical debilitation it presents, the terms and symbols we've come to attribute to it, and the systems and social mechanisms we've developed (and are developing) to combat the disease. But these meanings do not just emerge naturally; they are, of course, social creations and one must ask how they have become implanted or formed and what incited them to that end? This is where the AIDS epidemic poses its challenge to the social theorist.

AIDS is a biological, material phenomenon to be sure. But it is also a social and textual one as well; it is the yield of a number of contending language practices including western medical discourse, religious, sexual and other cultural discourses all struggling with each other to establish the "reality" of the epidemic. This meaning struggle makes the AIDS epidemic inherently

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political for a number of reasons. First our discursive acts and practices with regard to AIDS are decisively political in the tone, subjects, plots, persuasions, silences, and appropriate contexts they articulate, all of which attest to dominant ways of living and being within particular social formations. It can be argued, for example, that the featuring of gay sexual practices within the clinical language of AIDS, and the consequent voyeurizing of the reader and speaker of that language to those areas of gay life that were once private, is less a product of the necessary representation of the immediate biological mechanism essential to an understanding of AIDS, than the extension of the historical social inspection and, as Foucault has observed, the pathologization of the gay person so pervasive in western society. Second, these practices are also political, not only in terms of those aspects which are centered and deemed essential to it, but because of the host of background assumptions, rules, historical interpretations which are carried or implied by the discourse, and which legitimate, or to use a more ideological term, naturalize that centering. Thus, the invasion of gay sexual practices is supported by justifications, legal and moral, which allow an invasiveness that would be seen as violations of privacy in other groups.

The AIDS epidemic thus truely forms what Foucault has
called a site of discursive production: a location where power and knowledge are transformed into discourse. By drawing upon these forming or existing ways of speaking when we want to "paint the picture" or "tell the story" of AIDS, we come to fix our political commitments which are imbedded in the particular voices and strategies legitimated through the discourses used. These voices and strategies, as they exist in discourse, speak for a material world through "approved" vocabularies and specific metaphors and imagery. They sustain or resist, in short, what can be termed as nothing less than the AIDS industry: the thousands of researchers, medical providers, writers, media communicators, administrators, social organizations, persons with AIDS and their loved ones, priests and so on, who together make up a constituency in the "business" of "producing" AIDS, that is, producing the language by which we are coming to know and understand AIDS. AIDS is a social text in the making, and it is in the making of that text with which we are concerned.

Surveillance as Textual Practice

In Discipline and Punish, Michel Foucault writes that the image of the plague stands for all forms of confusions and disorder, yet also it exists as a "compact
model of disciplinary mechanism." The order that confronts the plague,

lays down for each individual his place, his body, his disease and his death, his well being, by means of an omni-present and omniscient power that subdivides itself in a regular, uninterrupted way even to the ultimate determination of the individual, of what characterizes him, of what belongs to him, of what happens to him. 39

The social response to plague strives for the ideal "exercise of disciplinary power," for the "panoptic" display of ceaseless inspection and "permanent registration".40 And it is in the language of plague that the pursuit of order articulates itself. Consequently without an appreciation of how the politics of surveillance is shaped by representational practices, that is, the language acts we use to attribute social meaning to the epidemic, we only see part of the picture of how dominant power is effected through the AIDS epidemic.

How then does the language of AIDS participate in the broader economy of surveilling power? To answer this question one first must understand that surveillance as textual operation does not relegate itself to only those ways of talking in which it is named. As a language practice it is part of a larger disciplinary mechanism that functions to establish the parameters of a political normalcy in service to power. Surveillance is the product of a social process by which the conceptual
ground is figured, by which the raw language resources are shaped for their eventual use in the cultural and political manufacture of the surveillance problematic.

For the purposes of this inquiry, textual surveillance is thus broadly conceived in two ways. First it is viewed as a set of textual practices which legitimate and naturalize authority. Surveillance is thus an ideological mechanism: a way of establishing and supporting, privileged interpretations of meaning that advance domination. 41 Michael Shapiro, in his review and critique of modern conceptions of ideology, offers a distilled compilation of ideological textual operations which helps to fill out our approach in terms of the process by which surveillance asserts itself. 42 Shapiro sees ideological production as involving certain strategic "gestures" which seek "acceptance of some authority". As representation, ideology is a "kind of writing", and thus ideological thinking, a form of reading, which results in an enforced dislexia wherein the reader is disenabled by being encouraged to adopt a politically obtuse view of the surrounding social formation and the objects, relationships and events it contains. 43

While it is not our purpose here to get into a lengthy treatment of ideology, it is important to review those mechanisms that Shapiro summarizes since they are of great assistance as points of inquiry in our reading of medical discourse and the AIDS epidemic. All of these
operations can be brought to bear on our understanding of
the textual structuration of surveillance, both in its
authoritative capabilities and in its victimology, and
can link this project to the broader history of political
inquiry as ideological analysis. Briefly then:

1) There are textual operations of legitimation which
seek to justify power through the establishment and
maintenance of what is termed the "authority of the
referent". This authority is constructed as either
something that is not to be problematized, or whose
justification for control lies in some foundational
experience that is seen as fundamentally outside of
discourse (e.g. the divine origin of the authority of
Jesus is unquestioned in the Bible). In addition, the
legitimation of the referent also necessitates securing
the "authority of the scriptors". These are the
producers who provide the commentary on the referent
without which the referent has no credible voice (e.g.
the value of the Apostles as narrators of Jesus’s
divinity). 44

2) Ideology has traditionally come to mean the
process of "reification" which historically, from Marx
onward, has meant alienation, the process by which people
experience the loss of their authentic meaning (e.g. the
commodification of the "athlete"). Thus when objects
become 'reified', they may trade upon the remnants of
this meaning, but its value has been emptied as a result of the appropriation of that object for some other, and usually lesser, purpose. Within the postmodern perspective, reification becomes more useful when conceived of as those textual operations which succeed in "severing the connection between the object and its original meaning system", and upon which is imposed a new meaning, one more 'efficient' to the economy of power relations in which they exist.45

3) One of the most insightful conceptions of ideology and its operation is what has been termed "dissimulation". As a form of thinking and textual practice, dissimulation is that process which "turns human practices and contrivances into something natural and timeless."46 This naturalization, and in turn, universalization, of objects which are, after all, the product of social construction, invites a gross misreading of the workings of human power and authority. Naturalization mystifies power, acts as closure to potential discursive threats, and legitimates disciplinary practices. It can be a concealment immanent in discourse, as in silence, or in the form of a secondary discourse which hides the constructions, divisions and ambiguities. As a textual operation, it again relegates the sources of that authority in areas beyond the reach of allowable political discourse. One
could cite here, for example, the varying religious or psychiatric constructions of the homosexual that fix the individual as being innately immoral or sick, and as we have reported, the subject of a host of disciplinary measures which have traditional formed themselves around those constructions.

4) Finally, there is what Shapiro calls, quoting Fredric Jameson, the ideological "strategy of containment".47 Two aspects of this operation deserve our attention. First there is the textual politics of repetition. This is a process by which disturbing information is presented and repeated to the point where it becomes all "part of a known and catalogued world and thus somehow in order."48 The effect is to depoliticize and exhaust, and thus to tame and domesticate challenges to power. Second, the making mundane of the remarkable would not necessarily be the impact of such repetitive representation, Shapiro informs us, if it were not for the structure of that representation which "fragments aspects of social totality and thereby robs people of the ability to recreate the whole of which the fragments are a part."49

Surveillable Identities

In addition to those practices which authorize politicized meaning, textual surveillance includes the
representation of subjects, and their individual and social context, in ways that, as an immanent necessity, require them to be examined, interrogated, inspected, registered, categorized, classified and rendered judgement about. This immanent necessity may be attached to several fictions including that of unalterable circumstance, unchangeable personality, universal essences or needs, philosophical or legal foundations, determinate human or physical nature, divine intention or the transhistorical requirements of order itself.

The agency that drives movement within discourse resides often in the way in which characters are constituted, the actions they engage in, and the impositions that plot and setting, and, of course, other characters make upon them. Surveillance, as we have said, is structured into discourse through the various figurations of these textual strategies. Yet it is the subject, or character, which most effects the ideological resonance within us, and in turn, reflects the contours of power. Thus, one of the primary concerns in looking at the language of AIDS is in what we can call the construction of surveillable identities: those characterizations of individuals as particular types of identities that have, as an inseparable component to either notions of self or other, the obligation to submit to inspection.
Surveillable identities are constituted in a way that invites surveillance in the meaning of its very presence. The notion of surveillable identity is predicated upon the premise that social representations of the self and other reflect the prescriptions of the dominant order, and that these identities are continually created and dispatched to facilitate the workings of power. The recognition of these identities as the impositions of institutional power is the beginning of empowerment and resistance. Yet, as has been recently argued, in making this latter assumption we presume that the representations of self or other are more than merely an assemblage of dominant modes of personage. The subject as represented through a discourse of 'self' or 'other' is more "a set of forces, a potential which constitutes both a yearning for accommodation to an order, and a resistance to it." To argue the notion of surveillable identities as a politicizing move implies, in principle, the ability to resist such scripting. Thus in the analysis of surveillance within the language of AIDS, the potentialities within process of "subjectification" are of particular interest; that is to say that both oppressive and emancipatory possibilities exist within the discursive economies which represent AIDS, and within the particular subject-making that takes shape within its text.
The surveillable identity is one which surrenders to power and order. But the question is both how, and with what effect? In his analysis of the "dangerous individual", Foucault offers us one version of this kind of subjectification. He argues that with the "psychiatrization of criminal danger" in the 19th century, crime became "no more than an event which signals the existence of a dangerous element . . . in the social body."51 No longer was the system sufficiently satisfied with simple admission and punishment. To punish within the framework of criminality, the nature of the offender must be known, the question no longer being "what did you do", but "who are you and what were your reasons for this act"? Thus, as Foucault points out, a whole industry has emerged to address these questions -- lawyers, jurors, judges, and to this we can add counselors, parole officers, -- which cannot play its role without the information provided by the individual himself(or herself).52 The construction of the offender in this way, and to the extent to which it is internalized by him or her, provides automatic license for the biographical examination that individualizes and, in a way, depoliticizes the framework by which "criminal acts" are assessed. The location of criminality is implanted in the person making the social environment
(institutional or economic racism, for example) a non-player in the 'causation' of crime.

**Surveillance and Medical Discourse**

The history of infusing disease with fear and negative meanings is a revealing and complex one. In Saul Brody's work on leprosy in medieval literature, he finds that the ecclesiastical and literary traditions of the time conspired to represent the leper as morally, psychologically, and spiritually corrupt. Leprosy was both a punishment and an emblem of sin.\(^5\)\(^3\) Medicine, it seems, concurred with this judgement. Conditioned by this tradition, along with medicine's perception of leprosy as a venereal disease, and the authority of humoral medical theory which linked physical phenomenon with temperament and predisposition, the physician often described the disease as the result of illicit sexual intercourse, with sexual excitement being symptomatic of the patient.\(^5\)\(^4\) In this, and in other descriptions, the practitioner helped to shape the attitudes of his society, to create an atmosphere in which a disease, sufficiently horrible in itself, was viewed with unnecessary fear, loathing and condemnation.\(^5\)\(^5\)

By conflating moral fiction with medical fact, Medicine, it was clear, provided the critical link between the popular conception of the disease and official surveillance by religious and royal power.

Modern medical authority and its discourse remain a
primary vehicle for the imposition of surveillable identities in many areas of contemporary social life although the power it represents is different and in many ways more complex than that in medieval Europe. Yet medicine continues to form a bridge between state surveillance and the individual. As Foucault observed,

The developments of medicine, the general medicalization of behaviors, conduct, discourses, desires, etc. take place at the point of intersection between the two heterogeneous levels of discipline and sovereignty. 56

Medical discourse for Foucault is a mediating discourse between the power of the state and the power which seeks to move within individuals' own internalized notions of normative order. The deployment of identities in medical discourse places medical (and consequently state) authority between the individual and the choice of identities and meanings of the epidemic. Similarly both John O'Neil and Ivan Illich argue that the growing "medicalization of the body", that is, the "seeing" of the body within medical discourse, is a primary mechanism by which the tremendous 'summoning' ability of common stages of human life -- birth, sex, death etc. -- is brought within the authority of professional medicine and thus under the jurisdiction of administrative and bureaucratized centers of social control. Under this interpretation, the AIDS body functions both as an object of disciplinary power, and as a strategy for securing the
continued growth of that power. Thus the question of medical discourse, of the identities and order it creates, of the surveilling practices it requires, is part of the larger question of what kind of political "meaning-net" the epidemic is being caught up in.

As the AIDS epidemic moves toward totalizing an increasing number of lives within itself, it has added fuel to the modern medical mobilization of technical and political power. For medicine's professional ranks and institutions, this discourse details the specifications of their growing participation in the mediation of the epidemic, along with the arrangements of service boundaries and rules for the commercial exchange of patients. For others, those whose lives are conscripted to serve in the epidemic's death-project, we also find the specifications of names, roles, duties, obligations, patterns of consumption and production, that encode these lives with the requirements of the political economy of medicine.

Reading AIDS

Surveillance, as an ideological/textual practice of medical discourse, acts as a mechanism that calls us to the expansionary and hegemonic agenda of both western medicine and the modern state. To more fully understand the operation of this agenda requires that we read AIDS
from the perspective of how power asserts itself within those social practices which deploy meaning about the epidemic to society and to the body. The following reading of the NAS report will be informed by the theoretical considerations just discussed. But theory can only take us so far. It is the NAS text that must in the end structure our inquiry. We must allow it to lead, allow it to speak first if we are to assess its political impact.
NOTES

1. See, for example, Edward Albert, "Illness and Deviance: The response of the Press to AIDS" in Douglas A. Feldman and Thomas M. Johnson (eds.), The Social Dimensions of AIDS (New York: Praeger, 1986), pp. 163-178. Albert observes: "The media portrayals of AIDS reflects the confusion and ambiguity experienced by the society at large. Further, the media's confusion over the illness/deviance has resulted in the raising of issues of personal responsibility in ways that give rise to questions of the degree to which situational difference becomes normative violation." (p.167)


4. Brandt, No Magic Bullet, pp. 6-8, 35.


8. G.L. Engel's work on pain is discussed in Helman, Culture, Health and Illness, p.96.


10. See, for example, Lon G. Nungesser, Epidemic of Courage (New York: St. Martin's Press, 1986) and


12 See Helman, p.72; Rubel, p.2.

13 Rubel, p.48.


22 For a Marxist view see Nancy Krieger and Rose
23 See Chapter I, endnote # 61.


25 Ibid., p.3.

26 Ibid., pp. 21, 27.

27 Ibid., pp. 21, 45, 54, 55, 56.

28 Ibid., pp. 57-58.

29 Altman, AIDS in the Mind of America, pp. 193-194.


32 Susan Sontag, p. 57.


34 See Dennis Altman, AIDS in the Mind of America, pp. 58-59.


45 *Ibid.*, pp. 36, 44.


52 Ibid.


54 Ibid., p. 58.

55 Ibid.


CHAPTER III

CONFRONTING AIDS: AN OVERVIEW

The present effort [public education on AIDS] is woefully inadequate. It must be vastly expanded and diversified . . .

Confronting AIDS

Given the theoretical nature of this inquiry, there is an inherent dilemma in any attempt to summarize for the reader the NAS report. If we have established anything, it is that no neutral representation of any text is possible since all representations are translations filled with power effects and political commitments. And when the subject of inquiry itself is the understanding of the textual production of those effects and commitments, then the dilemma is made all the more problematic. Yet we recognize that the value of the critique itself is dependent on an appreciation of the popular representation of this report, and consequently the critique's contrast with it. Thus there is a need to contextualize this report within a conventional framework that, for the moment, is blind to its own discursive
politics. This orientation and summarization is offered, however, with the proviso that it is a temporary stage setting that may be dismantled in later chapters.

This review is also a gesture of respect as well, one which pays tribute to the depth and breath of effort and intellect expended in creation of the NAS report. It is also our contention that the kind of politicised reading we are doing is not the only reading possible. The NAS work is material in that it exists in a form and structure. Yet, the kinds of texts that it evokes in its reading is an interpretive endeavor, and that interpretation is related to the kinds of meanings one is searching for. In this chapter we first seek to locate the NAS report within the variations of medical discourse; we then move to discuss the specific entry of the NAS into the AIDS arena, and then follow with an overview of the report and its major arguments and recommendations.

Locating the NAS Report

The dimensions of the medical text that establish the social and physical topography of AIDS are of several different sorts, and this recognition is in itself helpful. These dimensions consists of varying interpretations of what is usually termed basic research. On the front line are the journal articles through which
basic medical research is established and critiqued. There are then summaries and reviews of collective bodies of research that are meant to give a broader understanding to this research by placing individual projects within the context of related or comparable works. Following this are those writings which attempt to translate these works to a wider audience whether that be professional groups or the population at large. Included in this later group are everything from those writings that bring research developments to other professionals who have a practical or theoretical use for the information, as well as press and media reports of medical advances.

These distinctions are important for two reasons. First, heavy demands have been made for the production and reproduction of these kinds of works as a result of the AIDS epidemic. Consequently, the research literature on AIDS has become nothing less than voluminous. The epidemic has necessitated the constant and widespread dissemination of medical information in the attempt to heighten the level of the public's awareness of prevention strategies, as well as improve the skills and extend the knowledge of the many professionals who are provisioning health related services to those who are ill. This sheer mass of AIDS literature not only cultivates and shapes our knowledge of the disease, but as
material and very productive enterprise, affects the politics of AIDS.¹

Second, we can assume that these translations act as different genres of medical world-making. That is, they have different strategic agendas and, as a consequence, constitute their meaning differently. They may not be, as is assumed, just a simplification, or more relevant interpretation for specific audiences. What often becomes 'simplified' are just the problematical dimensions that call into question the authority of the original text. For example, whereas in one text there may be the recognition that the original assignment of the 'AIDS virus' as a member of the HTLV family by Robert Gallo of the National Cancer Institute was a highly questionable gesture even on scientific grounds, (if not an outright self serving act) the translation or secondary text may have confidently declared HTLV-III to be the 'cause' of AIDS.²

In addition to this literature which is overtly identified as medicine speaking to itself, is the symbolic invocation (more or less competent and tactical) of medical understandings in the works of those speakers outside the medical cadre. In this literature, medical knowledge is called to legitimate some other stated agenda. The most common example is the frequent recitation of the bio-mechanics of HIV transmission as a
means to validate various public health infection control measures. Of course medical knowledge of AIDS has been declared to support almost every conceivable venture ranging from the saving of lives, to that of taking them. In any event, these medical understandings are seen as essential to the gathering of authority for particular political interpretations, and are the base line, or original discourse, for making claims about the truth of the flesh.

These varying dimensions are important for our purposes, in that some distinctions have to be made on which literature best serves the examination of medical authority and the surveillance problematic. In this we have sought the difficult middle ground. By this we mean that we do not intend to survey the most fringe or reactionary wing of medicine that speaks most directly to the issues of quarantine, imprisonment, or tattoos and the like. While no one underestimates the power of that voice and its resonance in American popular culture and politics, our concern it must be admitted lies with the medical mainstream which dominates health care as we know it. Thus we have selected a work which represents one of medicine's most regarded attempts to deal with the epidemic, one that is at its most respectable and competent best, and yet also a work which seeks to find dissemination beyond the strict confines of the more
technical professional readership. We’ve selected thus, one of medicine’s most able truth narrative about AIDS, one meant for wide consumption, and which roots itself most clearly in recognizable medical power.

The NAS Entry into the AIDS Epidemic

The issuing of the National Academy of Science Report on AIDS in the fall of 1986 was by far one of most important events in the history of the epidemic in the United States up until that point in time. It represented in a number of ways the first real serious look by, and the mobilization of, American medicine at its highest levels. The voice of medicine was now writ large on this disease beyond those at the few universities, institutes, hospitals who were in one way or another dealing directly with the epidemic. It was also the voice of a liberal medicine and one not adverse to dispatching its own critique of the nation’s response to AIDS and especially that of the federal government.

Following, as it did, on the heels of the U.S. Surgeon General C. Everett Koop’s own report to the nation on AIDS the week before, the NAS report was seen as the most significant validation to date of what others had been saying for years about the proportions of the epidemic and, as the NAS argued, the "woefully inadequate" response of the federal government. In all
fairness to other critics, this inadequacy was established beyond doubt at least by early 1985 with the issuance of an evaluation of federal efforts by the Congress's own Office of Technological Assessment, a rather maverick and somewhat independent federal agency. Yet the NAS report was not some minor part of the federal techno-bureaucracy talking, a voice only to be heard by Washington insiders and those persistent and interested enough to track down these kinds of reports. No, this was the face of American scientific medicine speaking, and it was speaking with all the authority and media presence it could muster.

The unveiling of the report was an event infused with the importance its writers thought of the issues involved, and it must be understood, of the perceived value of their own contribution. The NAS choreographed a national press conference with its prepared statements, opportunities for sound bites and photos, and the required national television coverage. The response of the national press was, understandably, and without exception, laudatory and uncritical. Most press accounts noted the "prestige" of the NAS, and the participation of "prominent" scholars such as "Nobel laureate" David Baltimore, a biochemist at MIT and co-chair of the report committee. The report was said to provide the most "authoritative endorsement of the gravity of the AIDS
"epidemic" as the New York Times was to say, and that the crisis it portends and the mobilization of the massive resources it required, was something very "real". 6

The scientific press, reporting in magazines such as Science and Nature, was less gushy in its response although it too unanimously praised the report as a "turning point" and "essential" to those trying to grapple with the host of problems presented by the epidemic. 7 The usually skeptical gay press was also impressed with the report noting that the issues of concern to gays were "very sensitively developed". 8 The only discontent voiced was the predictable defensive response from a representative of the Reagan administration to the effect that the government was in the process of "putting together a strong program for health education, risk reduction, and information dissemination". 9 We need no reminder that as of the end of 1988, this "strong program" has yet to materialize.

Since the report offered few surprises with the possible exception of the amount of money -- $2 billion annually for prevention education and research -- the wide public attention it received was as much a response to who was speaking the report, as to what was being said. The authority in which the report was embedded played a critical role in delivering the impact the NAS felt was necessary in order to provide national guidance.
An understanding of the NAS as authoritative speaker must be prefaced by situating the report within the mixed history of the Academy. The NAS is a quasi-official and self-governing scientific advisory body created through an act of Congress in 1863. It was spawned with little fanfare and enthusiasm through the efforts and personal political friends of scientists such as Louis Agassiz who, in a bold and well-timed maneuver, took advantage of the United States Navy’s need to review various military inventions that could assist the Union in the war effort. The Academy thus emerged out of the need of the military to assess these technical devices and, one must add, without any serious debate over whether the country had a serious need for such a body. In any event, the Academy grew to become in its early years an honorific hall of fame for American scientists only to quickly settle into a body encrusted by seniority, political impotence, and for most of its history, an institution which rarely took the political initiative on social policy related to its advisory mandate.

The rise of a number of scientific issues in the 1950s (nuclear power, space exploration) and the political criticism it was subjected to during the 1960’s and beyond for its work on weapons research, challenged the historical lethargy of the NAS and provided the
incentive for change that is reflected in the more proactive body seen today. Yet through it all, and to the present, the NAS retained a complex but awkward relationship with the U.S. government, a relationship that continues to center around the problems associated with the centralization of institutional science under government auspices.\textsuperscript{12}

The NAS report on the AIDS epidemic, then, must be viewed within this institutional history and the increasing sensitivity of the NAS to criticism of its leadership role. Early in the epidemic the Academy took little interest in AIDS. But as it came under mounting pressure to take a leading role, especially in light of the abysmal federal response offered by the Reagan administration, it began to mobilize itself and give the epidemic the serious kind of attention it deserved.\textsuperscript{13} The report thus represents the Academy’s renewed participation in the struggle for dominance over the numerous competitive and fragmented American science institutions (and which are now vying for control over the AIDS scientific agenda), and its continuing effort to break with its own historical reputation of dormancy in national social policy.
Arguments, Findings and Recommendations:  
The Biological Picture

The six major sections of the NAS report, when viewed both individually and collectively, present an impressive accounting and assessment of extant contemporary medical and social science research related to AIDS. The job of the NAS report is to weave through the voluminous scientific literature, and related research on the epidemic, and to separate fact from fiction, the essential from the peripheral, and the useful from the useless. The following review is not meant to be comprehensive, but rather indicative of the material encompassed by the report.

The first section entitled "Understanding the Disease and Dimensions of the Epidemic" provides summations and assessments on the causative agent of AIDS, the pathogenesis of the virus, its natural history, the clinical manifestations of the disease, its modes of transmission, as well as a delineation of those populations at risk of infection. In each of these areas, basic research, applied clinical research and epidemiological research are referenced and brought together to build a biological picture of the disease. Some of this information was presented earlier in Chapter I of this dissertation. However, the report details the biological mechanisms in each of these areas very
specifically and with a technical competence that reflects the knowledge not of the generalist, but of the specialist.

In the discussion of the causative agent of AIDS, for example, not only is there an accounting of the history of the clinical discoveries which have led to the positioning of HIV as the central cause of AIDS, but there is also a history of the scientific knowledge of retroviruses and other related viruses such as lentiviruses which are biologically similar in many respects to HIV. The report, however, is clear in this examination that the research supports the dominant etiologic role of HIV in AIDS: tests of sera from AIDS and ARC patients reveal HIV antibodies; HIV can be isolated from the lymphocytes from most of these persons with the failure to isolate the virus from all infected persons being seen as a problem of technical limitations. In addition, the pathogenic operations of the HIV virus and how it affects the human immune system confirm its critical role in AIDS. While the mechanism by which the virus destroys white blood cells (the cells which resist pathogens) remains a mystery to science and the NAS, the evidence the report amasses points to the special relation between HIV and T4 cells which result in the cytotoxic consequences of infection by this virus.

With the identification of HIV and the development of
antibody testing, the study of the natural history of this virus becomes possible. The report provides information on the time between seroconversion and evidence of clinical symptoms, between transmission of the virus and seroconversion, and the proportion of HIV infected individuals who will develop AIDS. Yet knowledge of this natural history is full of unanswered questions such as the number of viral particles necessary to initiate infection, and the role of cofactors in precipitating infection or the onset of clinical symptoms.

The modes of transmission of the virus are also clearly spelled out in this section of the report. The NAS is convinced by the epidemiological data that HIV is limited to sexual, parenteral, and maternal-infant routes of infection.

There is no evidence for other routes of HIV transmission. In fact, casual contact, including regular close contact (such as occurring in sharing accommodations, eating utensils, or even toothbrushes), that does not involve parenteral or sexual exposure, despite the fact that HIV has been reported to have been occasionally isolated from saliva and tears in small amounts.15

Each of these ways of being infected with HIV are examined in their numerous variations from the perspective of the comparative risk involved. Within sexual transmission the report argues that receptive anal intercourse and increased numbers of sexual partners are
the primary risk factors for HIV infection in gay men. Yet the data on the relative efficiency of transmission of the virus within the varieties of sexual expression between men and women, men and men, women and women are neither clear nor adequate enough to make further informed observations. In parenteral transmission, that is infection through contaminated blood, contact with the virus comes primarily through injection of HIV infected blood, blood transfusions, and the use of infected blood products. The third route consists of children being born to infected mothers. In this last regard, the report argues that while perinatal transmission is not inevitable, pregnancy itself may unfortunately increase the risk of developing AIDS or ARC in HIV infected women.

Two other parts of this section warrant our attention. The first consists of the delineation of population groups who are at increased risk of HIV infection. The report targets homosexual males, IV drug users, neonates born of infected women and persons who receive pooled blood products as being at the highest risk of HIV infection. Risks vary, of course, relative to the particular behaviors of the individuals involved and the extent of exposure to the virus. With regard to homosexuals specifically, the report offers a sympathetic voice to the problems of discrimination against gays, and examines the difficulty in assessing the size of the gay
community. The work goes on to recognizes the changes in the nature of the gay community and their increasing visibility in recent years. But these changes have had their effects relative to AIDS.

One component of the sexual liberation of the 1960s and 1970s was a proliferation of bars and bathhouses that fostered frequent, sometimes anonymous sexual liaisons among a certain proportion of homosexual men (Lesbians have tended to have more exclusive relationships.) Some homosexual men reported hundreds or even thousands of sexual partners during their lifetime. A consequence of this sexual freedom was a dramatic rise in the rates of syphilis, gonorrhea, amoebic dysentery, hepatitis, and other sexually transmitted diseases. If

Finally the section spends considerable effort to discuss epidemiological surveillance methods, the mechanics of national reporting requirements, and the clinical classification system introduced by the CDC. The report is careful to distinguish between epidemiological surveillance and epidemiological research, with the latter being a more detailed study of certain populations. Findings of these studies are present both in terms of the prevalence of HIV infection, and the sorting of "AIDS cases" by risk group, geographic area, sex, age, race and disease presentation. International data on AIDS prevalence is also discussed.

The Future Course of the Epidemic 17

As we mentioned in Chapter I, the NAS accepts the U.S. Public Health Service's projections on the future
course of the epidemic. However, while arguing that these estimates are reasonable for planning purposes, much of this section is devoted to examining the "substantial uncertainties" to which these projections are subject. By pointing to the limitations of the data, the NAS hopes to encourage improvements in the kinds of information that goes into the modeling of this epidemic.

The limitations on AIDS growth projections take two forms: those problems that are inherent in the particular information collected (or not collected as the case may be), and problems in either the actual mechanics of collection or methods used to analyse the data. In the first instance, the NAS report argues that the survey data collected on particular high risk groups, or on others such as those in the military, does not adequately represent the general population. Even national prevalence in high risk groups and the likely spread of the disease in these groups is difficult to assess given the differences in seroprevalence within these groups among those of different ages, locations, sexual practices and other factors.

In addition, the NAS report observes that given the "long and uncertain time lag" between infection and symptoms, the time of the introduction of the virus into these populations is critical to understanding the potential spread of the disease. This critical piece of
information is not known. Further, the lack of knowledge about the natural history of the disease gives planners many problems in deriving meaning and useful estimates out the the figures and projections presented.

In the second instance, the NAS report claims that the CDC criteria are much too restrictive and don't include all the expressions of HIV infection. Further, the underreporting of AIDS by physicians, and the effect of delays between diagnosis and the reporting of the disease can affect the statistical basis for projections. Estimating the distribution of error is also difficult, as the NAS report comments, because confidence intervals surrounding these projections are "mathematically and biologically problematic." And finally these estimates of the future incidences of persons with AIDS do not take into consideration either changes in the natural history of the disease or future improvements in medical treatment which may prolong the life of these individuals.

Along with this critique of the models by which we are determining the dimensions of the epidemic, the report also offers its own analysis as to why adequate national resources have not been utilized to combat the epidemic and why important segments of the public and private sector have not become sufficiently involved. These reasons include lack of awareness of the problem,
reluctance (for a number of reasons), lack of inducements, commercial disincentives, lack of research data on which to judge commercial development, and uncertainty as to the federal agency responsibilities. In response to these issues, the NAS recommends the establishment of an advisory body, the National Commission on AIDS, as a mechanism to mobilize these resources and overcome these pragmatic and theoretical barriers.

Altering the Course of the Epidemic

In this section, the report addresses the most important question dealing with this epidemic: what public strategies will best control the spread of HIV infection? The report offers a number of options both in the areas of public education -- what should the content of it be, who needs this education and who should do it -- as well as in the kinds of testing and reporting measures, and policies which should be pursued. The expressed intent of the NAS writers is to encourage maximal use of the available means of control given that there is little hope of a vaccine within the near future, and that those exposed to the virus, sick or not, must be seen as "chronically infectious".

In the arena of public health education, the report argues for educational programs that will focus on
attitudinal and behavioral changes that reduce the risk of infection, and on information which prevents undue public alarm by affirming those behaviors which do not spread the virus. Educational campaigns must include the advocacy of condom use, and clearly explicate what constitute safer sex behaviors. The NAS writers are also much concerned about misguided efforts to frame the epidemic in language that is vague and euphemistic. In its critique of a CDC directive that "empanels local review boards to determine whether materials developed for AIDS education are too explicit and in violation of local community standards", the report complains that such efforts may result in cutting "off frank, explicit information from areas where it is needed most."

The use of professionals, and peers, as well as the establishing of AIDS hotlines are all stressed as strategies to reach high risk groups, sexually active youth, the worried well, minorities, students and those in a position to affect the opinions and decisions of others. The NAS singles out IV drug users specifically for special consideration in the planning of programs and research. For it is this population, according to the report, which is most difficult to reach, has the most severe medical problems, is regarded as expressing many self-destructive behaviors, and is the least amenable to preventive education.
In its recommendations on public education, the NAS complains that the present federal education effort is "woefully inadequate" and needs to be "vastly expanded and diversified." In addition to what we mentioned above, the NAS recommends that authorities experiment with removing legal barriers to the sale and possession of needles and syringes, that the Assistant Secretary for Health (U.S. Department of Health and Human Services) be responsible for developing and implementing this massive educational campaign, and that approximately $1 billion be raised from private and public sources to mount this effort.

The other important issues examined by the report that speak to needed public health measures concern those dealing with mandatory screening, voluntary testing, and the use of coercive means in protecting the public health and safety. In general the report eschews compulsory measures and finds, for example, that the mandatory screening of high risk individuals is not "ethically acceptable", and that the decision whether to be tested for HIV infection should be left to the individual. The report opposes mandatory testing of selected high risk groups -- homosexuals, pregnant women, prostitutes -- and sees these measures as discriminatory, impractical and ineffectual. The NAS believes that mandatory premarital testing, for example, would be "inadvisable".
And, as a general policy, children with AIDS should not be prevented from attending regular primary and secondary school classes.

Yet, the report accepts, as a last resort, the compulsory closing of bath houses, as well as the use of compulsory measures in those places where the government has special responsibilities -- prisons, military, mental hospitals -- and in the case of a "recalcitrant individual who refuses repeatedly to desist from dangerous conduct." These measures, however, must be done within the full due process accorded by law.

In contrast to these compulsory measures, the NAS argues for a system of voluntary confidential testing with pre and post-test counseling. The NAS prefers this approach and the public health benefits it offers rather than a strictly anonymous system of testing. However, anonymous testing should be made available if the person so desires. The NAS encourages voluntary testing and advocates for its easy accessibility and use by those who fear they may have come in contact with the virus but are unwilling to be identified to authorities.

Finally, the NAS argues strongly that "discrimination against persons who have AIDS or who are infected with HIV is not justified" and the report advocates laws prohibiting discrimination in employment and housing. The NAS also recommends that representatives of high-risk
groups should be included in the policy-making process and also be part of community counseling and education programs.

Care for Persons with HIV Infection

Attention in this section is directed to an assessment of how the health care system presently is, and could, meet the needs of both health care providers and persons with HIV infection. Thus a range of topics is addressed: the needs of health care providers for HIV education; the systems of health care available and that necessary for desirable level of health care to be achieved; the variety of psychosocial and other needs presented by persons at various stages of HIV infection; ethical issues in providing care; and, the cost and financing of health care to HIV infected persons. It is in this section that the report articulates its most direct proposals for public policy consideration with regard to the planning of those future health care services that will be needed to handle the epidemic.

In its effort to be as comprehensive as possible, the report pushes for a broadly integrated arrangement of health care settings that includes reciprocal and supplementary exchanges between hospitals, outpatient programs and community-based/home care agencies. Given the wide variety of medical, neurological, social, and
psychological needs of these HIV infected individuals as outlined in the report, systems of hospital and community care services need to be developed that can provide the ongoing kinds of care -- in some cases 24-hour a day -- that are required by these individuals and their families and friends. If the health care system is going to gear up for the epidemic then clear and careful planning "is critical". Specifically the report outlines a continuum of services that includes AIDS-dedicated inpatient and outpatient care units in geographical areas with high concentrations of persons with AIDS, as well as the creation of more agencies providing hospice, social work, homemaking, housing and other forms of both professional and volunteer services.

The NAS also identifies a number of ethical issues which effect the nature and quality of health care. Besides those issues which reflect on the conduct of medical research, the report highlights the ethical problems associated with health care providers who for a variety of reasons shun AIDS patients, inappropriately publicize their diagnosis, or refuse to treat these patients altogether. The report clearly asserts that health care professionals have "an ethical obligation not to avoid infected persons or discriminate against them in providing care." In addition, there is strong support expressed for the encouraging of dying persons to
indicate their wishes regarding the course of terminal care treatment. The host of ethical concerns about when to resuscitate or if heroic efforts to continue life should be used, are of upmost importance for those providers and patients affected by this epidemic.

The costs of health care for persons with HIV infection, and the means for meeting those costs, are also extensively discussed. All studies which have reported current estimates and projections of these costs have problems because of the variety of medical conditions associated with HIV infection and as a result of uncertainties mentioned earlier within the model of epidemic growth. Cost estimates per person with AIDS range from $50,000 to $150,000. The wide range is due to differences in data base, methodology, location, and population studied.

Much of the research on cost, according to the NAS does indicate that AIDS is an expensive disease. For AIDS patients, hospital stays are longer, more time is spent in expensive intensive care units, greater staff time and infection control supplies are required, and patients present many medical problems requiring a number of specialists. These greater than average costs, as they are multiplied by the growing list of persons infected, are reflected in the staggering health care costs projections the report puts forth. By 1991 the total cost
of care in that year for persons with AIDS will be anywhere from $8 to $16 billion. And this is a conservative estimate. It doesn't include persons with ARC or with asymptomatic HIV infection but under care, as well as individuals who may still be living with AIDS but whose lives may have been prolonged through experimental therapies.

In its analysis of the public and private mechanisms which fund health care in the United States (private health insurance, Medicaid, and Medicare), the NAS report identifies a number of gaps in coverage for HIV infected individuals, and it argues that many IV drug users who become infected do not have health insurance of any kind. Besides recommending a broad based study of the financing of health care services to HIV infected individuals, the report stresses specifically that a number of policies be considered including state risk pools for high-risk individuals, federal catastrophic insurance, incentives for using cost-effective modes of care, and modifications of current Medicaid reimbursement regulations to meet the actual costs incurred by these patients, as well as to reduce the financial short fall experienced by hospitals when treating AIDS patients.

Future Research Needs

By far the most extensive attention in the entire NAS
The report is accorded to the articulation of what the NAS considers to be the ambitious research agenda necessary to mount an effective campaign against the epidemic. In this regard, the report advocates for an extensive research program directed towards the investigation of: 1) the structure, replication, natural history, and transmission of HIV and related animal viruses; 2) antiviral agents and vaccines; and 3) behavioral and attitudinal factors in the prevention of HIV infection.

The NAS belief in HIV as the primary cause of AIDS is certainly seen in the predominance of research recommended into the nature of this virus. The report calls for continued and intensified basic research into the molecular and virologic aspects of HIV as an "essential adjunct" to applied studies. Knowledge about its genetic structure and protein components, lifecycle stages, replicative mechanisms is quite necessary to the generation of antiviral strategies and agents. More comprehensive understanding, for example, is needed about what constitutes the infectious state with this virus, the relationship of Kaposi's sarcoma to HIV infection, and the connection between HIV and a host of potential endogenous and exogenous cofactors. These questions require information on the multiple and varied effects of HIV infection on the human immune system -- indeed the normal functioning of the human cellular immune system is
still mysterious -- and on the lymphoid and central nervous system if treatment of persons with AIDS is to progress.

To pursue this knowledge and understanding, the NAS recommends a number of basic virologic and epidemiological research directions as well as suggestions on how to facilitate such research. These later suggestions are interesting in themselves. They include the "wide and free distribution" among researchers of viruses, cell-lines and other materials along with information on research results; the broadening of the pool of researchers engaged in AIDS work; more reliable serologic and virologic tests; and the expansion of research facilities, including expensive "biological containment facilities". In the area of epidemiology, the report emphasizes the need for extensive and reliable surveillance and reporting mechanisms. In addition, the NAS recommends that these mechanisms should be supplemented by individual and cohort studies meant to get at more detailed data of the manifestations of HIV infection over time.

In regard to antiviral drugs, the intent of such drug research is to find ways to inhibit the replication of HIV. The report reviews the host of drugs now under clinical study including the well known AZT (Azidothymidine). The problems in the development of
these drugs, as seen by the NAS, goes straight to the core of what constitutes the nature of viral infections, i.e. that these pathogens reproduce themselves within the cells of their host. Thus agents that will eliminate or inhibit their growth also often severely affect the health of the host itself. With HIV there is also the very difficult complication that the virus crosses the blood-brain barrier causing neurological complications that are not easily addressed with these agents.

The NAS recognizes that the development of drug therapy for HIV infection will take time, with no guarantee of success. But there is urgent need for treatment. Consequently, the NAS recommends that a massive, coordinated, rational, scientifically and ethically sound program of research into these drug therapies be mounted. This means random clinical trials using placebo control groups as a way not only to prove effectiveness but also prevent harmful drugs from entering the market.

Even more scientific difficulties are considered by the report when it comes to the discussion of vaccines. Vaccine development faces a diverse, complex, and persistent retrovirus. Experience in animal retrovirus vaccines is depressingly limited and unsuccessful. Thus the NAS believes that a viable vaccine is 5 to 10 years away with its discovery dependent on a greatly expanded
understanding of HIV. While calling for a similar expanded research effort in this area as with antiviral drugs, the report is more critical of the "inadequate federal coordination of vaccine development" and encourages strong federal government leadership in a reorganized vaccine development program under National Institutes of Health. Of specific concern is the need for government incentives and support (including product liability reform) of industrial research. And lastly, the NAS finds it "imperative that ethical and pragmatic problems be addressed simultaneously with scientific ones" in the testing of HIV vaccines.

In contrast to research in the physical sciences, NAS recommendations for social science research are much less concerned with advocating basic research in human behavior and more interested in communications and organizational issues. Thus we see an emphasis on research in AIDS care and prevention stressing educational and informational strategies that are successful in reducing HIV transmission through behavioral change, communication approaches that will limit public fear, apprehension and panic, and research that will promote better health care service system organization and practices for HIV infected persons.

In this latter category of research on institutional practices, the report is concerned about poor access to
health care by persons with AIDS, fragmentation due to professional specialization, hospital management practices which may limit options for care, the burnout of front-line staff, and the day to day difficulties professionals have in dealing with hard to handle patients such as IV drug users. The NAS also wants comparative research in other countries that will generate new ideas for care.

To fund this entire program of new research into AIDS-related physical and social science research, the report recommends that another $1 billion annually be generated in public monies, specifically to be appropriated to the public health service, by 1991. This money is to be new money and not taken from other necessary health care projects. The report justifies this massive outlay by observing that now is the time to put a very high priority on AIDS research, rather than wait to see how bad the problem will become. "If the epidemic worsens dramatically, as is quite conceivable, it may be too late to mount the required effort." 21

International Aspects of AIDS 22

In this final and relatively brief section of the report, the NAS presents a summary of the patterns of the epidemic that affect nations other than the United States and some of the special considerations that these
patterns suggest, and also argues its reasons why the United States should be actively involved in global AIDS control and prevention efforts. As is well known, the face of the epidemic, the people it affects and its prevalence, are different depending upon social, material and biological conditions of the area in which it is found. In Africa, as we indicated earlier, members of both sexes are equally infected, for example. Thus prevention and control programs need to be designed with local conditions in mind if they are to be effective. It is felt strongly by the writers of the report that the U.S. should assist in the promotion of these programs both through aid to international organizations and through bilateral arrangements.

As a foreign policy consideration, U.S. assistance -- primarily financial and technical -- would be a "logical extension" of existing development programs, and without this aid, the spread of HIV infection may in fact work against those programs (such as child immunization programs) that already receive significant U.S. aid. Further, the NAS observes that the United States has "traditionally recognized a responsibility to promote better health world-wide."

Participation is also suggested where the opportunity to engage in "mutually beneficial research" presents itself. This research would not only be of assistance to
peoples of other nations but also to the U.S.'s own domestic AIDS activities.

Not only is it desirable to understand the disease in all its settings, but new knowledge critical to prevention and treatment may be more readily obtained in situations outside the United States. The extent of perinatal and heterosexual transmission in central Africa offers opportunities for U.S. research resources to complement local expertise in mutually beneficial investigations. Only by thoroughly investigating the disease in all its settings will the factors become known that are unique to its occurrence in the United States and other countries.

The world-wide magnitude of the AIDS epidemic requires, according to the report, that the United States "make clear its commitment to global prevention and control of AIDS and HIV infection." That clarity could come in the form of the commitment of resources to this international effort such as the provision of $50 million annually directed towards international research and an increased contribution to the W.H.O. There is also the need for coordination and assessment of the global research activities as well as the opportunity for the U.S. to assist other countries in developing their own national data bases on AIDS.

Summation

As we indicated at the beginning of this chapter, this overview of the NAS report was not meant to be comprehensive, but to give the reader a reasonable familiarity with its content and direction without
attempting to prematurely impose our own analysis upon it. In the next chapter, however, we leave this space, and the comfort of this textual zone, and proceed to one more precarious and full of danger for the theorist. The ground represented behind us is one that is well known, well lit with familiar arguments, well camped by professionals and entrenched in popular histories. The ground before is much less established with few models to guide our inquiry.
NOTES


2 On Gallo's taxonomic politics see Shilts, p.593; For a critical discussion of HIV as cause of AIDS see Peter H. Duesberg, "Retroviruses as Carcinogens and Pathogens: Expectations and Reality", *Cancer Research* 47, March 1, 1987, pp. 1199-1220.


4 "...OTA finds that while the Federal Government has designated AIDS our country's number one health priority, increases in funding specifically for AIDS activities have come at the initiative of Congress, and PHS agencies have had difficulties in planning their AIDS-related activities because of uncertainties over budget and personnel allocations. Furthermore, in some instances, coordination between PHS researchers and between DHHS policymakers and PHS researchers could have been better managed."


8 *Advocate*, December 9, 1986.


11 Cochrane, p. 60; Lapp, pp. 42, 44, 161-163.


13 Shilts, And the Band Played On, p. 360.

14 See generally Confronting AIDS, Chapter 2, pp. 37-83.

15 Ibid., pp. 50-51.

16 Ibid., p. 59.

17 Ibid., see generally Chapter 3, pp. 85-95.

18 Ibid., see generally Chapter 4, pp. 95-135.

19 Ibid., see generally Chapter 5, pp. 139-175.

20 Ibid., see generally Chapter 6, pp. 177-259.

21 Ibid., p. 245.

22 Ibid., see generally Chapter 7, pp. 261-278.

23 Ibid., p. 267.
CHAPTER IV

THE INSCRIPTION OF MEDICAL AUTHORITY

From within the theoretical framework we’ve adopted, we are proposing that medical authority is exercised through the production and reproduction of a discourse that mediates social relations in a way that serves dominant constituencies. In the pursuit of that authority, the discourse must constrain threats and challenges; it must give constituencies a way of speaking through these threats that normalizes authority and power. In this process of pursuit and constraint which the discourse effects, and in turn is an effect, we have sought to locate the phenomenon of surveillance. Part of what we have described as surveillance practices includes the naturalization of authority. In the next two chapters we are concerned with how the NAS report inscribes medical authority into the epidemic through its textual practices. Chapter VI will take up the question
of surveilling identities.

We are directed to the workings of medical authority within the epidemic for obvious reasons: historically medicine has asserted itself into the course of plagues and infectious diseases as a natural part of its duty to protect the flesh. In fulfilling this duty it exercises political power. Yet we are concerned with its practices not so much because this authority requires a number of ideological operations in order to actualize itself, but more because social control has on a broad scale become medicalized. With the shifting of modern social control from the institutional to "the self-administered discipline of minds and bodies in the therapeutic state", as John O'Neil observes, medical authority has become the vehicle for clinicalization and moralization of the problems of order.

The medical model of social control moves the site of our discontents from the streets into our souls. There we find we need more health, more education, and more welfare. Thus the therapeutic state is the modern soul writ large.

Thus the concern with the articulation of medical authority represents not simply the limited politics of a specific societal sector, but a particular expansionary field of representation that has increasingly come to restrict our political response to the demands of dominant power.
The NAS Report and the Promise of Medicine

As a work, and a text, the NAS report trades on both what it articulates directly (in its discursive practices) and what it invokes, often times only through subtle reference, of other major social, cultural and historical narratives which act as 'offstage' meaning makers and sources of legitimation. These two aspects of textual meaning combine into a unity that becomes, through our reading, the voice of the work/text. The work is always interdependent with the broader text to which it gives materiality. In the NAS understanding of AIDS, and in turn, the world it represents, there is established not only the basis of medical authority, but also the system in which it can be maximalized, a world of the real, in other words, which reflects its own vision and centeredness. Authority cannot stand on its own; it must be favorably situated in a social context which constructs its privilege as a natural outgrowth of the real.

One popular cultural text that the report trades on for the construction of its authority is the narrative of western rationalist medicine. As a preface to our discussion then let us state simply what we consider this narrative to be. In the long human history beginning with the activities of Hippocrates, and moving through Aristotle, Galen, to Pasteur, Cury, Salk, and others,
there has emerged a rich, meaningful, and unmatched Western tradition of healing. Through the persistent and strict application of rationalist thinking, and what was to become the scientific method, western medicine has recorded an impressive advancement in basic and clinical knowledge of the body, in the technical procedures and equipment, and in the medicinal substances available to us to aid or substitute for bio-chemical processes. As a result, the profession has developed an increasingly sophisticated capacity to protect the biological integrity of the body from those elements, both self and non-self, which seek its impairment or destruction. This, in turn, has enhanced substantially the ability of its practitioners to alleviate human pain and suffering, delay death, and promote overall physical and mental well-being of the individual. Modern medicine, as the professional progeny of this distinguished history, is viewed as embodying a continuous and progressive scientific process forever unlocking the body’s secrets.

Moving hand in hand with Western civilization, medicine has thus symbolically and literally represented the most noble of purpose, and the highest of human achievements. Of primary importance has been its conquest of infectious diseases, such as syphilis, tuberculosis, and a host of childhood afflictions, that
have visited the human populace since the beginning of
recorded time. At its most intimate level, it is a
narrative of the personal histories of physicians and
scientists -- histories of courage, of hard work, of
intellectual and social drama, in front of which the mass
of humanity stands in awe, respect, and gratitude.3

This narrative in its numerous variations, factive or
fictive, serves both as a representation of the ideal,
and as a description of the real. In this later role, the
narrative provides the ideological basis for the
extension of medical power beyond the boundaries accorded
to it by the expertise it has achieved over the flesh.
The narrative exerts its hold on us through its dramatic
portrayal of the common struggles over the assaults on
the flesh; but there is more. It is a narrative of hope,
of confidence in an impairmentless and pain-free future,
one that caters to our secret aspirations to immortality.
AIDS, with its cureless prognosis, its debilitating pain,
progressive incapacity, and premature death, is a threat
to this comforting narrative. And as a threat to the
narrative, it also threatens medical power, and the
future envisioned by it.

The medical narrative as medical history has its
critics. This criticism takes to task the massive denial
which, by necessity, emerges as a by-product of its use.
It denies, as Ivan Illich argues, any portrayal of the
considerable iatrogenic effects of medical practice, or as others have demonstrated, the class relations embedded in medical practice.\(^4\) There is also the denial of more specific histories when it comes to the area of infectious diseases. As Thomas McKeown observes, the reduction of deaths from the bulk of infectious diseases was not substantially influenced by medical treatment or immunizations, as is so often claimed, but by improvements in the environment such as water purification, sewage disposal, food, hygiene, and better nutrition.\(^5\)

But the narrative's most powerful legitimation source, as well as its most vulnerable modern pathway for critique, is its association with science. The narrative rests heavily on precisely those two great myths of science, which Lyotard tells us have justified institutional philosophy and research since the Enlightenment: that through science we can witness the grand unity of all knowledge, and that through pursuit of science humanity will be liberated.\(^6\) Yet it is the very destabilization of these myths that presently confronts contemporary ways of knowing, and that constitutes the legitimation crisis inherent in it.

The work of the NAS is fully committed to the reproduction of this legitimation narrative for its continued authority. Beyond the immediate context in
which it appears, the work expresses this intertextual relationship in a number of ways: through the particular way it identifies and reproduces the nominating function of medicine as well as the heavy emphasis it places on credentialed and institutional science.

Nominating Authority

To name something, as well as to describe it, and to have that designation recognized and affirmed as the truth of that thing, is to be able to exert some authority over it. From its taxonomic entry into the world of knowledge, AIDS has been secured as a medical product. Afflictions of the body are unquestionably the turf of medicine. What AIDS is, its essence as it were, is the biologic description which NAS articulates: HIV is determined to be its "causative agent", with the "pathogenesis" and "natural history" being expressions of that agent in conjunction with other forces. In the work, cellular reality of AIDS becomes the reality, a reality which, it goes without saying, fits the institutional, disciplinary, and knowledge production activities of those who speak this truth. To reproduce this cellular reality in the American context, and within the authoritative allocations which are textually associated with it, is also to reproduce the power of the U.S. Centers for Disease Control, the institution which
constructed the surveillance definition of AIDS.

In the typical bland prose which matter-of-factly
puts forth these representations, we read:

By the end of 1982, the Centers for Disease
Control had established a surveillance definition
of AIDS that could enable its incidence in the
United States to be monitored . . . This definition
described AIDS as a "reliably diagnosed process that
is at least moderately predictive of a defect in
the cell-mediated immunity occurring in a person
with no known cause for diminished resistance.

The professional and political structures and
authority through which this nomination is secured is
seemingly affirmed and without challenge. Yet, this
confidence is misleading. For example, while there is
substantial support expressed in the report for the
coordinating activities of the World Health Organization
in combating the epidemic, there is no mention of the
W.H.O.'s own clinical definition of AIDS developed in
1985 and now widely in use in a number of Third World
countries. It can be argued that this exclusion frames
the U.S. definition, as well as its institutional
context, as universal. The NAS does admit its
observations are confined to those conditions in the
U.S. But when reading the NAS's summation of reports of
research on AIDS in other countries we are confronted
with the question of whether we are documenting CDC AIDS
or something else.

The differences between the definitions are as
telling as the de-legitimizing impact of the NAS's
silence. The CDC approach was not useful to the experience of other countries. In contrast, the W.H.O.'s definition has been described as "highly specific for adults with AIDS (90%) but relatively insensitive (60%) for HIV infection". It includes a spectrum of easily identifiable conditions which may as a consequent include persons who may not be HIV positive. This reflects the reality of the lack of facilities and diagnostic capabilities of Third World countries. What constitutes the clinical entity of AIDS is as much a representation of the social and political conditions that account for the underdevelopment of health resources, as it is a product of pure science. The important, yet highly technical and reductionistic, cellular reality of AIDS is replaced by more pragmatic and more globally useful reporting criteria given that in either case a cure is not available. Yet since this is a definition which is less exact and precise, less 'scientific', in other words, its value in legitimating medical authority in the West at any rate is limited. By confronting the conventional character of the definitions used to structure Western science, a window is opened by which one can see the role of medicine in the general neglect of the Third World by the West.

The CDC definition of AIDS is very powerful, however, when seen in the context of how it goes beyond the
requirements of public health reporting and scientific articulation, to functioning as a key defining element within a whole host of resource distribution relationships. To produce the linguistic packaging of AIDS within the context of American capitalism, is, in addition, to have produced a commodity for circulation. The power of those constituencies and interests associated with it depends upon the extent of that circulation and the nature of the institutions to which it becomes of central importance. The model of standardization, replicability, exchange efficiency, is the model for knowledge production for capitalism as well as mainstream science. Thus it becomes a potential magnet for industry creation, service careers, expertise, and professional boundaries.

In the systems of reimbursement and treatment that make up mainstream American medicine, the definition of AIDS, and its diagnostic function, act as a critical link between the person with AIDS and a complex and interdependent array of social and financial entitlements, and institutional protections of civil rights. Being so labeled and categorized within this definition determines the eligibility for programs essential to that person's care and quality of life. These programs include Medicaid, Social Security, and the legal protection of the disabled from discrimination.
The power of the nominating authority is directly related to how its definition lines up in the struggle between competing economic interests. For example, within the course of the AIDS epidemic we have seen the expansion of the definition of AIDS move hand in hand in accordance with the battles over a number of important issues for persons with AIDS. One such situation was the push for inclusion of the neurological impairments increasingly associated with AIDS to become part of the official surveillance definition. Once the original definition became incorporated in the discourse of handicapping conditions it entered into a health service economy of well defined competitive interests. With this inclusion a major obstacle would be removed for the determination of social security and other benefits, and in turn, access of medicine to increased reimbursements for services. Thus, the understanding of the political power of this definition rests on how well it serves the mediation of the conflicts of those interests and in what direction. One must be reminded, however, that the definition is allied with partisans in those struggles, and the material benefits that emerge as a result of those battles may be affected by the discursive die that is cast by the definitions.

The NAS portrayal of AIDS affiliates the NAS work
with the historical mission of medicine central to the narrative of promise, that is, to identify, define, and eventually cure pathology. But more important it is the work's relationship to that nominating authority that intrigues us. Although it reproduces the CDC view, the NAS does recognize the difficulties in producing definitions of complex phenomenon. It well understands the difference between the limitations of the language of medical surveillance, and the fluid nature of the physical world, or at least our knowledge about it, which finds much difficulty in keeping itself within the confines of useful definition. In pointing out the differences and problems of surveillance and clinical classification systems, the NAS offers a genealogy of sorts of the historical generation and debatable nature of these language devices. Unlike other medical discourses about AIDS, it does not accept the CDC definition unreflectively and reveals, albeit if only minimally, a problematic history of construction rather than one of mere naming of clear referents. In this examination, the report also judges the ground rules of the AIDS nomenclature, and while in the end it does not seriously contest the CDC definitions, and finds them adequate for now, it recognizes that more needs to be done.

Developing and improving the definitions of AIDS, ARC, and PGL (persistent generalized
lymphadenopathy - author) have been important in understanding the epidemic. However, like other definitions designed for epidemiologic investigation, they are meant to be specific and easy to apply. When used in individual clinical situations, they are somewhat arbitrary and do not fully reflect the morbidity caused by the illnesses associated with them.17

Definitions of AIDS and HIV related conditions "must therefore be applied cautiously." It is in this curious process of review that we see the strategic impact of its textual practice. The work positions itself equal to the nominating authority of the CDC. It views itself as party to that broader authority which creates the boundaries of medicine itself; its relationship to the power to name is intimate. In this subtle caution, the report both confirms the medical authorization of the medical AIDS reality, while simultaneously inserting itself into the political hierarchy that structures the authorship of the disease.

Rhetoric of Credentialed and Institutional Science

Beyond its close affiliation, reproduction and delicate appropriation of the nominating authority of medicine, the NAS work employs a host of strategies that mark the AIDS epidemic as a phenomenon that is situated within the boundaries of institutional medical science. It is a context, one must add, within which the NAS, as a body, exerts considerable influence.18 These strategies include 1) a strong representation of credentialed
authorship, 2) the kind of activities, knowledge, and technologies centered by the report, and 3) the type of constituency expansion and development most advocated.

As already mentioned, both the NAS report itself, and the press reports about it, have sought to reproduce the Academy's high standing within the world of medicine through a directed commentary on its own impressiveness. In addition, one must add the meticulous and detailed presentation and cataloguing of the numerous authors and consultants to the report. The foregrounding of this information both in a prelude to the text and the biographical sketches found in the appendix are testimony both to the effort involved, but more important for our purpose, to the broad authority the work is seeking to achieve over the management forces concerned with the epidemic. By prefacing itself with strong authorship credentials, the work seeks to enlist the reader into a convenant -- as all prefaces and introductions attempt to do -- with that authority. The terms of that authority are understood by the reader far in advance of reading this work; that is, the credentialed authorship resonates with social and cultural emblems that broadly shape the reader's recognition of that power, and become part of the covenant the text desires to establish. For the text to be fully effective, that covenant must be
internalized as an interpretive filter through which the textual material is transmitted. It is only through the success of that covenant to commit the reader to the authority of the text, that the ideological program of emphasis and silence, of inclusion and exclusion, becomes actualized.

Since the report gives us no indication as to who wrote what, what disagreements may have occurred, whose points of view were included or excluded, what levels of expertise, or professional competence were considered more or less important to the major questions at hand, or how textual decisions were made, we are left with the powerful impact of their collective imprimatur as witness to the authority of the work. It is a unity that comes with a price as we will discuss later, but it is a unity that also begs the question as to what value this collective authorship serves for the work.

The question of value is not unlike that asked by Francis FitzGerald in her insightful book America Revised. In this critical reading of American high school social history textbooks, she observes that the relationship between the names of the historians and consultants listed on a textbook, and the work itself, is highly problematic upon investigation. Given the nature of contemporary textbook production and marketing practices, the secrecy of their assemblage, and the
pressures and demands publishers are subjected to,

the text houses often choose . . . specialists
for their prestige or their influence with school
boards rather than their skill in collaborating
on the writing of histories for children. 22

"What all these people actually do on the books", she
goes on to say, "is not entirely clear, but their names
give . . . a certain weight of authority". 23

The extraordinary lengths to which the NAS work
elucidates on its own authorship is telling us something
about the extent to which it must go to empower its
discourse within the modern mechanisms of production of
medical knowledge and authority. It seeks a broad
authority for its statements and recommendations; thus it
has to achieve a broad empowerment of its discourse. But
this authority, the work recognizes, has often less to do
with what is being said than with who is saying it. The
detailing of the distinguished authors, consultants,
their institutional affiliations, academic degrees,
biographies and so on, serve as legitimation strategy
meant to position the work within the hierarchy of
medical, and consequently political power. This also
maintains a connection to the historical narrative of
medical promise and the professional ancestry which has
traditionally delivered on this promise.

But the question we must still ask is how does the
NAS accomplish this legitimation through this particular
strategy? We can discern three effects whose combination
solidifies the powerful presence of the NAS statement. With the help of Foucault and his discussion of the "author-function" as a conceptual framework, we can see the first effect through the understanding that modern authorship reflects the movement of discourse from simply a host of interconnected situated actions, to a commodity, more specifically to a number of commodified and contentious discourses, which exists within a social, legal, administrative environment dominated by concerns over property rights. Thus we are faced with a political economy of professional 'speaking packages' whose 'authority-to-voice' is heavily conditioned by institutional and credentialing practices. Commodified discourse is a property to which a privileged authorship asserts its claim.

This notion of commodified discourse and claims to authorship, we must be reminded, is not just a theoretical gesture borrowed from Foucault or Marx to suit our arguments. On the contrary, and especially with regard to the AIDS epidemic, it is a very real frame for understanding the struggles of power within modern capitalist society. For example, with the increasing commercialization and high profit potential of biomedical research, and especially that of molecular biology -- a field of immense consequence to persons with AIDS and the search for viable drug treatments or
vaccines -- there are increasing legal and political battles over control of knowledge which have had serious effects on the free exchange of information. As Dorothy Nelkin observes, even "ideas themselves have increasingly become a focus of intellectual property disputes."25

The NAS authorship strategy asserts in no uncertain terms its claims to ownership of the 'AIDS turf' in the battle over control of the research, care, and prevention agenda. Through its amassing of the authorized speakers of those discourses which frame the structure of the health industry, it seeks to signify not only the personal recognition of the NAS leadership, that is, of the authors themselves, but also the disciplinary recognition as well. Even in the face of disciplinary competition, this collection, put forth as it is without dissent, trades on the myth of the unity of science which Lyotard argues is one of the most effective legitimation devices.26 Through this unity, the NAS work positions itself as the knowledgeable owner and speaker of the AIDS phenomenon.

Second, and related to our first point, the extensive listing of authorship reflects the modern construction of power of the health and illness industry in a way that addresses the authority considerations that are necessitated by the AIDS epidemic. It reflects the multiplicity of spoken and unspoken arrangements,
professional agreements, disciplinary boundaries, that are a structured part of the modern American health scene: an industry pressed into service by an epidemic whose medical and social demands cross a densely articulated, negotiated and re-negotiated frontier of competitive human services and professions. These names are symbols of treaties, in effect, between what Robert Alford calls the "structural interests" that make up the health care delivery system in the United States (interests, it must be noted, which have typically offered innumerable barriers to health care reform).²⁷

To one familiar with the constant struggles between these interests, the authorship listing can be seen as a major coming together of typically antagonistic parties. We see in the host of contributors and consultants, not only a number of medical specialties, but political representations from the areas of public health, economics, law, ethics, public policy, and other disciplines and corporate interests. The author-function here serves as the insignias of these arrangements and boundaries, and consequently, as a political code to both the broad professional audience the report courts, and the public at large whose support it seeks to mobilize. And it is also this aspect of the NAS report that marks it as particularly American and Western. The corporatization of American medicine, in both the
specific and general meaning of that word, means a public front of denial of those struggles which contest these authority arrangements, and a political strategy of an anti-politics image. The result is that in this denial the work expands to a broader interdisciplinary, professional, and social level the same political problems to gaining public power that medicine has experienced throughout its own history: How to contend with the competitive demands of medical specialties whose divisiveness threatens to reduce medicine to stasis. As Alford observes,

The professions face the political dilemma of maintaining a united front viv-a-vis outside threats and at the same time finding some viable method of dividing up the body and the spoils among themselves. The more they squabble . . . the more they expose to the general public the mundane origins of the allegedly scientific basis for specialties. However, the more they maintain a united front, the more the technical and administrative basis for specialty dominance becomes reinforced.

Finally, the listing of the experts attempts to overcome, and this is our third point, the anonymity of authorship in scientific discourse. The author functions in scientific discourse, not as authority, as Foucault points out, but as handy reference to a theory, point of view, specialty concerns and the like rather than a validation of the discourse itself. This anonymity has to be broken through if the NAS is to establish its work as a "marked" or "proven" discourse, one in which
authorship validates the truth of what is being said.\textsuperscript{31} This authority-by-numbers is a difficult approach, but an understandable strategy given the large numbers of researchers, science writers and others who are already seeking to authoritatively speak about AIDS, the often technical and complex nature of the material, as well as the fragmentation and chaos of the debate, and the general suspicion of those who make their voices heard. But as witnessed by the press reports mentioned earlier, the blast of this collective authorship broke through the faceless image of modern medical science with its many inaccessible and conflicting voices, and the report speaks remarkably with a singularity of purpose and direction that, together with the trappings of institutional medicine, combine into a powerful construction and assertion of authority.

Again we ask the question of how the NAS report goes about gathering authority through its association with the medical narrative. One answer lies in the kinds of activities, knowledge and technologies it centers. To say the obvious is to state that the report focuses on the activities of a range of medical scientists -- immunologists, virologists, epidemiologists, neurologists, dermatologists, and a host of other clinical and basic research medical disciplines. The technologies and
knowledge base discussed in the report follow the standard disciplinary orientations to scientific inquiry, lab procedures generally agreed upon as valid and replicable, a common geography of the body and blood, and a common methodology for scientific inquiry. All of this is reflected in the heavy clinical and bio-science orientation to the various chapters and the resulting recommendations put forth by the work. The report concentrates on questions of cell-mediated immunity, the continued clarification of the pathogenesis and natural history of HIV, the identification of host co-factors that may effect viral production, the continued deliniation of routes of transmission, as well as basic epidemiological research on incidence and prevalence of infection within various targeted populations.

Social science considerations are similarly oriented in that they are directed toward behavioral changes regarding sexual practice, attitudinal studies which are designed to facilitate prevention efforts, and health service design research meant to provide direction for the construction of a service delivery system in response to the needs of persons with HIV infection. Social science research funding is advocated to support these various projects, and cost issues are also similarly addressed in research terms. The report recommends studying the fiscal burden of the epidemic as it relates
to the cost of care relative to the complex structure of health services and reimbursement mechanisms in the U.S.\textsuperscript{32}

But it is not our strategy to simply state the obvious, of course, but to understand how the obvious contributes, or not, to the attempt by the work to accumulate and assert medical authority. In this sense the centering of science activities has three effects that work to legitimate its connection to the medical narrative. The first is in the general production of a dominant, overdetermined epistemology, one in which the ways of knowing and speaking the epidemic are restricted within very rigid theoretical paradigms (disciplinary parameters in Foucault's sense of the term) which validate the authority of those who work within its boundaries. Thus the unproblematic understanding of what constitutes science in this work articulates well with the universalist, transhistorical, transcultural, model of knowledge inherent in the narrative. It is rationalist, specific, technical, and efficient. And one can argue, that as a model for knowledge building within the narrow areas of body chemistry and genetic manipulation, it is a model of tremendous efficacy and potential. The problem is that this model becomes less and less useful and universal as it enters into the "human sciences", the area of human preception,
interpretation, values, language, culture etc, where the reading of the meaning of behavior is the center of activity. Thus social science research, for example, as it is seen as an adjunct to medicine --identifying attitudes, evaluating programs, tracking social practices, specifying behaviors of target groups and other such efforts -- at the very least is relegated to a disciplinary practice that denies the rather arbitrary, strategic, and relative process of meaning-making described earlier in this dissertation.33

Again, these social science activities, in themselves are worthy endeavors and are of much public value. The point is, however, that the normalized model of knowledge building assumed in the report constrains the legitimacy of other kinds of inquiries into the meaning of the epidemic that do not fit with the model. More important, it places the knowledge boundaries of credible inquiry into the epidemic within the established authority structures of medicine and its legitimating narrative. Medical science has set the epistemological ground rule for speaking AIDS in its setting of the model of truth, and the NAS report articulates the dimensions of hierarchy of knowledge in its constructions of the information needs of the epidemic.34

Second, the centered activities of institutional and academic scientists, and its dispatching, as Shapiro
calls it, of a "house epistemology", contributes to the construction of an official history of the epidemic which works in tandem with the history of progressive enlightenment through rational science offered by the narrative. The NAS work presents a version of the epidemic over time that is parallel to medicine's own activities, as those activities are seen in a particular way. The epidemic "begins" with the official reporting of the discovery of symptomatic gay men in 1981, and is subsequently narrated as a series of orderly and continuous research discoveries, a series of scientific episodes, establishing critical linkages and pieces of knowledge that together are moving medicine towards the cure and prevention of AIDS.35

The medical history of the epidemic is definitely not seen as a collection of fragmented, discontinuous, chaotic happenings within a field of competitive and secretive knowledge-producing practices, a collection of chance meetings, idiosyncratic memory recalls, political subterfuge, and professional sabotage.36 In other words, the history offered by the work is a history that speaks to the political agenda of the text in establishing its authority. As part of that agenda, it avoids the risk of alienating any sector of the coalition of disciplinary and professional interests that marks that power. It is a politicizing history, in the sense of maintaining the
constellation of professional assent to its authority; and it is also a depoliticizing history to the extent that, in order to accomplish the first task, it must exclude tremendous amounts of material which contest that orthodox historical interpretation, an interpretation which is in service to its power claims. We will come back to this depoliticizing aspect of the NAS report in the next chapter.

Third, the centering of credentialed and institutional scientific activity, and indeed the result of all the activities noted above, establishes a base of support for a crucial claim of the work, and a claim for medicine in general, that is, the assertion of the legitimacy of its control over the mechanics and distribution of medical knowledge. Within the NAS work, the claim comes in the form of a rebuke of the media coverage of the epidemic, a move which asserts in one gesture the symbolic conditions which make regulation necessary, and an assent to the normalization of that regulation.

AIDS sufferers can obtain much information about the prospects for new treatments from the lay press alone. Yet the media have sometimes provided a distorted view of hopes of success. This tendency unfortunately is abetted by the inclination of some scientist to herald results of clinical trials prematurely, sometimes in forums outside the mechanism of peer-reviewed journals.

Despite the criminality evoked by "abetted" or the
deliberate misrepresentation signaled by "distorted", the claim is made unremarkable by the casualness of its textual presentation. Yet, this is no small claim one must be reminded, when we consider the dominant position medicine occupies in the regulatory apparatus overseeing the management and constitution of sickness as it relates to obligations of material production, as well as the extensive catchment of medicalized phenomena falling under its disciplinary umbrella. This claim is also a vital part of the authority asserted by the NAS work since again it is one that legitimates the area of circulating power in which the NAS is a major player; and, one, if allowed full expression, which exerts power over a considerable discursive territory when it comes to the AIDS epidemic in particular.

In the production of medical scientific information in the U.S. regarding AIDS, there are only a dozen or so American and international journals which have provided the bulk of clinical and laboratory data commonly used by professional and public audiences. These peer-reviewed journals are arguably the quality-control mechanisms in the production of commodified scientific discourse. In professional medicine, however, they are also, among other things, the entry points in the researcher's personal journey towards institutional recognition, the makers and breakers of scientific
careers, the facilitators of grants, awards, academic appointments, and avenues to a host of other professional benefits and entitlements. This aspect of making medical science is witnessed within the AIDS epidemic although not recognized by the NAS work. Competition for journal publication of AIDS research has led to the delaying and withholding of potentially life saving information, the infusion of tension and greed into scholarly exchange, and deliberate positioning and imaging by journals themselves that have resulted in the sensationalizing of their reporting.

The regulation of medical knowledge through control over its publications presents a site as well as a spectrum of activity where textual practices converge with institutional practices to declare the terms of power. They function, therefore, as markers of accumulating disciplinary influence and as such, are a critical component in the political economy of professional dominance. Prestigious journals especially, are the sites where knowledge and text turn into palpable power: where knowledge games are seriously played out. Because of this, these journals often constitute more than the enactment of the professional search for truth. They are arenas of important disciplinary political and ideological struggle. By failing to recognize or admit to this struggle the NAS,
in effect, represents institutional medicine as a respite from politics, a position closely aligned with the narrative of scientific medicine.

The identification with institutional medicine is further articulated through the NAS work in two distinct ways: first through the bureaucracies, functions, agencies, professions that are put forth as necessary elements in the battle against AIDS, and second the position of medical authority in relation to these forces. As one would expect, the report calls for major expansions of medical research, treatment and care programs, academic and corporate collaboration, serologic testing facilities, increased experimental animal stocks, and supportive financing schemes. The medical industry is the primary sector of growth being promoted. Calls for housing support and other "non-medical" community care programs for persons with AIDS are certainly heard. However, the overall detailing of recommendations, and the specificity and preponderance of named projects, rest in service to expanding medicine's own capacities and resources for dealing with the epidemic.

Concessions to other than the purely clinical demands of the epidemic reflect again, not only the social impact of this disease, but the complicated nature of modern
medical authority and the political and textual strategies required to maintain it. This is especially true when we examine the structuring of "leadership" in the report. The NAS calls for strong "presidential leadership" to designate AIDS as a national priority and insure sufficient resources are made available. It also recommends the creation of a national commission (advisory only), the coordination of all governmental agencies whose functions have anything to do with the epidemic, and the appointing of an Assistant Secretary of Health to coordinate government public health education efforts in line with the goals of the report.45

But how do these arrangement relate to medical authority? The emphasis in the report is clearly on the effecting of maximum coordination, facilitation, and the efficiency of doing the tasks that are seen as needing to be done. It is a delegation of sorts, a structuring of an exogenous power relationship, where authority concerning the goals remains located outside the positions of official leadership. Leadership becomes mechanism not source. The source of legitimation and authority over the epidemic is retained by scientific medicine and not public decision makers. Thus the report does not favor a possible "centralized directorate", argues against the commission having authority to dispense funds, and encourages Congress to maintain its
"strong interest" in the epidemic by insuring sufficient federal funds. It is obvious that the Congress's role is to balance the Reagan administration's resistance to AIDS funding. But of this agenda we are told nothing.)

The leadership structure advocated is one of a coordinated governmental effort under a fragmented governmental authority. Yet this strategy is more than simply a response to the battles surrounding AIDS, that is, a response that attempts to position AIDS favorably within the major contending influential forces of right and left that dominate national politics, or one that hopes to address the particularly decentralized federalist structure of government responsibility for health services. Certainly, to the extent that this positioning and construction of the disease circulates well among the dominant players, medical authority is once again reinforced. But it is also a structure that works well with the complexity of disciplinary forces that make up medical authority. While it is true, as the report points out, that no particular group can provide the total solution to the epidemic, it is also true that no single profession or specialty can now represent the entire health industry. It is this internal coalition politics, and its relations to the rest of the political world, that the work mediates, and it is this particular structuration of medical power the text reproduces.
NOTES


2 Ibid., p.355.

3 Rene Dubois, in his Mirage of Health (New York: Harper, 1959) traces the history of this narrative and its various symbolic oscillations between the myths of Hygeia and Asclepius.

"For the worshipers of Hygeia, health is the natural order of things, a positive attribute to which men are entitled if they govern their lives wisely. According to them the most important function of medicine is to discover and teach natural laws which will ensure to man a healthy mind in a healthy body. More skeptical or wiser in the ways of the world, the followers of Aesclepius believe that the chief role of the physician is to treat disease, to restore health by correcting any imperfection caused by the accidents of birth or of life." (pp. 110-111)

For example, the fascination with Rousseau's noble savage and its correlate in the return to nature orientation of the personal health regimens and literature dominated 18th century thinking about what constituted the medical utopia of health and happiness. Eventually this was met with the brutal occupational hazards of industrial development, the incision of Darwin into intellectual thought, and the emergence of the germ theory of disease, all of which push popular mythmaking to seek refuge in the promise of medical science. (See Dubois, pp. 1-25)


8 Ibid., p. 37.


11 Confronting AIDS, p.46.


13 For a good discussion of the relation of health to underdevelopment see Lesley Doyal, The Political Economy of Health (Boston: South End Press, 1981); For a discussion of AIDS and development see AIDS and the Third World (Washington D.C.) The Panos Institute, Dossier no. 1, Chapter 5.


16 See Confronting AIDS, pp. 64-65.

17 Ibid., p.38.

18 For discussion of the elite status of the Academy and influence on funding see Anton G.Jackson, Scientific Policy Making in the United States (Southern Illinois University Press, 1971), p.43; and Lapp, p.42.

19 Confronting AIDS, pp. iii-iv, 339-352. There were over 30 co-authors and consultants to the Academy's report, plus staff, and numerous papers commissioned.

20 This idea of the reader's covenant with the writer comes from John O'Neil, Essaying Montaigne (London: Routledge & Kegan Paul, 1982), pp.4,9.

21 Francis FitzGerald, America Revised (New York:
22 Ibid., p.22.
23 Ibid., p.23.
26 Lyotard, p.37.
28 The corporatization of health care has led to an increasing complexity of medical authority while exerting more pressure to maintain unity. Starr points to this complexity in his discussion of hospitals. Corporate hospitals have started "unbundling" their services in one direction and "rebundling" them in conjunction with services in other sectors of the health industry. Thus while a hospital may be deconstructing its traditionally unprofitable services and contracting them out to the private vendors, it is also reconstituting itself with interests and organizations owed by the corporation with which before the hospital had only a distant relation. [See Paul Starr, The Social Transformation of Medicine (New York: Basic Books, 1982), pp. 538-439] This makes for a broader and shifting basis for medical authority, and consequently more difficult to express dissident views. The same effect is seen with the movement of physicians from independent practitioners to corporate employees.
29 Alford, p. 198.
30 Foucault, "What is an Author", p. 126.
31 Ibid.
32 Confronting AIDS, see pp. 155-173.
33 Ibid., p.238
34 The hierarchy of knowledge is reflected in the prioritization and structuring of research needs
into basic research, natural history, social science etc. (see summary pp.23-31) It is the embodiment of a realistic science that suffers no philosophy.

35 See Confronting AIDS, Chapter 2.

36 See generally Randy Shilts, And the Band Played On (New York: St. Martin's Press, 1987) account of the events leading to the initial recognition and early specification of dimensions. (pp 53-102); see also his account of the scientific backstabbing and glory grabbing accompanying Robert Gallo's contribution to AIDS research.(see pp. 366-367, 371-372, 592-593)

37 Confronting AIDS, pp. 99-100.


40 "... many medical experts worry that this single journal, and perhaps a handful of others, exercises undue power over the flow of information on medical research. It is information that influences government policy, promotions, careers, financial markets, science policy, grants and, not least, the treatments of patients."


41 Shilts, And the Band Played On. See account of the New England Journal of Medicine, and other publications, and their delays in printing critical information about AIDS. (see pp. 63, 67, 124, 172.) Also see his account of sensationalism exercised by the Journal of the American Medical Association regarding AIDS. (see pp.330-301)


43 Confronting AIDS, pp. 33-35.
44 Ibid., pp. 141-146.
45 Ibid., pp. 31-33, 111.
46 Ibid., pp. 32-33.
CHAPTER V

DEPOLITICIZATION AS TEXTUAL STRATEGY

It is our contention that the NAS work engages in a systematic and strategic practice of depoliticization as a surveillance mechanism for both advancing medical authority over the epidemic (within the broader circles of national power), and as a way to satisfy the contending professional and corporate interests which make up the basis of that authority itself. Medical discourse is a vehicle for both extending and legitimating medical authority beyond the borders of medicine and for controlling the divisiveness and fragmentation within medicine's own ranks. It is important to remember that the NAS work seeks a very broad and compelling authority. Consequently the nature and extent of depoliticization is critical from the point of view of understanding the political meaning and ideological processes related to the social construction of the AIDS epidemic.
We realize that in examining the depoliticization of the work, any work really, a certain caution must be exercised. While primarily concerned with the depoliticizing impact of textual practice, the degree of silence imposed by a work is relative to the potential degrees of politicization possible given the historical circumstances, events, and the availability of alternative ways of talking within the discursive economy. Therefore, a judicious sense of relevant possibilities must enter into the critical reading of the work.

However, we are not so much concerned with the conscious intentions or awareness of the authors, but rather how and if depoliticizing strategies are sedimented into discourse, and how they allow for the circulation of certain kinds of power and authority.

Several textual strategies of depoliticization are discernable in the NAS work. They range from 1) the most obvious exclusions of important political histories relevant to the epidemic and the prevention of HIV infection; 2) to a rhetorical style and form of argumentation that attempts to structure the reader's response in favor of medical authority; 3) to the encoding of symbolic and potentially politicizing material in ways that preclude any transformational impact. Each of these strategies seeks to contain the threats to medical authority that the epidemic presents.
through representations that place them within the social and disciplinary order structured by and around medical authority.

**Producing the Historical Gloss**

The representation of official medical history of the epidemic by the NAS work excludes, as we have argued, an overall conception of historical process that testifies to the chaos, disorderliness, and the role of chance and struggle in human experience. This is clear in the portrayal of the course of scientific research. History is 'essentialized' into disembodied explanatory connections that move in a relatively unproblematic fashion from one research or clinical event to another. Controversy is between different theoretical implications and not between persons. This sense of consensus history fits well with the medical narrative and legitimates that authority because it doubles as a representation of the embodied or political history of medicine (and its role in the AIDS epidemic) as well. Legitimation of the authority is effected when the uncertainty and fearfulness inherent in human experience are compared to the secure and orderly representations offered through the medical narrative. The history constructed by the NAS report is thus a gloss that serves the power agendas of the work.
But the production of the gloss requires the active subjugation of embodied political histories that reveal the role of power in the construction of scientific medical knowledge. The AIDS epidemic poses no exception. The major histories of AIDS excluded by the NAS work are those that contest or call to question the predominant bio-explanatory discourse of AIDS, those histories that detail the activities of scientists who forsake the pursuits of truth for those of glory, and histories of major scandal which call into question the integrity of medical authority itself. While it is not our intention to render an exhaustive account of these histories, examples of each will serve to show the extent of depoliticization to which the work is committed.

In the course of the AIDS epidemic, a number of scientific controversies have arisen that contest the dominant view of the limited range of transmissions possibilities of HIV, or have even doubted the pivotal role of HIV as the causal agent of the immune incapacitites that lead to subsequent opportunistic infection or cancer, and death. One of these includes the possible role of insects in the transmission of the virus. On this the NAS report is clear.

There is no evidence to support the hypothesis of HIV transmission by insect vectors. . . Not withstanding a report that regions in DNA of various insects from central Africa are homologous with HIV proviral DNA. . . other sources of data suggests that vector borne or casual transmission is
unlikely... [The] relative inefficiency of accidental needlestick transmission, the relatively small volume of blood carried by most common vectors such as mosquitoes, and the low blood titer of HIV all suggests that mechanical transmission by insects is unlikely (sic).

End of story. No recommendations are forthcoming for further research. Yet every point made by the NAS is, at the very least, highly debatable. For example, on the issue of needle sticks, some researchers argue that one time needle sticks of healthy health-care workers can’t be compared to the continual exposure to insects experienced by the malnourished, immunocompromised people in the tropics, for whom a hundred bites a day, some on broken skin, are not unusual.

But the NAS statement more than just flattens intellectual debate. This rather benign, and seemingly reasonable representation of opinion and consensus, is also misleading since it masks a long, and often bitter, scientific and political dispute among AIDS scientists that reflects the contentious underbelly of medical authority. The dimensions of this dispute touch the core of institutional medicine’s legitimation through science. Accusations of faulty science, name calling, bureaucratic incompetence, the low institutional status of arbovirology, have all been invoked over this issue. There is also the sense that official medicine reflects the domination of First World considerations over those of the Third World for whom insect transmission of disease is a powerful experience of everyday survival.
While none of the dissident scientists are saying that insect transmission represents a present major route of infection, there is the future to be concerned about. Should the epidemic reach some point of critical mass, and become concentrated in those areas where disease transmitting insects thrive, the question of insects becoming part of the chain of transmission due to more frequent contact with contaminated blood is a serious one. However, the NAS work with its narrow reading of the evidence, and its silencing of the contentious discourse about this issue, denies this risk, and thus the efforts and resources needed to adequately address it.

Another depoliticizing practice is that related to the determination of HIV as the "causative agent" of AIDS. Infection by HIV is argued to result in a "wide range of adverse immunologic and clinical conditions". And evidence is amassed in the report to support that basic relationship. The report readily admits to the need for more research in a number of areas relating to the activity and nature of the virus, and thus to a potential treatment or vaccine. This is particularly evident in the discussion on the lack of evidence regarding cofactors -- "environmental agents, genetic influences, or coexisting infectious diseases" -- which may increase the potential for HIV infection or clinical
disease. The general understanding of the central role of HIV, however, is uncontested in the text. Certainly medical authority over the epidemic at this point rests heavily on the discovery of this retrovirus, and the consensus over its critical significance for AIDS.

Yet again, the NAS work excludes histories in the interpretation of evidence that contest this central thesis. These are both histories of intellectual skepticism that emerge from the early days of the epidemic and still continue, as well as histories of professional and institutional struggles that lie beneath the ascendancy of HIV as causal agent, and call into question the relation of power to that scientific determination. And we must add, these are hidden histories (often sequestered in gossip) which are only now being recovered and written. Several of these are worth briefly reviewing.

General skepticism of HIV as causal agent has always been present since it was first hypothesized that retroviruses may play a part in the disease process. Early on in the epidemic wide-ranging speculation on causation was heard concerning "immune overload" or the effects of inhalants, or the role of CMV and other biological and environmental scenarios. With the announcement of HIV as the cause of AIDS by Robert Gallo in late 1983, and the accumulation of evidence supporting
the association of HIV with AIDS, theories of causation began, for the most part, to circle around the contributing factors to the central deadly work of this virus. Yet there has always been a questioning of this, now taken-for-granted scientific fact. The most recent and most articulate point man for the generalist attack has been Peter Duesberg, a leading virologist, who argues that the association of the virus with AIDS does not mean "cause". For a host of reasons, Duesberg concludes after a lengthy examination of scientific arguments, that while HIV is a useful indicator of contaminated sera that may cause AIDS,

it seems likely that AIDS virus is just the most common among the occupational viral infections of AIDS patients rather than the cause. . . [Thus] the AIDS virus is not sufficient to cause AIDS and that there is no evidence besides its presence in a latent form, that it is necessary for AIDS.10

The kind of criticism offered by Duesberg has a long and honored place in the history of the study of microorganisms. Concerns over whether microbes were the cause or merely associated with human disease have been a critical aspect of the medical debate about infectious diseases since the emergence of the germ theory after 1850.11 Because of the invisibility of viruses until recent times, these sub-microscopic particles of life have always been a "creature of reason".12 Important to understanding their contribution to disease, thus, has not only been the mechanics of their relationship to
human physiology, but also theoretical quandries of what constituted cause and effect within their universe. The traditional pragmatic representation of that causal relationship within virology, the Koch postulates, have been unfullfilled when it comes to HIV according to Duesberg. 13 This critical contradiction is unexplored in the NAS report.

Specific criticisms of the HIV-as-cause theory have come in regard to investigations of the relation of other diseases, e.g. syphilis, to AIDS. To some experts, syphilis is masked in HIV infected people. They observe that the epidemic may, in fact, be a new manifestation of syphilis, and HIV "an artifact of syphilis-related immuno-suppression."14 Again, the debate and history of exchange on this topic is a heated one with accusations of incompetence traded among the several parties involved. The focus on syphilis is the "height of folly" and "completely unwarranted" by one respected scientist, while another on the other side of the issue asks "How do we know?" and emphasizes the unreliability of testing results (for syphilis) in AIDS patients.15

The NAS report reflects none of this ambiguity or controversy either in the case of the general critique or in the case of syphilis. Syphilis is only narrowly reported as associated with persons with AIDS or as a possible risk factor for HIV infection.16 But the debate
is far from over and not without potential real impact. As one observer notes,

One effect of this adulation of HIV is partly that research funding and effort is wasted on what could be just a benign passenger virus. But the more important result is that promising lines of inquiry -- such as research into transglutaminase, an immuno-suppressive enzyme that may be responsible for the immune suppresion characteristic of AIDS; the possibility that AIDS is caused by a variant of the African Swine Fever Virus; and the alleged relationship between AIDS and syphilis -- are not funded, or not allowed space in medical journals, or both.17

The scientific history of the epidemic produced by the NAS report neglects not only portrayals of the intellectual controversies which call into question the confidence of its claims of fact, but also the scientific intrigue and warfare which have characterized the epidemic since its initial recognition in 1981. The report makes this social knowledge unremarkable in a context in which they have played a rather large part in the production of AIDS science. The meaning and credibility of scientific information are inseparable from some recognition and understanding of the context of this struggle from which it has emerged. Again, it is not our intention to present a detailed rendering of these histories, but only to suggest the extent to which their exclusion depoliticizes the NAS text, and the representations of the epidemic offered by it.

To summarize several of these 'in-house' struggles,
we can point to the international political and legal conflicts between French and American researchers (and their governments) over "who" discovered the virus, the subsequent battle over the taxonomic designation of the AIDS virus and the emergence of the 'compromise' candidate known as HIV. There has also been the accompanying accusations of viral pilfering, intellectual sabotage, and character assassination leveled against prominent members of the AIDS research community. Further, we have witnessed the hoarding of critical biological material (such as cell lines) as a strategy to exclude scientific competition, and the particularly virulent nature of overall institutional hostilities within the official medical bureaucracy over control of the AIDS turf.18

The effect of these histories within the NAS report would be to document both the complicity of medicine in the exacerbation of the epidemic, as well as the political nature of its scientific repertoire. It would be to place politics within the very essence of medicine, to make power intimate with medical authority. The submergence of these histories, however, has compelled a form of mythmaking that keeps politics at a distance, outside its door as it were. Yet it is also clear that these exclusions have had implications for the direction of scientific inquiry into the epidemic, and the
responses of the health care delivery system, the consequences of which in the past have meant the loss of lives.19

Rhetorical Style and Authority

The rhetorical style of the report and its form of argumentation must also be considered as a potential legitimizing strategy for medical authority, and thus worth our consideration. We must ask how well does this textual presentation serve the ideological agenda of power within this particular context?

One aspect worth noting immediately is the tone of the work. In what is one of the most oft quoted, and considered highly political charges of the NAS, we read:

The present level of AIDS-related education is woefully inadequate. It must be vastly expanded and diversified, targeted not only at the general public but at specific subgroups, such as those in which significant transmission can be anticipated, those in a position to influence public opinion, and those who interact with infected individuals.20

This "devastating" critique, and one that creates a real "sense of urgency" as the press commented, is, in fact, a rather dry and dispassionate plaint.21 The tone, typical throughout the report, reflects little outrage, is empty of emotional excess or appeal, and is tightly specific and controlled. The report’s tone is part of the overall rhetorical structure: it is a planned, utilitarian and efficient discourse with a measured
cadence, and exhibiting a learned confidence over complexity. There is a certainty in its prose even in the face of ambiguity and ignorance. Although we may not know the answers, the questions are made clear enough as in this comment on HIV infection and its effects on the human immune system:

The factors that determine the initiation of this immunologic decline, the rate of its progression, and its ultimate outcome are unknown. While it is possible that specific strains of HIV may be particularly pathogenic, or have proclivities to induce specific types of immunologic or neurologic pathology, such correlations have yet to become evident.  

The world is made up of probabilistic orders, orders that within the accommodating context of the report's passive voice, "have yet to become evident." But what is the effect of this report-like prose, of its affectively-blunted, non-provocative, and orderly language? It is clearly an 'orderly' language in both the sense of its stylistic structure of explanatory detail, and in the social order it seeks to reinforce.

Yet, more important, the work articulates a language which normalizes its authority. It accomplishes this by first meeting the demands of that complex, contradictory, and coalitional authority through its very placid, reasonable, centrist, and unremarkable linguistic politics. By this we mean that its tone reflects little of the frustration, struggle, anger, suffering, fear, condemnation, and sadness that makes the epidemic a human
experience. Its disembodied and depoliticized tone alienates no one, speaks to no one, feels for no one, and accuses no one. As the hard edges are blurred, the text is 'sensitized' and authority is normalized precisely because its components can be encompassed easily within its discourse. The familiar tone provides assurances that all is within the boundaries of established patterns of control; it does not seek to make strange, complicit or problematical, the present construction of medical order.

This rhetorical style stands in high contrast to an epidemic narrative invoked by the work that is constituted through varying accounts of irrationality, hysteria, fear run rampant, unbridled emotional expression, and violence, all induced by the presence of the plague. It is a narrative that arises both from the experience with AIDS but more from a collective tradition kept alive in medical histories, stories, literature, films and other avenues of popular culture. For example, as we previously mentioned, infection through rape seems a constant theme of this literature. In Camus's, The Plague:

One of them [a plague story] was about a man with all the symptoms and running a high fever who dashed out into the street, flung himself on the first women he met, and embraced her, yelling that he'd "got it." 23

It is the cut of these kinds of at-large images that are brought to bear on our understanding of the epidemic
and the necessity of medical authority. According to the report there is "an alarming degree of misinformation" that fuels an atmosphere of "hysteria and irrational fear". To combat all this we need a "level-headed" attitude and the leadership of a network of people "firmly grounded in the facts of the disease."24 The instrumentalist and rationalist reasoning and its rhetorical strategy -- the measured cadence, lack of expressive language, passive voice, affectless response to injustice -- identified with medical authority in the work is juxtaposed to the plague as represented by its very opposite. But we must add that it is never medicine which is unreasonable, irrational, or acting from fear or fright. Thus, the capturing of the rationality text by the report, and the subtle yet undeniable reference in the report to the epidemic narrative, articulates medical authority as a defense against the image of public hysteria portended by the popular narrative.

The rhetorical familiarity of the text is also key to understanding the normalization of medical authority over the epidemic when the language of the work is considered as a reflection of its intertextual utility. The tone is equivalent to the work's status as a "report". This situates the work as part of a professional genre that exchanges well with those works of planning, policy, service coordination, management, business, trade, and
academia. Fictional and even journalistic accounts would not be legitimate in this arena no matter how well they represented the problem to be solved. As part of policy making, the work is a part of those privileged discourses which form the 'class-speak' of American politics.

The authority of the NAS work rests in part on its very ability to attract and dispense mutually legitimating authorizations that circulate within this textual milieu. This is especially true when the subject is more loosely tied to its purely scientific concerns. The NAS work excels in this regard since it deals extensively with the system of service planning, development and coordination necessary to meet the medical needs of the person with AIDS. The modern language of established science moves easily within the business end of the production and financing of medical services. 25

In addition, the rhetorical strategy of absorbency is dependent upon argumentation that is at times highly equivocal, that at other times participates in the structuring of its own demise, and that often uses conceptual dichotomies sympathetic to its power aspirations. Political equivocation, for example, is in the work's explanation of why mounting a national response to AIDS has been so difficult. A listing of reasons includes lack of funds for services, commercial
disincentives, reluctance due to stigma associated with persons who have AIDS, uncertain federal responsibilities, and others. What is striking about this rationale is the both the ease with which one can honorably displace responsibility for inaction, and the absence of identified faces (accountable agencies, leaders, policies etc.) connected with these problems. To paraphrase Francis FitzGerald, these problems are mystified: they come from out of nowhere, are perpetrated by no one, and everyone is interested in solving them. These are "authorless crimes" that are the result of "sideless conflicts."  

An example of arguments that exhibit the seeds of their own destruction would be the discussion on the critical issue of mandatory screening for HIV infection among selected subgroups (i.e. IV drug users, prisoners, homosexuals, prostitutes etc.). Here the NAS work, on the one hand, clearly asserts that it is opposed to such screening. Yet its argued rationale of ethical and practical considerations is heavily conditioned. Screening, we are informed, "may not be feasible", or "would at least appear to discriminate", or "might prove unnecessary". These conditionals act as a counter-factual road map that offers considerable enticement and direction for those who would disagree with the NAS position. The genius of this strategy, it must be
recognized, is that the NAS work seeks to enlist the proponents of both sides within the compass of its medical authority.

Finally, we pose the question of the efficient use of various object constructions and relations, which in their very structuration validate medical authority. Examples in the work abound, and we will discuss some others later in the next chapter. For now we will focus on one rather 'fundamental' dichotomy utilized extensively in the medical and policy literature, and in the NAS report: the portrayal of the hospital/community dyad. Two considerations are of importance: what is the particular nature of the work's articulation of this dyad and the relations of power framed in that specific textual construction? And what relations of power are made possible by the evocation of that dyad as it functions within the larger economy of medical authority?

In its discussion about health care settings appropriate for the treatment and care of persons with AIDS, the NAS argues in a number of places for a strong and coordinated relationship between the hospital, outpatient facilities and community agencies.

The care of patients with a progressive and complex disease such as AIDS, if it is to be both comprehensive and cost-effective, must be directed as much as possible to the community. Yet this care must also include access to appropriate inpatient facilities when hospitalization is required, as it is in essentially all cases.
The real power of coordinated AIDS care plans is found in the integration of hospital and outpatient care with those facets of patient care based in the community. 30

Every profession and agency has its place in the spectrum of services necessitated by the biologic course of the disease and the social repercussions it triggers. The integration of providers forms a collective of professional and institutional relations in which each is situated with its responsibility according to its differing purposes and competencies. This functionalist constellation is meant to provide the efficient mechanism of care and treatment which characterizes American modern medicine and its proliferation of related services.

Now we must ask the political question, namely, within the imagined web of this system of services and providers (we must remember that they are not all in place or so friendly to each other) what is the direction of power and control? What connects the links of that chain, the tread of the continuum of care? The NAS is not without direction in this regard as in this understanding of what constitutes community care.

Community-based care can be broadly defined as care occurring at a patient’s residence to supplement or replace hospital-based care. At best, this care includes the administration of medications with nursing supervision, the use of home-based infusion of fluids and antibiotics, and home hospice programs delivering social support and palliative care in the terminal stages of the disease. 31
Community services are seen as having been successful in "shortening the length of hospitalization required by AIDS patients." To achieve this success, good planning is essential: "The several components of community-based care . . . obviously overlap so extensively that coordination of services is critical." Thus "careful planning of responsibilities of involved agencies" meeting regularly is required. And certainly,

To further optimize this planning, hospital personnel . . . should also be included. In this way, as outpatient or inpatient nursing personnel recognize new needs of patients, these needs can be brought to the attention of community-based agencies for efficient planning.

Yet, the rhetorical strategy employed contests the rather democratic orientation to the organization of health care services spoken by the work. If we accept the notion that the hospital is the site of medical authority, both literally, and as we shall advocate, figuratively as well, what becomes clear is that the work seeks to position that authority, through the particular representation of the hospital/community relationship, as the paramount authority over services to persons with AIDS. It does so by constructing the hospital as an entity equal and comparable to the community as a whole, not as part of it, as say one of many agencies offering health services to persons with AIDS. In addition, community services are defined in
terms of the hospital, as substitutes for, or supplements to, hospital care. And finally, the NAS work sets the hospital as the determining force in establishing the "needs" of persons with AIDS, more specifically, of "patients" with AIDS. The hospital, as it represents medical authority, is the major institutional dispenser of legitimacy in terms of the nature of services to be offered, as well as the producer of identities for the players, both of the sick and of those who heal. All subjects and objects are thus located within the constellation of those subjects and objects already established as medical property and traditionally under its authority.

But there is yet a broader picture in which this strategy becomes more than simply a political/textual gesture on the part of the NAS. The strategy must be placed in the ongoing contemporary struggle of medical authority to retain its power and legitimacy in the United States and in other Western countries. By the 1970's with the increased role of the federal government as a major provider and funder of health care services, the incessant rising costs of those health services, and the pressure of insurance companies, employers, and subsequently the federal government to control those costs, medicine began to loose its mandate to an ever-expanding part of the fiscal pie. This cost crisis was
also complicated by the decreasing legitimacy of medical authority as it came under fire for not only its financial excess, but also the institutional, cultural, racial, sexual, and political character of its service. And finally with the rise of the Reagan administration, and the conservative "reforms" in health care -- both in terms of reduced support for health care services (and research) and the privatization of those services -- medical authority was confronted with both the deinstitutionalization of its most powerful centers of concentrated control, and the decentralization of those services traditionally under its direction -- allied health care, social work services etc.

As the hospital becomes more and more restricted as a credible site of medical power, it is transformed into a metaphor for the extension of that power beyond that site. The hospital itself is sacrificed in order to reproduce the authority it represents in the new world of medical services, namely, community and home care agencies; it was to be a smaller hub for a larger wheel. Medical authority was to become portable, reproducing mini hospitals -- at least when it came to the structuration of power -- within homes and agencies. With the increase in modern, computerized, miniaturized equipment, and a surplus of personnel, the hospital was now only one of many sites of the medical gaze. But the
breaking of the hospital meant also the loss of exclusive control and the development of the coalitional face of medical authority as a strategy for its continued political viability. But it is an unstable coalition and constantly needs shoring up through linkages of power that retain medical authority, thus the use of the hospital, both as headquarters, and as the representational basis for extending those disciplinary economies within these new sites of control.

In the context of this struggle the AIDS epidemic necessitated action. The intransigence of the virus, the exacerbation of the crisis of costs, the institutional and professional neglect of persons with AIDS, acted all to the detriment of medicine's image. All this in the face of the incredible potential for expansion offered by an epidemic which knows no bounds.

The Encoding of Suffering

The legitimation of medical authority is further supported in the NAS report by the encoding of potentially politicizing material into forms which subvert their impact. One such strategy is to situate this textual material within the technical. Not only does this remove the overt designation of topics, acts, subjects etc. as political within the text, and thus invite a misreading of their political character, but it
also drafts the effects of their representation into the service of the dominant discourse and its constituency.

One can argue that the NAS work, as a work which on a grand scale seeks a technological salvation to the epidemic, masks the political as an overall way to focus energy and resources in those directions of the most practical value. After all, people are dying, and remedies, if they are to be found, must be addressed pragmatically and expeditiously. And while we certainly are not against the search for solutions, we are concerned with how the 'technicalization' of the epidemic serves power. One critical example should clarify the direction of this point: the manner in which the work treats the relationship between suffering and order.

To be brief, NAS does not offer any experiential or phenomological reading of the suffering of individuals with AIDS. Suffering, when it is signalled at all, is reconfigured as a series of mutually reinforcing translations that involve the cataloging of clinical symptomatology, which is then often heavily invested with a theory of needs. These needs are then addressed by variously classified professional specialties or services, which in turn need to be financed. Limiting the representation of suffering appears critical to the centering of the technical and service discourse on which medical authority depends as is the case in this NAS
Infants with AIDS may be the most tragic of all AIDS cases. Often born to mothers who use IV drugs, they frequently have no family support for their medical care and social needs. This situation is now reaching crisis proportions in New York City and Newark, New Jersey. In certain hospitals in these areas, 15 percent of the pediatric beds are already occupied by AIDS cases. . . There is a critical shortage of foster care families . . . 38

The tragedy of infants with AIDS is defined within the framework of medical order, and is transformed into the tragedy of inadequate services for "cases" of AIDS. Local accounts of suffering as distinguished from clinical descriptions and service categorizations differ in that they have different orientations to power and mediate different social relations. 39 Suffering becomes encased in a professional, administrative and financial language which standardizes the experience within the rules of medical exchange and disciplinary boundaries. Clinical and service discourses negotiate the relations between the doctor, patient, and the political economy of the health industry from the perspective of that industry's interest. The local voice of suffering, on the other hand, mediates the relations of the individual, doctor, and the immediate social network of the person who is ill.

The effect of this translation of suffering is, as we have been well taught by Illich, to medicalize our most personal pain, and distance our suffering from
ourselves. Suffering is medicine's turf, a patient's labor which is expropriated by the owner of the discourse of production. Outside of this order, and the social and cultural iatrogenesis it has been accused of perpetuating, however, is an experience which stands in awkward relation to medical authority. It is a suffering which at times is ungrateful to medicine, a suffering which often claims to be exploited, ignored, exacerbated, and numbed by medicine. It is a suffering which, when given the opportunity, wants to name itself, to order itself, to mean itself. Suffering becomes, within medicine, a local and subjugated discourse of the sick, and a non-circulating and unprofitable one as well. And, as Klienman argues, medicine is ill-equipped at the level of practice to handle this local voicing of pain.

Practitioners . . . are not trained to be self reflective interpreters of distinctive systems of meaning. They are turned out of medical school as naive realists, like Dashiell Hammett's Sam Spade, who are led to believe that symptoms are clues to disease, evidence of a "natural" process, a physical entity to be discovered or uncovered. They are rarely taught that biological processes are known only through socially constructed categories that constrain experience as much as does disordered physiology. . . 42

Incorporating a more local knowledge of suffering would also be to legitimate the individual's own illness experience and to shift the locus of control over the social meaning of that illness back to the person who is sick and his/her immediate network. Such a shift would
contest the privileged representation of disease and the complex and dense system of disciplinary knowledge and accompanying service arrangements that shape the social, political, and medical context of that suffering.
NOTES


3 Ibid., p. 59.

4 Ibid., 58.

5 Confronting AIDS, pp. 7, 38-42.

6 Ibid., p.45.


8 See Dennis Altman's AIDS in the Mind of America (Garden City, NY: Anchor Press, 1986), Chapter 3.


10 Ibid., p. 1215. This article was circulated to many in AIDS research for comments prior to June of 1986. (see 1199n and 1215 acknowledgments)


13 Duesberg, p. 1199; Koch's postulates are: 1) the pathogenic agent must be found in all cases of the disease; 2) it must be possible to isolate the agent and maintain it in pure culture; 3) healthy hosts must develop the disease upon inoculation of the pure culture; 4) it must be possible to re-isolate the agent from such hosts and again grow it in pure culture. See Waterson and Wilkinson, p.67n.


15 Ibid., p.22.
16 Confronting AIDS, pp. 66, 190.


19 See generally Shilts, And the Band Played On, for discussion of the scandal of the Blood Bank industry's early response to AIDS.

20 Confronting AIDS, p. 97.


22 Confronting AIDS, p. 193.


25 Ibid., see for example Chapter 5.

26 Ibid., p. 93.


28 Confronting AIDS, p. 120.

29 Ibid., p. 142.

30 Ibid., p. 143.
31 Ibid.
32 Ibid., 145.
33 Ibid.
34 See Mary Douglas, How Institutions Think (Syracuse University Press, 1986) for discussion on how institutions confer identities.
37 See Confronting AIDS, pp. 46-48, 139-152.
38 Ibid., 146-147.
39 For an excellent discussion on how "description" mediates different social relations see Dorothy E. Smith, "On Sociological Description: A Method from Marx", Human Studies 4, 313-337 (1981).
41 Illich, Medical Nemesis, Parts I, II, III.
CHAPTER VI

THE PRODUCTION OF SURVEILLING IDENTITIES

He knew that over a period whose end he could not glimpse, his task was no longer to cure but to diagnose. To detect, to see, to describe, to register, and then condemn -- that was his present function.

Albert Camus, The Plague

We have tried to make clear from the reading of the NAS report offered in Chapters IV and V, that the exercise of medical authority through the production of medical discourse is located within a political economy of medicine. Yet the politics of that 'economy' are radically at odds with the sterile representations put forth by the discourse and its supportive narratives. It is further argued that the textual surveillance practices which assert and guard that authority involve the language games of legitimation -- presentations of credentials and the naturalizing of institutional arrangements and elites -- and a portrayal of the world that eliminates mention of potential threats to the credibility of the discourse's self-assigned, moral and
scientific, purpose and identity. Into these practices must now be read the phenomenon of surveilling identities.

From Word to Flesh

Fictional and documentary accounts of plague provide us with a series of dramatic movements that challenge medical order. The shifts from fringe to core, peripheral to central, partial to total, inconsequent to extremely consequential, form a chaotic and dynamic thrust within epidemics that medical authority must confront, and symbolically subjugate to its discourse, if it is to offer both a response and a meaning to the epidemic. In the course of the individual's experience with AIDS, for example, one may first discover a mark, a blemish, experience fever, or fatigue; the augural quality of these signs may at first be neglected, or remain a bio-text unread and kept at a distance. As the sickness grows, what was once an object of curiosity surrounded by life, now becomes a spectre that offers little room for life itself. The effect is catastrophic.

The transformation for a community is similar. As Camus writes in his fictional account of the plague that visits the populace of Oran,

[M]any continued hoping that the epidemic would soon die out and they and their families be spared. Plague was for them an unwelcome visitant, bound to take its leave one day as unexpectedly as it had
come. Alarmed but far from desperate, they hadn't reached the point when the plague would seem to them the tissue of their existance.¹

The "whispering of the plague" which everyone in Oran tried not to hear, in the end became a roar that could not in any way be shut out except by madness or death.

[T]he plague had swallowed up everything and everyone. No longer were there individual destinies; only a collective destiny, made of plague and the emotions shared by all.²

The deafness of Oran is not lost upon the essayers of the present epidemic. Even before AIDS has reached its projected death peak, lamentations over the public indifference to the premonitionary beginnings of AIDS are already being heard.

Later everybody agreed the baths should have been closed sooner; they agreed health education should have been more direct and more timely. And everybody also agreed blood banks should have tested blood sooner, and that a search for the AIDS virus should have been started sooner, and that scientist (sic) should have laid aside their petty intrigues. Everyone subsequently agreed that the news media should have offered better coverage of the epidemic much earlier, and that the federal government should have done much, much more. By the time everyone agreed to all this, however, it was too late.³

History is full of renderings of medicine's struggle to make sense of epidemics, and their chaotic course, as history is full of the efforts of its chief rival in the meaning production of illness, namely religious interpretation. But more often than not these primal rescue narratives have historically failed to recognize the omens of plague, and subsequently to deliver a usable
meaning-context for its experience. One sees in these accounts true tragedy befall a community when so afflicted by a plague too powerful for ordinary human capabilities, the community is simply overwhelmed. The meaning frames and social order of both these contending authorities are outstripped by the sheer number of deaths the plague brings, and as often, the form of dying it precipitates. As Thucydides documents in his own experience with plague during the second year of that ancient war between Athens and Sparta:

At the beginning the doctors were quite incapable of treating the disease because of their ignorance of the right methods. In fact mortality among the doctors was the highest of all, since they came more frequently in contact with the sick. Nor was any other human art or science of any help at all. Equally useless were prayers made in the temples, consultation of oracles, and so forth; indeed in the end people were so overcome with sufferings they paid no further attention to such things.  

And this disaffection from meaning sources had its effects. The most terrible thing was the despair into which people fell when they realized they had caught the plague; for they would immediately adopt an attitude of utter hopelessness, and by giving in in this way, would lose their powers of resistance.  

How much more powerful, then, is the epidemic in the context of modernity where the elimination of local meaning has itself grown to immense proportions! And what options are there should medicine, now the only credible and central discourse of the flesh, fail to cure or give
solace? What kind of medical order is prepared to meet this onslaught should it come? As Montaigne warns us, the diseases of the body become clearer as they increase, but those of the soul only become more obscure as they grow.6

The AIDS epidemic forces upon us a questioning of medical authority, the order it creates, the surveillance practices it utilizes, and the meanings it dispatches. Modern medicine now confronts the epidemic with this disciplinary assemblage of technology, hierarchy and mechanisms of control; it also presents a particular shaping of bodies and identities which form the human linkages and material practices that keep this order together.

"The body", observes John O'Neil quoting Merleau-Ponty, "is our general medium for having a world." It is a "vital and critical resource in the production of those small and large orders that underlie our social, political, and economic institutions."7 We are encouraged to ask the question, according to O'Neil's formulation, in what sense do we understand the body that enters social life. We ask, in our immediate examination of the AIDS epidemic, a similar question: In what sense do we understand the body as it enters medical order? What kind of flesh has the medicine made? How have we made human this disease known as AIDS? More specifically, what is the nature of the AIDS body that is
made real through this medical discourse about it? These are all important questions in that the way we shape and constitute the meanings and social functions of bodies is a supremely political practice since the successful disciplining and orienting of bodies both displays and expands power.

AIDS bodies, as seen through the "gaze" of medical order (and the NAS report as well), fall clearly between the two broad classifications it makes of humanity: those who are "seropositive" or infected, and those who are not. But the divide is not the chasm of difference for medicine as it is for those who may be directly affected by the disease. It is more a broad continuum of holding stations from wellness to sickness. Within the ranks of the infected we find a progression of major diagnostic categories ranging from those who are "false negatives" (infected but no detectable antibodies), "asymtomatic carriers of HIV", to those who have ARC, and the final endpoint, AIDS. The other side of the equation finds room for most of the rest of us: those who engage in risky sexual behaviors (which includes most of the sexual acts that we now have in the public repertoire), the "worried well", and various specified populations aligned on the risk scale from the sexually active to those named target groups such as prostitutes and IV drug users. The order consists then of a broad matrix of
progressively lethal identity slots into which many, at one time or another, may fit as the epidemic broadens its death grip on the population. In this way, the epidemic acts much like the subway worker who pushes and packs crowds of vastly different sorts of people into the one waiting train heading out on the single track. The epidemic as it is being processed through medical order invites a similar gross simplification of its subjects.

Under the pressure of mounting deaths, medical authority solicits individuals into its classificatory schemata. As charged by the NAS plague managers, to identify oneself to oneself in this way, even if not to others, is a moral imperative. The stopping of the spread of infection requires us to do so. But this solicitation has other effects as well. One mechanism for self identification advocated by the NAS and many others is that of voluntary HIV antibody testing and counselling. Even if the testing is anonymous, as is the case in many states, the individual becomes aware of the potential she or he has to infect, or not infect, others with the AIDS virus. With that information, one can then act accordingly and responsibly. But voluntary testing, however, works to normalize medical order as well. The testing encounter introduces the individual first hand to the specifications of the classificatory identities. It produces the opportunity to assess and verify the
individual's level of internalization of the medical epidemic discourse. In so far as this occurs, testing serves as a recruitment and socialization frontier for the infusion of bodies into the medical order and its dependent service sectors. And it is in this highly individuated and highly charged context, that the contract with medical authority is secured. One simply affirms in one way or another, "Now that I am this, what is required of me?"

The ordering of bodies under medical authority places that authority between the individual and the choice of identities and meanings of the epidemic. Partly, as others have argued, this is because the effect of this subsuming of the body to medicine is to "defamiliarize" the body from a more direct and local self both through the general inaccessibility of medical language and technical jargon, as well as the sequestering of control over that language within the closeted communicative practices of the medical elite. The coding of bodies through these identities allows for an increasing dependency on medical authority as the broker of the epidemic's meaning.10

To maintain that distance, or lack of familiarity, and the dependency it engenders, requires not only the traditional sorts of monitoring and eternal vigilance over the transformation from one status to another and
the appropriate triggering of services, but also that these categorizations represent a direct part of what the individual interprets as his or her 'essential' or 'authentic' self. The subject's attachment to them are vital if the individual is going to ride them through the rigors of the medical gauntlet. But since medicine is often perceived as being dominant in its knowledge of the ways of the body, the medical body is always in a prime position to become a kind of 'real' self. Within the AIDS epidemic both the testing process and the widespread use of a medicalized vernacular in the press and media, a populist and sympathetic "AIDSspeak" as it were, assures a rather smoothed entry into medical order. Yet even within this secured portal to the public's discourse of the self these identities are still part of a world that offers few other alternatives.

Medical Order and Compliance

Surveilling identities form the bridge between medical authority as it is seen in textual practices on the one end, to the way individuals act as its agents or subjects on the other. Within the NAS report, individuals only exist in relation to their medicalized position within the epidemic. So we have AIDS patients, cases, high risk populations etc. Again, this is not unusual or necessarily of any importance if this were an
ordinary medical text. But we recognize, again that text is not only a medical work, but a grand attempt to mobilize a broad public response to the epidemic at many levels. Further, these categorizations of persons that structure medical order are used in many other social and political contexts as frames for situating individuals within the epidemic.

Of critical importance in establishing the connections between these surveilling identities and medical order, is that they are enshrouded within representations of a depoliticized, dis-embodied world that both centers these identities as essentialist, and filters out other possible alternatives. The cornering of the meaning potential of the epidemic in this way configures the pain of sickness as a demand for medical order. The epidemic becomes a tragedy whose effect may be to make medical order totalistic, and given the modern character of medical authority, in ways never before possible.

But how do we cross this bridge from identity to action? For this answer we have to explore the force that the text exerts on its readers, more specifically, the problems it generates that compel its readers toward this kind of action. For our purposes we are concerned with how medical authority, and the NAS report in particular, problematize issues of compliance. We will
go further. Compliance is the premier problematic in the
pursuit of medical authority.

How, one may ask, can compliance be central when it
could be argued that the claim is denied by the work
itself? The NAS report is very clear, for example, in
its opposition to compulsory measures to secure HIV
testing.\(^{11}\) To answer this objection one must again
recognize that the ground of compliance has shifted from
an orientation centered on the actions of the state and
its attempts to secure control, to one in which
compliance issues have become a more diffused,
individuated, and normalized problem of order. The shift
reflects the re-direction of the exercise of modern
power, and consequently its study, from its operation as
a function of institutionalized practices, to its
circulation within sets of non-sovereign, or disciplinary
practices.\(^{12}\) The spoken-to issue of compulsory testing,
and compulsion in general, are treated in the report
solely as products of the state acting upon the
individual, with the ineffectiveness of that approach
fully recognized.

But in the report the language of compliance is
secured through the appropriation of the language of
behavioral and prevention education. As the report itself
comments,

Education in this instance is not only the transfer
of knowledge but has the added dimension of
inducing, persuading, and otherwise motivating (sic) people to avoid transmission of AIDS.

The education program described must be "massive" and "decentralized", with the evaluation of education research (and thus the agenda to guide the educational effort) centralized. Education provides for a more individuated circulation of power that is not without its relation to the state or institutional concentrations of authority; and as we have observed before, medicine itself forms an effective and sympathetic link between the two.

Compliance issues are also centered through another textual strategy. The NAS report juxtaposes the epidemic narrative mentioned in Chapter V (that narrative of irrational disorder) with the dispassionate and depoliticized (and should we say orderly) medical discourse. Compliance in this formulation is translated as an obligation of high priority. The enforcement of medical authority over the epidemic, and the implementation of its impressive agenda of compliance, is dictated, in part, by the extent to which the individual sees compliance as a moral duty of some magnitude.

The insinuation of the moral impetus into AIDS conspires with the task of normalizing compliance, and it is a critical component of the 'realist' agenda established by the plague managers. Just as expressive of that agenda is the containment of threats to that
compliance. Under what is determined to be the brutal effects of the epidemic, alternative meanings that neither address the direct search for medical relief, or are not synchronous with medical authority are excluded. Thus while medical explanations may be incorporated as legitimate within religious texts, the opposite does not occur. In the report no mention is made of pastoral counseling or the mobilization of religious services for those living and dying with AIDS. No consultants or authors are from any major clergy. It is only the ethicist who serves as the medical point man for morality. Even this input is often regulated in the report to a moral reading of the professional obligations of health service providers.14

While it is assumed that science does not court religion, and thus the denial of religious speakers is seen as natural, it is an odd silence in that the Academy seeks to place at least some emphasis on the "palliative" and psychological care of persons with AIDS,15 a task that religious organizations have traditionally performed. One could theorize that given the 'grass roots' level of internalization of medical authority which the work seeks, it is very careful about its validation of religious authority, an authority which often has significant standing among local communities.

One could also include in this list of exclusions the
silence of the work when it comes to 'fringe' or alternative forms of treatments from chiropractors, acupuncturists, naturopaths, and other "holistic" practitioners. Validating these healers would contribute to competing readings of the body’s bio-text, as well as a de-emphasis of the clinical modalities that shape the AIDS body, and consequently the self. These practitioners are, for the most part, not on the medical track because they contest the priorities contained within the specifications of the body established by medicine. They are, in a very practical sense as well, in constant conflict with medical authority. The threat to medicine’s hold on the AIDS body by these and other non-traditional practitioners is very real, however. Persons with AIDS are more than casually interested in using alternative therapies. As one person with AIDS has remarked:

A joining together of established medical procedures and established Western medicine working with alternative medical treatments and alternative medical disciplines may be the best mode of medicine. All people must recognize that the doctor is not god, and that the doctor doesn’t have all the answers. 16

Targeting "Prostitutes and Homosexuals"

The NAS report produces a number of distinctions that invoke, or set the stage for, the use of other cultural texts that establish surveillance identities, and consequently the text participates in the targeting of
individuals so identified for institutional surveillance activities. The obvious naming of groups such as homosexuals, prostitutes, IV drug users, hemophiliacs and others make for easy surveillance references. Once such a tag is attached to the individual, he or she may be caught up in the actions of the state or meet with the more local retributions of neighbors, employers etc. as we have already documented earlier in Chapter I. Two identities heavily relied upon in the NAS work need examination in this regard, namely, the prostitute and the homosexual.

In the large production of work on the relation between AIDS and prostitution one finds very little recognition of the problematical nature of just what exactly constitutes "the prostitute". Typical references in the AIDS medical literature simply refer to prostitutes "as women who exchange sex for money or other items."Prostitutes are seen as a "reservoir of infection" for sexually transmitted diseases including AIDS, and are often "targeted" as a high priority group for medical surveillance. The NAS work for its part merely reproduces this kind of categorization with little questioning of the appropriateness or implications of this designation. Prostitutes are seen as the objects of study and as dangerous to those who "patronize" them; "business travelers, military personnel, and others who
have sexual intercourse with prostitutes are at risk of infection," the report flatly tells us. 19

Yet the proposition that a person "is" a prostitute embodies a whole host of cultural, political, social, legal and sexual frames that are by no account universally agreed upon. As Barbara Meil Hobson in her exhaustive study of prostitution asks, is prostitution a sexual relationship, a work contract, a private act or public commerce? Is it to be primarily seen within a politics of civil rights or one of exploitation? In any event, prostitution for Hobson is an "ideological mirror" of social order.

On the one side, we see a prostitution economy that expresses social and sexual inequalities within society -- women are overwhelmingly the sellers of sex and men the buyers. The class and gender bias within the controls and penalties aimed at prostitutes reflect these inequalities. On the other side, we see that reform movements have continually sought to alter prostitution policies, but the strategies they have proposed and the influence they have achieved have been shaped by sexual politics and class interests. 20

As such the "prostitute" is less of a type of person than textual emblem or marker for the history of unfinished arguments and conflict concerning the moralization of sexual practice. 21 To invoke prostitution then, can never be simply a neutral or innocent gesture since it is at once a contestable descriptive and normative designation which represents the current political status of that historic struggle. Thus the
The uncritical reproduction of the prostitute through the language of AIDS as some sort of universal person/entity does have an effect. The NAS text, as do other medical texts, invests into that language the regulatory priorities of the criminal justice system, and in turn, further legitimates and medicalizes both the prostitute identity and the criminalization of individuals that it now represents. The arming of medical discourse with the identity designations of the enforcement sector of society not only validates those designations by cloaking them in science, but also legitimates medicine's own inspection, categorization, and surveillance of individuals so labeled. Political entities are represented in the same manner as clinical entities as though they are determined and complete. Medical discourse thus politicizes the "prostitute" by trading on the popular suppression of these individuals in support of its right to inspect, while at the same time it depoliticizes prostitution by failing to recognize the social circumstances and oppression (poverty, sexism, foreign tourism etc.) by which one
becomes conscripted into these identities. Thus surveillance is 'normalized' in that it appears directed to those individuals (prostitutes) over which the state has traditionally sought control.

The targeting of the prostitute identity authorizes state action. This argument is more than mere theory. During World War I, more than 30,000 women (prostitutes) were incarcerated in the United States in an effort to control venereal disease. This gross violation of civil liberties, as historian Allan Brandt reminds us, had no effect on the rates of infection, yet it must have had tremendous effect on the lives of these women.23 In 1986, 275 Kenyan women were picked up by police and tested for sexually transmitted diseases including AIDS. These women faced criminal charges if infected. No similar sweeps were done on the men that frequented the bars at which these women were found.24

There is a cruel irony here. Given the difficulty of transmission of HIV from women to men, these women identified as prostitutes are more likely to be infected that to infect. And studies in the U.S. also tend to confirm that the single most important risk factor among "prostitutes" is not sex but IV drug use.25

Finally one should also add that this production of the prostitute identity is far from helpful when it comes to the prevention of AIDS. As part of the language of
AIDS it augurs poorly for the development of any personal, therapeutic, or pedagogical relationship meant to reduce risk since it may trigger paranoia and fear. But more important, it sets the ground for public health strategies against AIDS within the operations of the criminal justice system rather than within the health care sector.

We have already commented on how the history of the criminalization and medicalization of homosexuality may impact on both the operations of the surveillance state and on the reactions of gays afflicted with AIDS. Much of the AIDS medical literature, although certainly not all of it, has moved beyond seeing homosexuality in these terms (i.e., as either criminal sexual acts or medical disorder). And to a lesser degree, much of the early moralizing on the "promiscuity" of gays that peppered clinical papers and medical discussions on AIDS has disappeared. Although the representation of gay persons with AIDS continues to be produced in these draconian terms, more subtle textual assemblages and reinforcers of these surveillance identities are also active in medical discourse and in the NAS report.

One such operation in the NAS text is the construction and relation between the homosexual "community" and the heterosexual "population." Homosexuals have community groups, leaders,
organizations, clubs and other forms of group association. Heterosexuals, ostensibly the other side of the great and immutable sexual divide (bisexuals having no independent status in the report are lumped in with gays) are seen somewhat differently. Within these textual unities -- "homosexual community", "heterosexual population" -- as they circulate within medical discourse and the NAS report, and within the popular American cultural inter-text, lurks a normative order that says that homosexuals are not the same kind of subjects as heterosexuals. The strangeness one hears in saying the "heterosexual community", for example, reveals the double achievement of medical discourse in bringing to bear this covert normative order.

Heterosexuality is, as it were, beyond community. It is the ground of sexuality -- everywhere and invisible -- in contrast to which the homosexual "community" stands apart and separate. In addition, the homosexual "community" carries the weight of either some constant known as "homosexuality" or some other set of connections -- "lifestyle"? -- that not only separates gays from the straight community, but bonds homosexuals together. Yet given the diversity of sexual behavior in both groups, and the differences in the meaning of those practices, using biologic practice as a model for some kind of fundamental human behavioral or cultural classification
or type is at best misleading. As Simon Watney, who identifies himself as gay, comments,

On the one hand we are invited to think of ourselves as a coherent unified group, roughly analogous to race, deriving from a supposedly shared primary level of sexuality. On the other hand we actually experience our social being as a series of discontinuous exclusions through which we move at work, in our families, and elsewhere, always modified by the contingent factors of class, education, the nature of our employment, and so on. This is why the notion of belonging to a single "gay community" is ultimately unhelpful and unconvincing. For whilst we may collectively resist particular instances of injustice, campaign for the improvement of our civil liberties, and celebrate and support ourselves within a culture of sexual affirmation, this does not imply any essential unity to homosexual desire as such.

What constitutes the meaning of homosexual, or homosexual community is dependent on its historic and cultural environment. Foucault in his study of sexual pleasures in ancient Greece found the modern notion of homosexuality "plainly inadequate" as a means to understanding the very different meanings the Greeks attached to these practices. The Greeks did not recognize "two" competing forms of desire, or kinds of sexual drives.

We can talk about their (the Greeks) "bisexuality", thinking of the free choice they allowed themselves between the two sexes, but for them this option was not referred to a dual, ambivalent, and "bisexual" structure of desire. To their way of thinking, what made it possible to desire a man or a woman was simply the appetite nature had implanted in man's heart for "beautiful" human beings, whatever their sex may be.

The power of the "homosexual community" for medical authority is precisely in its ability to travel in
differing and often opposing textual contexts. To use the phrase is a political pledge of sorts, a 'fake left' one could say, a textual maneuver that ultimately masks, however, its targeting function. The appropriation of the language of gay liberation by medical discourse is not to affirm that liberation -- indeed the entire history of medicine's relation to anything gay belies that contention -- but to bring homosexual "patients" within the circle of medical authority through the sympathetic affiliative sense the term evokes.

Within the context of the medicalization of the AIDS epidemic, and the surveillance practices it requires, the reproduction of the "homosexual community" as substantially separate from the heterosexual 'norm' works strategically to immediately generate a class of surveillable subjects by the textual imposition of associations they may in everyday life not share. Because these undefined associations are dictated to exist, those who are thus classified become available human targets for medical inspection and registration. These associations reinforce those more oppressive legal/religious classifications that form the basis for the host of negative sanctions against persons engaging in 'unapproved' sexual practices, and validate these regulatory sexual prescriptions through their status as some sort of clinical or scientific categorization.
Besides the 're-membering' of homosexuals into a questionable collective, the meaning of which becomes of service to medical authority, in addition one discovers in the NAS report a contrasting 'dis-membering' of individuals including gay persons from their social environment as well. From the point of view of medical discourse infected persons are their surveillance classifications i.e. prostitutes, IV drug users, homosexuals, seropositives, seronegatives etc.. Once so classified, people are scripted as anomalous, as disconnected from the social world, and thus to the human context which bestows on them their humanity. This dis-membering of the infected person silences the potential relations and interests they may share among themselves, and that may be at odds with those determined by medical authority.

The increasing recognition of those shared interests in the two areas we mentioned and in others -- class, race, sex, or culture -- could lead, and to an extent already has, to the voicing of critical commentaries on the handling of AIDS by medicine.

For example, Chris Norwood argues that risks to women have not been specifically and adequately addressed by medicine. And she observes that

When the history of AIDS in the United States is finally written, it may be remembered above all that women were deceived.
Similarly, Richard Goldstein writes in regard to race that

AIDS is a clear and present danger to the urban poor. Blacks and Hispanics are 20 per cent of the population but they make up 39 per cent of Americans with AIDS . . . We are not being told in a tone audible enough and in a language direct enough, that AIDS is a crises for minorities. Within the public health establishment the silence is pervasive.31

As clinicalized individuals within the NAS report, persons with HIV infection are configured as standardized subjects necessary for the production of that authority. They become constituted as members of a diagnostic class which resembles in character the serialité described by Jean-Paul Sartre, namely that passive, impotent grouping of people in which individuals are unified by a strange alterity, relating to each other as one "inert Other among Others".32

The Radical equalization of the AIDS body

Under our reading of the NAS report, and by implication, of the medical literature in general regarding AIDS, we have argued that the articulation of the medical discourse asserts medical dominance over the epidemic in a number of ways: by the targeting of surveilable subjects, by the 'dis-membering' of subjects from their local networks, by problematizing compliance within a decentralized internalization/ centralized agenda-control structure, and by depoliticizing medical
order with its comprehensive identity matrix. All of these textual practices have effects that are produced or invoked by the NAS report and function to insert medical authority into a position of increasing command over individual relations to the plague experience. As such, the textual event we call the NAS report represents an achievement of a professionalized elite, working in conjunction with the corporation and institutional medicine in its attempt to harness the tremendous mobilizing energy generated by the epidemic.

These textual practices form the networks and mechanisms for exploitive power because together they create a powerful ideological campaign for the radical equalization of the AIDS body under medical authority. It is in this tight packaging of the person with AIDS (and in fact anyone's relationship to the epidemic from the well to the sick) that relations of dominance are made clear. The normalized order is built on so many textual fronts, and constitutes so narrowly a spartan medical subject, that not only does this subject process well through the procedures and institutions of established medicine, it also resists, neutralizes, or places in secondary status, alternative meanings. As more and more intimate sectors of our society become rationalized and 'administratable' by dominant constituencies, the demand for subjects constituted to
meet these requirements also increases. The medicalized AIDS body is in demand both within medicine, and as a medicalized body within other social sectors that feed off medicine -- journalism, for example.

Surveillance over the AIDS body is the maintenance of that major proprietary interest to medicine upon which we now witness the building of a major component of the health industry. And it is only through this constant maintenance that the appeal and universalism of its categorical order be sustained. But the standardized body is made unremarkable not only because it is seen everywhere, both textually and visibly in medical contexts, but because it is rationalist, and thus is of value within a telos whose order is that of a reductionist medical discourse, a discourse which has become the totalizing representation of human well-being. The radically equalized, standardized, rationalized body is a reflection of the subjection of the person with AIDS to the atomistic thrust of medical capitalism, a process which, as Bert Hansen says in paraphrasing the 15th century scientist Nicholas of Cusa, puts the patient both at the center (as an object of inspection) and at the circumference (as a voice of value or power) of concern. 33

The damaging effects of that dependency and subjectification in practice have been already discussed.
The progressive loss and restriction of meaning within medical discourse and the domains it controls, is the face of domination. We can also say, however, that pathogenic medicine, through the way it asserts its authority and the individuated subjectification demanded by it, is a threat in itself exclusive of the expropriation of meaning it effects. The deskilling of individuals which it accomplishes leads to a reliance on institutional and clinical practices which traffic in, as a matter of everyday normal business, a whole series of abuses, incompetencies and neglect that inflict heavy physical and emotional damage on people who can least tolerate these assaults. 34
NOTES


2 Ibid., p. 157.


5 Ibid., p. 125.


"The diseases of the body become clearer as they increase. We find what we were calling a cold or a sprain is the gout. The diseases of the soul grow more obscure as they grow stronger; the sickest man is least sensible to them."


8 See Confronting AIDS (Washington D.C.: National Academy Press, 1986). "CDC Classification System for HIV Infections", Appendix F, pp. 320-325. If one were to follow the lead of Masters and Johnson, for example, not only would everyone fit into some context relating to the epidemic, but virtually everyone would be at risk of infection, young and old, sexually active and non-active. See William H. Masters, Virginia E. Johnson, and Robert C. Kolodny, Crisis: Heterosexual Behavior in the Age of AIDS (New York: Grove Press, 1988).


10 O'Neil, Five Bodies, p.19; Again see generally Ivan Illich, Medical Nemesis (New York: Bantam, 1976).

11 Confronting AIDS, p. 130.


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13 Confronting AIDS, p. 96.


15 See comments on hospice care of persons with AIDS in Ibid., p. 146.


18 Ibid.

19 Confronting AIDS, p. 269.


21 This notion borrows from Walter Kendrick, The Secret Museum (New York: Viking, 1987) where he argues in regard to pornography: "From the start, "pornography" named a battlefield, a place where no assertion could be without summoning up its denial, where no one could distinguish value from danger because they were the same. The reason we now use a relative neologism -- and a learned one at that -- to designate a class of objects most commentators take for eternal is that "pornography" names an argument, not a thing" (p. 31).


26 Confronting AIDS, pp. 57, 92, 101, 118.


29 Ibid., p. 180.


34 This is basically Illich's argument. See Ivan Illich, Medical Nemesis (New York: Bantam, 1976).
CHAPTER VII

MEDICAL DISCOURSE AND AIDS POLICY-MAKING

It is our hope, Mr. President, that you will: use our report as your national strategy; harness the goodness that awaits your effective leadership; continue to advance the nation in conquering the virus; and lead us to take advantage of waiting opportunities for more healthy and wholesome lives.

James D. Watkins
Chairman
Presidential Commission
on the Human
Immunodeficiency Virus Epidemic

The Centers for Disease Control must provide clear direction for expanded and improved surveillance, including endorsement and support by national leaders, other federal agencies, and state and local leaders.

Presidential Commission Report

In this chapter we conclude our study of the NAS report by an examination of its relation to public policy-making. After reading the preceeding chapters it would not be unexpected that the reader would question why, given this non-typical kind of political/textual
reading of the NAS report, do we now turn our attention to AIDS policy, an area heavily weighted with traditional political analysis. There are several important reasons for this shift, and, as we will discuss, reasons that are not entirely at odds with the theoretical thrust of our overall inquiry. It is easy to argue, after all, that to move to concerns over AIDS policy is in keeping with the nature of the NAS text itself; it is, by its own expression, a document which means to infuse itself into the thinking of policy makers, and to persuade them to act in very specific directions. Just as important, however, is that within the American political context, much of the major political action over AIDS is happening in those social and professional sectors usually associated with policy formation. Moreover, the NAS has had, as we shall discuss, a major impact on AIDS policy as witnessed by the creation of the Presidential Commission on the Human Immunodeficiency Virus Epidemic, and the recent completion and public presentation of their report to the President.¹ Consequently our analysis of the report is also one which looks at the political effects of the report in terms of the pursuit of the public agenda it articulates.

There is also a more direct rationale for focusing on public policy. We ascribe to a politics and form of political analysis which continually seeks to locate
itself within the everyday actions of the world; and while it is difficult at times to do, a politics that is comprehensible to that world. We understand the postmodern theoretical paradox inherent in valuing comprehensibility and intelligibility (that is to say that the more familiar is one's language, the less its will to power/truth may be recognized by others, and the less awareness that particular way of speaking has about its own will to power), we do take seriously the imperative to act politically in the present life-world whatever the consequences for theory. Yet, we do think that political theory, as we have pursued it in this inquiry, pushes us to different kinds of political action.

Thus we engage consideration of the policy issues on a number of fronts: what constitutes AIDS public policy-making as a thing to be examined; the effects of the conflation of medical and surveillance state policy discourse, with a particular emphasis on the issue of confidentiality; the impact of the liberal political narrative imbedded in the NAS report which defines political parameters; and the imperfect replication of the NAS report (as an official policy document) by the Presidential Commission on the Human Immunodeficiency Virus Epidemic.
Asking the Policy Question

To inquire now as we must on the impact of the NAS report on public policy, and more particularly, the implications of our critique for the study of that impact, is to confront another theoretical crossroad. On the one hand we can try to see our reading within the current context of modern policy analysis, that is, an orientation which is rational, decisionist, methods dominated, empiricist (assuming a radical separation of value and fact), and, holding a view of policy itself as an epiphenomenal response to "problems" in the outside world. In its most positive light, contemporary policy and policy making are "modern" practices to the extent they are dynamic, cybernetic, emphasize process, feedback, and the transformation of information. And modern policy-making is "rational" when compared to more traditionally democratic value-laden approaches -- those concerned with civil-order -- of Harold Lasswell and other policy thinkers of the early 1950s and 1960s.

Modern policy making makes claims to inclusivity, for the fusion of quantitative and qualitative -- although quantitative methods predominate -- and the normative and empirical. In this sense then, policy-making, as a model of knowledge, is aggressive, and one that seeks to engender use, investment (as in careers and money) and commitment (as in a commitment to the outcome of fair
process). However, modern policy analysis makes no claim of allegiance to either pluralists or elitists political paradigms -- any overt gesture towards any side undermining its legitimation and potential power in the intellectual marketplace. Yet, as with many modern social, political and cultural practices, it offers pluralist identifications primarily as a recruitment strategy, while being, in effect, an elitist political instrument. 4

The other direction of this theoretical crossroad is one that is more consistent with our overall approach. The above conception of policy has a dominant and thus not unimportant place in our understanding of the politics of AIDS. Yet, again, it is blind to the narrow epistemological constraints of its own discourse, a discourse that produces and reproduces its own objects, norms, voice, strategies, authoritative agents, and legitimating knowledges and disciplines. From our perspective, policy must be reframed as a form of State discourse, or to put it in a more Marxist sense, a kind of privileged class-speak. Each of these notions of policy (and we would argue also that one cannot in any reasonable way separate policy, policy analysis and policy-making here) has implications for its exchange with the medical discourse of the epidemic.

Indeed, even within some studies of modern policy
analysis we see a shift towards seeing policy-making as discourse in the sense that writers now view modes of argumentation, rhetorics of persuasion, and the ways in which policy analysts make rational truth claims within the democratic public discourse of the citizenry as important. However, much of this thinking, including the most recent consideration of how an understanding of narrative paradigms of communication can have an impact of policy debate, is concerned primarily with only the tactical political effectiveness of the forms of advocacy engaged in by policy analysts and not in terms of how discourse constructs meaning.

Other writers come much closer to the mark. Donald Schon, for example, has written on the effects of what he calls "generative metaphors" on the process of problem-identification or definition in modern policy analysis. This is an area or stage in which policy analysis is at its most obscure, although problem-identification is seen in most writings as crucial, vital or critical in the analytical process. Schon writes that he has become persuaded that the essential difficulties in social policy have to do more with problem setting than with problem solving, more to do with the ways in which we frame the purposes to be achieved than with the optimal means for achieving them.

Schon argues that problem setting is mediated by stories, narratives, and deep generative metaphors which
"shape our perceptions of phenomena." These stories and the metaphors they present shape policy discourse in ways that often remain unexamined in traditional policy analysis. His critique of the significant differences in housing policies that have been carved alternately on seeing slums as "blight" (draconian urban renewal measures) or as "communities" (community organizing and self-help projects) is a case in point.

Other authors have tried to analyze the nature of the framing story: the story that "encodes metaphorical inferences, preferred distances, constraints, and tolerances for imperfection." Thus "frame conflict" in policy making arises accordingly because of "different encoding of terms, different inferred constraints, or different tolerances ..." While important considerations are examined by these authors, all fail to appreciate to the political process by which particular metaphors and encodings are generated and how they contribute to the circulation of power.

To understand AIDS in a policy context as construed above is not to ask what policy is about but to examine and understand what Foucault calls the "rules of discursive formation": the "rules" informing discursive practices which have the effect of restricting the kinds of objects, subjects and identities fielded, the criteria and norms of appropriate and legitimate knowledge, and
the types of strategies and tactics allowable for the reproduction of the discourse itself. The structures of social and political power that informs the "rules", however, typically resides outside of the particular discourse itself and not accessible to it. Thus again, to ask the question of AIDS policy it is necessary to contextualize policy discourse itself rather than uncritically accepting the context which that discourse produces.

The historical evolution of policy as conceived by some policy thinkers is instructive in this regard. Under their interpretation, "policy" has had a continuous unchangeable existence and nature over time from Hammurabi's Code to Kautilya's Arthashastra, to Aristotle's Politics, to Machiavelli's Prince, to the Federalists Papers, and, one would suspect, to the NAS report on AIDS. To accept this historical version of policy is not only bad history, but bad philosophy. It is the sign of an aggressive, appropriating discourse driven by forces of professionalism, institutionalization and power. Both the concept of policy itself, and the practices associated with it have had a wildly discontinuous history that has traversed the entire spectrum of moral, instrumentalist, and metaphysical meanings.

From this perspective, then we must ask not only how
social and political relations are layered in policy
discourse, but also how that discourse functions to shape
and direct social control. The general question, in a not
so brief a form, would go something like this: What are
the controlling and competing discursive practices which
constitute the language of AIDS, (and in our study we
discuss medical discourse) and how will these language
practices be changed (transformed, appropriated,
accepted, discarded, cultivated, co-opted, exploited)
when processed (reinterpreted, reframed, absorbed)
through discursive practices that constitute the language
of policy; and what social groups (formations,
organizations, elites, forces) are affected and how? By
asking this question, then, we are getting closer to an
analysis and understanding of the mechanisms of social
control that determine what "policy actions" will
eventually be conducted. The inquiry then into this
question is a comparative one of interiority and
exteriority. It is one that understands AIDS policy as a
mediating discourse between medical and juridical social
control apparatuses, with that control being exercised
through the cultivation and positioning of persons with
AIDS and others in these apparatuses.

AIDS policy is thus a site of discursive struggle
among major social control sectors of society over
possession of the AIDS body. With corporate capitalism's
expansion into, and commodification of, medicine, the privatization of social services, the surplus of physicians, the growth of public and private surveillance organizations, and the competitive grantsmanship of modern institutional research, AIDS policy and policy-making becomes a battle ground of emerging elites and institutions whose success depends upon not only the immediacy of battles won in Washington for inclusion in the master budget, but the longer term struggles over resources through strategic positioning within the dominant discourse. This is the policy context in which we must situate the phenomenon of surveillance and in particular our emphasis on textual practices which naturalize and depoliticise authority, and which are in the business of distributing surveilling identities.

In sum, the two ways of seeing policy could not be more different. One sees policy as a political language, the other as a politicized language; one is reflective of objects on an unrecognized and delimited field of action, the other overtly places the production of that delimited field within the capacities of its own verbal acts; one privileges policy analysis as a master code, the other levels it to one (albeit important) of a number of competing ways in which power speaks. One thing is certain, however. The AIDS policy that makes its way through this struggle will reflect aspects of the
dominant order no matter how we see this public product and process. Whether that reflection is one that we recognize and understand is the question at hand.

Policy and Medical Discourse

Public policy on AIDS, as it acts out the agenda of the surveillance state presents a host of threats to human freedom. The opportunity the epidemic provides for the further expansion of surveillance through public policy must not be underestimated. Thus much of the discussion heretofore is a preface of sorts to the call for serious consideration of surveillance and medical discourse as these practices affect AIDS policy since policy opens up the opportunity for the coming together of the real, powerful, and material interests of medicine and those state-engendered surveillance practices which support them. Consequently, the uncritical acceptance of AIDS policy could allow for an extensive normalization of surveillance and the politics of class, professional elitism, corporate and state bureaucratic power it represents.

AIDS policy makers should be made aware of the alarming growth of the practices of the surveillance state, and the production of surveillable identities through the medical discourse on AIDS. The conflation of medical discourse, and the interests it represents, with
state authority combine to form a powerful front for the further development of the surveillance state. Unfortunately, in addition to being a deadly disease, AIDS has become an important vehicle for the legitimation of this empire building unlike any time in history. While AIDS policy must reflect an aggressive approach to dealing with the epidemic, one cannot overlook the historical and political context through which it is emerging, and the political dangers inherent in our response to it.

The incorporation of medical discourse on AIDS within the policy discourse of the surveillance state is a highly problematic process to assess. Let us examine briefly, for example, the issue of confidentiality. Certainly some gains in AIDS policy have been made that contest the problems in disclosure mentioned earlier. There is an expanded sense of confidentiality that is being forged as a result of the epidemic. This reconstruction is witnessed in the growing emphasis on anonymity. Political pressure from advocacy groups is making it necessary for national and state health agencies to develop strategies and mechanisms for anonymous testing at local health centers in an attempt to by-pass the traditional and now sensitized problem of insuring confidentiality. Rather, agencies now have to address the more difficult problem of insuring the
recorded namelessness of the individual from the point of
the individuals contact with the institution, to the
distribution of the test result. Yet, the growing
legitimation of anonymity in the everyday operations of
antibody testing, creates a different tension for these
agencies as well. The anonymity of individuals with HIV
makes working on the "balance" between individual rights
and public safety all the more problematic especially
when agencies are charged with retrieving information for
the purpose of sexual contact tracing, proofs of legal
liability, and follow-up counselling.12

We are also witnessing the expansion and articulation
of the specifics of information access and informed
consent. The complex detailing and operationalizing of
the legalities of the testing situation relative to AIDS
is without historical precedent. This dense specification
is a product of the radical growth of medicine since the
1960s, the modern mechanisms of information management in
which it is thoroughly embedded, and, of course, the
social anxiety over the consequences of making public HIV
test results. Instructive in this regard is the debate
over what constitutes "routine" medical testing for HIV
antibodies. Some physicians have argued that by making
HIV testing 'routine', that is, part of a standard
battery of laboratory testing done at certain points in
health care delivery (such as at hospital admission), not
only will valuable epidemiological information be produced, but both the antibody test and AIDS itself will be destigmatized as large numbers of people become more aware of the real nature of this disease. Others contend that suggesting HIV testing can in any sense ever be routine is, in fact, to be blind to the social and personal dangers presented by inadvertant disclosure or inadequate counseling. In addition, encompassing antibody testing under this medical rubric would be an attempt to avoid the perceived unwarranted demands of this consent specification and, thus, is nothing less than the partisan use of the de-politicising ambiguity inherent in this label. 13

All of these issues have their own history of some importance prior to the AIDS epidemic. Yet it is also true that the visibility of these issues and the intensity of their articulation has never been greater. Since the beginning of the epidemic, they have also become officially recognized if not acted upon. The CDC, for example, has considerably tightened up its procedures for the distribution of information. 14 The NAS has also noted the "low level of confidence" in confidentiality. The report validated fears expressed by gays and other persons with AIDS, and has argued for the use of punitive measures for "unauthorized disclosure of antibody test results", in addition to calling for a consideration of
new "administrative mechanisms" to protect confidentiality and sanction unwarranted disclosure.\textsuperscript{15} The President's Commission report also stresses the need for regulatory and legal protections.

But the emphasis on confidentiality is not without other effects or the tactical device of other not so benevolent strategies. As the effort to reconstruct confidentiality is becoming more broadly utilized, it serves not only as a signifier for the protection of an individual's personal information, but also as a rhetorical strategy for ensuring both patient compliance with medical regimens and research protocols, as well as the accuracy of the medical and epidemiological information obtained.\textsuperscript{16} The significance of invoking confidentiality is to prevent HIV infected persons from escaping the testing situation by going "underground" or giving false information. Yet given this kind of value for medicine, the centering of confidentiality can also be seen as a rhetoric against social control which is invoked as a recruitment device into the very system of surveillance from which the individual seeks some sort of refuge.

More important, the push for confidentiality, while very critical, is in the end a press for a technical solution to a political problem. The nature of that problem, as we have suggested before, can be briefly
described as the growing convergence of medical authority with the bureaucratic and regulatory structures of the state. The demands of the surveillance state are being articulated through the normalizing and depoliticizing voice of medical discourse, while the state, in turn, legitimizes the more intrusive demands of medical authority. Both state and medical authority depend upon the production of "administrable" and surveillable subjects that fit with not only the security and morality paradigms acceptable to the state but also to the proprietary interests of medicine.

While the stress on confidentiality serves as a powerful issue in voicing resistance to surveillance, medical authority has always reserved a privileged place in the management of both the rules and exceptions to confidentiality. Confidentiality poses few obstacles to the extension of medical authority. For example, since the transmission of the HIV virus can be viewed as an intentional and dangerous act, physicians may be legally liable for failure to disclose when harm is "foreseeable". The physician's "duty to warn" potential recipients of the dangers involved is well established in related case law, and may outweigh considerations of confidentiality. However, predicting dangerousness, with all the normative and practical dilemmas that entails, is a highly complicated, and extremely
unreliable affair.\textsuperscript{18} And, as Cindy Patton complains, without clear regulatory guidelines, especially when it comes to AIDS, doctors may "balance the common good against the individual's rights without a full understanding of the social, political, and legal ramifications of doing so."\textsuperscript{19}

The NAS report is fully committed to notions of confidentiality that recognize the problems and dilemmas involved in implementation and compliance. Yet it is blind to the paradoxical effects of success in these areas that result in the extension of the Leviathan. Partly this is because its own power is dependent upon the growth of state surveillance activities; but the text also suffers from a myopia that views its own power aspirations within a narrow and depoliticized world view.

**The Liberal Political Narrative**

The combining and synchronizing of medical and state discourse within the confines of public policy can occur in two critical ways. The first is that forms of state/policy discourse may already be embedded in medical discourse so that there exists upon its reading a natural linking of these two language practices. And second, there is the opposite, those forms and legitimations of medical discourse may be found within policy. We now look at instances of both kinds of practices.
Within the NAS report, medical discourse displays an adherence to what we can call a liberal political narrative. The effect of invoking this legitimating narrative is to situate within medicine the familiar myths of state politics and power. This is a move which not only naturalizes medical authority in ways that justify its depoliticizing strategies, and but one that also takes full advantage of its rationalist rhetorical character as well.

Medical authority, as it is articulated by the report, is contextualized within a vision of liberal pluralism through which politics is viewed as an artifact of public-policy making, as well as within the priorities of the private market economy. Within this particular representation of politics as policy, we find within the NAS report no elites, no class interests, no structural injustices, no institutional homophobia or racism, no political history of exploitation. It is a sterile narrative of politics that supports the disembodied representations of medical authority on the one hand, as well as masks any signs of those struggles over social control that take place as a result of the aspirations of medical power itself.

Discrimination against HIV infected individuals is a case in point. The report is clearly against "unfortunate
instances of discrimination in employment, housing, and access to social services" and recommends its prohibition by state and federal statute. However, the report limits its understanding of discriminatory practices to products of "unfounded fears" of contagion or "underlying prejudices" that "rationalize antigay biases". Discrimination within this framework becomes a clinicalized problem that requires technical policy solution -- legal and administrative regulations that forbid the creating of obstacles to the consumption of medical and social services by HIV infected persons.

The problem of discrimination is seen as one of ignorance and irrationality, to which the strong parental hand of the surveillance state must be applied. But something is missing here. Discrimination is not seen as a long historical problem of social order, or as part of an arsenal of group recruitment and cohesion strategies by powerful interests. It is not seen as something that has the status of institutional practice or norm, but rather as a limited and aberrant behavior of defective individuals. Thus medicine as institution is not implicated as an actor in discriminatory practices. All of this is supported by the representation in the report of the similarly depoliticized field of policy politics in which medicine operates.

The liberal pluralist narrative embedded in the work
also silences any critique of the market economy of medicine or the larger fiscal order within which medicine functions. Expenditures necessitated by the epidemic are totally conceived of within the existing levels of costs structured by the privatized system of health care in the U.S. AIDS is seen as workable financially within the already established order of medical services and their present reimbursement mechanisms. While the "many shortcomings in health care financing" regarding catastrophic illnesses are given token recognition, measures to address these issues are seen as already available and represent no radical realignment of the health care system. In contrast, others have seen AIDS as posing a threat of such significant proportion that it outstrips the capacity of the American privatized system to maintain even its present minimal equity of care and costs. Moreover, it is argued that the epidemic is already exacerbated by the deepening and extensive crisis of costs endemic to the present market system of for-profit commodified health care services.

Both the political vision and the economic silence of the liberal narrative offered by the report prevent representations which threaten the present basis of medical authority. More radical proposals such as those mandating a nationalized health care system, or the establishment of a public health service corps, are pre-
empted from consideration. As such then, the report does little justice to the varieties of political and medical experience of those constituencies affected by the epidemic, and can be seen as an effort primarily geared to holding the center of medical authority together.

The Presidential Commission on the Human Immunodeficiency Virus Epidemic

The other side of our equation is concerned with how medical authority gets infused into and used within AIDS policy. To what policy ends and in what ways is NAS text brought to bear on policy if at all. Fortunately, we have a direct documented link between the NAS report and a powerful expression of potential future AIDS policy for our examination.

As a result of the public pressure generated by the NAS report, and its recommendation to establish a national commission on AIDS, President Reagan created in June of 1987 an advisory commission to "investigate the spread of the human immunodeficiency virus and the resultant acquired immune deficiency syndrome." In a long process marked by controversy and the resignation of commission members including the initial chairperson, the Commission held numerous hearings and delivered, in June of 1988, its final report. The Commission report, and its nearly 600 very specific
recommendations, was immediately praised by most sectors concerned with the epidemic and was accepted in full by both presidential candidates (Mike Dukakis and George Bush) as the foremost document for a national AIDS strategy. Unfortunately, President Reagan's response was less than enthusiastic and he summarily ignored most of the important recommendations advocated in the report. However, with the coming to power of George Bush in 1989, the report still has a life in the determining of the new President's game plan for the epidemic, and is still regarded by many as the basis and direction for interest-group political action.

Our intent in pointing to this information is not as a prelude to an extensive examination of the report, but as an indication of the importance of the Commission's effort to an evolving public policy on the AIDS epidemic. By understanding this importance, we are better able to assess the value of any influence the NAS report may have had on the Commission's efforts, and thus the value of the NAS report on public policy in general.

Certainly, the Commission's report is a very different kind of product than that of the NAS. It is very specific in its recommendations (who should do what and when) and, yet in some cases, (as in the area of ethics and law) deals with some broader social issues than does the NAS report. But within its broad strokes,
the Commission's recommendations are in remarkable agreement with those of the NAS, and unlike its comments about other major players in health care, the Commission accepts without hesitation the NAS authority. On the larger issues, both agree on the importance of voluntary testing programs, on legal protections for confidentiality, on the expansion of public education programs as well as on more IV drug user rehabilitation centers and specialized street education activities, on an aggressive national and international research effort on HIV, antiviral drugs, and vaccines, on a policy of cooperation with world-wide AIDS prevention and control efforts, and on an overall dramatic increase in the public funds appropriated for reaching stated goals in all of these areas.

But our questioning of the Commission's account of the epidemic and the problems and obstacles encountered in stopping the spread of the disease, and its comparison with the NAS report, must go beyond these overall agreements and ask the question as to whether the Commission's account utilizes the textual mechanisms of medical authority as we have described in our study of the NAS report, (whether or not the Commission designates them as coming from the NAS) and its surveillance practices? Does it use those naturalizing and depoliticizing mechanisms to encode medical authority
within state discourse on AIDS? And how does it handle the replication or production of surveilling identities which we identified in the NAS report?

Thorough answers to these questions are more complicated than we would like, and would require another critical reading similar to that of the NAS report. Yet there are some indications that medical authority is both more naturalized, and utilized as legitimation for surveillance practices than even that allowed by the NAS report.

With regard to these ideological mechanisms of dissimulation that support medical power, we opine that the Commission is not as intent on respecting the coalitional aspect of medical authority (as we have previously described) and its maintenance, as is the NAS work. The Commission, in fact, is less delicate here and more narrowly defines health care professions within the more traditional doctor/nurse axis. Indeed, the "health care community" that the Commission envisions consists primarily of "physicians, dentists, paramedical providers, and nurses," so its textual incorporation of medical power into policy is much less sophisticated and less modern in many ways. Granted, the Commission's political agenda is much broader and more inclusive than just the interests of medicine, and its text reflects this more gross and less refined treatment of the
constituting authority of medicine. While this limiting designation certainly promotes medical power, it is one that lends itself to more internal disciplinary divisiveness within medicine especially since these designations are directly connected to the disbursement of potential resources. This is the type of divisiveness that the NAS report seemed to take much effort to avoid.

Probably more important in this regard, and similar to the NAS report, is the rapid transition from diagnosis, to need, to professional service and "symptom management" effected by the text. The impact of this practice, is, as we have previously indicated, not only to manage symptoms, but to also promote the internalization, maintenance and reinforcement of disciplinary turf boundaries. As in this example:

HIV-infected persons with lymphadenopathy or constitutional symptoms (CDC III and IV-A) also have a need for counseling and education and for regular medical follow-up by a primary care provider who can manage the patient's symptoms. These patients need psychological support services, some need financial counseling and assistance, and linkage to other social services. The person with constitutional symptoms may need periodic hospitalization usually for diagnostic purposes or for symptom management, and in some cases may need support in the home to carry out activities of daily living.

Again, at the risk of over-emphasis, we are not opposed to the notion of need or professional service. What we continue to point out here is that the trajectory from suffering to modern disciplinary medicine is repeatedly being naturalized through a language practice
which 1) accepts as universal the notion of need, 2) accepts as inevitable that certain needs are present within individuals within specific diagnostic categories (which are often times themselves framed within the concept of need), and 3) constantly professionalizes the meeting of those needs within service designations. This encoding process occurs, understandably enough, within a highly competitive, dense and power conscious health care sector. Thus, the notion of need, as it circulates within the Commission’s report, is one that has been transformed from a highly variable and culturally specific psycho-social possession of an individual or group, to a mechanistic indicator or sign that triggers a particular and well articulated medical system response.

The Commission’s report, in addition, constructs the health care system in ways that are similar to the NAS when it comes to the positioning of hospital care, and by our previous arguments, the positioning of medical authority as well. Both reports talk about comprehensive, coordinated and integrated care delivered by a continuum of services. Yet in the defining of that care, both locate the hospital as the central critical metaphor of those services and define other care options as an alternative or replication of that center.

"To date," the Commission writes, "hospitals are the primary providers of care for persons with symptomatic
HIV infection through inpatient hospital admissions." And while the report recognizes the "efforts of many religious and community-based organizations nationwide in providing compassionate care," the "availability" of these care settings are (and one must add, only) "an essential alternative to hospital-based care" [author's emphasis]. Again, we have argued that the extent to which the text replicates, as natural and obvious, this object (the hospital) as the primary site for the location of that-which-constitutes-the-essence-of health care services, is the extent to which the text normalizes, and places beyond discourse, the legitimacy, institutional arrangements and power of medical authority. Once the hospital-as-center is invoked in policy discourse as unproblematic, the text confirms a host of both local and more widely accepted disciplinary settlements and hierarchies that will determine not only the kinds of care people will receive (and be supported by the state), but also what kinds of illnesses and health experiences will be legitimated.

Finally, there is arguably a more striking and visible instance of a surveilling practice that extends those medical rationales which not only support medical authority through policy, but one that also extends the power of the state. The Commission's report recommends that HIV transmission be criminalized as serious offense
in those situations where individuals "knowingly conduct themselves in ways that pose a significant risk of transmission to others". This effort is to include as well the strict enforcement of prostitution laws. We are thus confronted with the strong adoption of the "prostitute" as diseased paria within an important policy context and text, and one that goes beyond anything suggested by the NAS report. The prostitute now becomes a surveilling identity, in which the power to dictate the fate of individuals so labeled is derived not only from the moral/security concerns of the state but also from the medical authorizations of what constitutes sickness and deviance as well.

What is unusual about the Commission’s recommendations on prostitution is that they go against much of the public health emphasis in the NAS report and elsewhere which tries to configure AIDS prevention efforts as separate from criminal processes as a way of ensuring cooperation from those at risk for infection. But the Commission’s report not only recommends the mandatory HIV testing of the prostitute, as it does for any person considered as a "sexual offender" (thus conflating the prostitute with the rapist, for example) but it assumes that the "strict enforcement" of anti-prostitution laws and AIDS prevention and control efforts are one and the same moral and medical endeavor. And herein is the grand
leap of grammar in which the oppression of many poor and disadvantaged women is justified. And while the NAS report, as we indicated, does not condone such a practice, its validation of the "prostitute" as pathological other, and its equivocation on how to handle this at-risk population does nothing to counter the continued criminalization of these women.

As we can see, these two social texts converge into a mutually sympathetic reading of the AIDS epidemic. The authority structures of one support the reality constructions of the other and vice-versa. Tactics are always arguable in these texts, but the sites of power almost never. Policy never confronts the "ownershiep" of health by medicine, and medicine rarely sees politics outside of policy-making. Or so it would seem. At least those are the rules by which these texts seek to gain power and presence in the discursive economy of this most tragic epidemic.

Conclusions

It is probably in the nature of this inquiry that the ground we have covered lends itself more to the raising of questions than that of answering them. But questions, in our mind, qualify as political/theoretical interventions as well as answers, and probably more so. Through the readings that are inspired by our questions
we come back to those questions, and we hope, others that
spark more consideration. By way of an apology we can say
that if those who read this study are dissatisfied with
our version of the will to power/truth of medicine when
it comes to AIDS, but yet find themselves drawn to pursue
these same issues due to our mistakes, then success is
ours. This is because the type of textual inquiry
attempted, and the sensitive nature of the subject at
hand, are both reasons for many to consider putting their
efforts elsewhere. The course is unsteady, the
theoretical models are less than instructive, and the
gains are often questionable.

Yet, if there is any contribution to be made, we hope
it is in the creation of a counter-text that feeds
empowerment, that refuses to accept the hidden
definitions of power without reflection, and that
expresses a political courage and critical imagination
worthy of respect. This is the moral and political
agenda which allows us to rush forward often into areas
of AIDS literature for which we were at first ill-
prepared to absorb, but in which our prior experiences in
breaking down intellectual and disciplinary boundaries
produced the persistance to move ahead. But the agenda
also counsels respect and patience as well as a
generousity of spirit to other readings and forms of
knowledge. And in this sense, nuance and history are
everything when it comes to looking at meanings of text, and what informs the rules behind them.

In this reading of medical authority, surveillance, and the AIDS epidemic, we engaged in a series of theoretical and historical moves that are intended to focus attention on how medical authority achieves its position and power within the discourse that is determining how we see the AIDS epidemic. We approached this task within specific postmodern orientations 1) that stress the central role of language in the making of meaning regarding illness and disease, 2) that see these meanings, and the authorizations they represent, as maintained and reproduced through both institutional and textual surveilling practices, 3) and that view the relations between medical and state discourse on AIDS, as it is constituted in AIDS policy, as also reaffirming those meanings.

Our interrogation of the NAS report in the context of these issues, however, has been less to proceed along a linear path of argumentation by which we can now reveal the progressive insight achieved, than to fill out a political and intellectual domain of inquiry. As such this dissertation is a series of readings each departing from a theoretical point that, when seen all together, attempts to support a way of thinking about the epidemic that is attentive to the workings and effects of power.
But what we have done here is not all that could have been done, or all that we would have liked to accomplish. Our first conception of this project was one through which we saw medical discourse as only one way of speaking this epidemic, one that was (is) in competition with others (such as religious discourse). It was our intention to examine the nature of the struggle between these contending discourses as they attempt to capture dominance over the 'meaning' of the epidemic through their surveilling practices. Yet the investigation into medical discourse itself necessitated such a depth of effort and examination, that the broader project is still left for future consideration.

And while we have addressed some of the questions dictated by our theoretical interests, they may not be the questions others would like to see answered. These include the issue of whether medical authority and its surveillances practices are in the end justified by the enormity of the epidemic and human sickness in general. Why bother with this kind of examination at all if we cannot say with certainty that medical authority is exploitive? What other social mechanisms could medicine in fact utilize to achieve the goal of human well being in any case?

The tremendous pull of these questions is admittedly resisted in this work. For one we see no contradiction in
seeing medicine, as a social practice, being invested with multiple meanings and effects than may span the continuum of moral and political judgements. But we also resist because the terms of the questions ask us to give up too much, to invest too many with moral authority, to accept an interpretation of history, of the body, of science, and of the state which is too constraining and binding on our intellect, and is to be blind to the abuse of power. They are questions which dichotomize ourselves into compliance.

And yet we have given answers of sorts. Our very intrusion into medical authority in this way subverts it. But ours is an uneasy subversion to be sure. It is a subversion of masked rules that govern human relations in a particular arena, a subversion of the translation of individuals into vehicles for power, a subversion of the power drives of the healing industry and not the healing relationship. There is the subversion of the exclusivity and inequity in medicine, of the closed shop when it comes to signifying and determining the nature of sickness, and of the often unbearable arrogance embedded into all of this. And finally it is a subversion of medicine’s tacit disciplinary and political ownership over the AIDS epidemic, the domination of those this disease affects, and the control of social meaning it dispatches.
NOTES


"Policy analysis is an applied social science discipline which uses multiple methods of inquiry and argument to produce and transform policy-relevant information that may be utilized in political settings to resolve policy problems." (p. ix).


5 See Duncan Macrae, Jr., "Discourse in Public Policy: Argumentation versus Reasoned Invention". A paper presented at the annual meeting of the American Political Science Association, September 1987, Chicago, IL.


8 Ibid., p. 255.

9 Ibid., p. 266.


11 Michel Foucault, The Archaeology of Knowledge (New


13 For a discussion of President Reagan's ambiguous use of the term, see Newsweek, June 8, 1987.


15 Confronting AIDS, pp. 15, 65, 119, 125.

16 See, for example, Ibid., pp. 14, 15, 126.


20 Confronting AIDS, pp. 133, 135.

21 Ibid., p. 22.

22 "The financing of care for patients with AIDS and other HIV-related illness now depends on the same variety of public and private plans that apply to patients with other diseases."


25 On President Reagan's limp response to the Commission's report see New York Times, June 28,
27 See Ibid., chapter 3.
28 Ibid., p. 9.
29 Ibid., pp. 18, 19.
30 Ibid., pp. 130, 131.