**Theory and Practice of Structural Agenda Setting:**

**A Case Study of U.S. HIV/AIDS Policy from 1979 to 1989**

Nathan Abell

University of Texas at Austin

Supervisor: Dr. Jeffrey Tulis

abell.nathan@gmail.com

ABSTRACT: Agenda setting is a widely researched area of political science, applicable to virtually any political structure, decision, or agent. The early response of the American federal government to HIV, however, presents a unique challenge to traditional theories about agenda setting, particularly American agenda setting. HIV was placed on the political agenda far after it should have been addressed, and a stronger American federal response, it seems, would have largely mitigated the scope of the current AIDS pandemic. One account of the process that occurred from 1979 to 1989 places the emphasis on the lack of knowledge surrounding the disease as making that weak response not seem “weak”, but rather proportional, since the terrible potential of HIV was simply unknown. Another account decidedly rejects that progression, and argues that active homophobia and xenophobia caused the executive branch to actively resist discussions of or treatment plans for HIV. This split in historical narratives mirrors, I will argue, a problem for studies of agenda setting insofar as it highlights the tension between models that places emphasis on individual agency and decisions as opposed to the epistemic structure used at the time the agendas were being set. This paper is an attempt to both understand the agenda setting process with regards to HIV/AIDS that had such disastrous consequences, and to see what that understanding can contribute to a knowledge of the agenda setting process at large.

**Introduction**

Agenda setting, while not the only important area of study in politics, is perhaps the only one integral to understand any political decision or action. Given that a sovereign, a people, or an American political official could act on any number of issues, yet choose a certain finite number due to both resource and temporal limitations, the process by which they decide to give attention or to ignore policy areas is particularly important. Indeed, it can frame the particular political debates in ways that influence their outcomes. This paper is an attempt to explore and understand those different factors which influence the agenda setting process, both drawing on and refuting parts of existing theories about the structure of agenda setting. My argument is that typical modeling in political science of how agenda setting works is inadequate, since it does not take into account the *structure* in which those decisions occur. As such, I argue that because agenda setting takes place within and is largely influenced by ‘structure’, that the story is not complete without an analysis of *structural agenda setting.* The means of showing this problem via the inadequacy of old models will be an analysis of the scientific and political response to the HIV/AIDS pandemic, from the U.S. federal government, from 1979-1989.

To that end, Section I will discuss the scientific background and role of structure on the epistemology of the disease. Section II will attempt to illustrate the role of this conceptual structure within the actual political agenda setting process within the American federal government, roughly from 1979 to 1987. Finally, Section III will outline possible prescriptive implications of the preceding analysis.

**I. Investigation**

Political and historical perspectives on the response of the United States government to the introduction of the HIV virus into the country typically fall into two camps. One side sees the federal government as mustering an extremely weak response to the virus out of deliberate malice towards the populations primarily affected (e.g. gay men, Haitian immigrants, intravenous drug users, and so on).[[1]](#footnote-1) The other sees the response of the federal government as understandable, given how little was known about the disease, in particular how it was spread, at the time.[[2]](#footnote-2) These competing narratives are indicative of the utility, here, of studying the HIV crisis of the 1980s. This particular historical instance combines, in the same subject matter, a lack of factual knowledge about a potential threat with extremely prejudiced nonscientific beliefs about that matter. As such, it provides a unique example to determine what role epistemic and social structures have on federal agenda setting when the factual information is incomplete.

My contention is that both perspectives are correct to a limited degree. HIV/AIDS was a little-understood and terrifying disease, and as such historical blame cannot be simply assigned to any individual political leader or group. Yet, given that the response had to take *some* form[[3]](#footnote-3), it channeled the pre-existing social prejudice against those groups in a way that did not conform to the typical agenda-setting models. It was far subtler.

 The first level on which this occurred was the basic initial scientific investigation into HIV once it appeared, and was noticed, in the United States. The set of cases typically termed the ‘first’ cases of American HIV occurred during mid to late 1979 and early 1980, with physicians noticing increases in certain kinds of ‘cancer’ among their patients. Several doctors reported those findings from several cities on both the West and East Coast. The first official announcement regarding the disease came on June 5, 1981 by the Center for Disease Control (CDC), whose focus was on a new form of pneumonia noticed in several Los Angeles hospitals among predominantly gay male populations. As the disease progressed, numerous explanations began to arise as to its origins and potential future dangers. The Gottlieb and Friedman-Kien reports are good historical examples of such outlandish theories (Rimmerman 2002, 2008). What is important to note, though, is that initially the state-affiliated medical community *did* notice the start of the pandemic in the U.S. and did take action to attempt to understand and control it (House Committee on Governmental Operations 1983, 1985).

 The public, for the first time, was made aware of the pandemic on July 3, 1981 vis-à-vis a New York Times article entitled “Rare Cancer Seen in 41 Homosexuals”. By December of 1981, the medical discussion of HIV/AIDS, while not called as such at the time, was in full swing, with several articles on the topic appearing in the *New England Journal of Medicine* (Behrman 4-7; House Committee on Governmental Operations 1983).[[4]](#footnote-4) In 1983, the actual name “AIDS” entered the National Library of Medicine, as a change from its previous name “GRID”, or “Gay Related Immune Deficiency” which had taken hold in the popular mind (Behrman 6).

 Even within the most rigorous scientific communities, HIV was explicitly characterized as a “gay” or “degenerate” disease, justified at the time because a majority of those infected with the disease came from a “4-H” category. The “4-H” categories, used publicly and by the CDC until an official change in 1986, were “homosexuals, heroin addicts, hemophiliacs, and Haitans”, with the third category often substituted for “hookers”. Explanations ranged from the Friedman-Kein hypothesis, arguing that gays had created a “sexual third world” in the United States that spawned the disease, to the thought that infected infants were such because of “immoral home environments”. In retrospect, the typical explanation offered is that doctor’s at the time conceptualized homosexuals as a stable identity category as opposed to a series of behaviors, and as such focusing on the “lifestyle” of American homosexuals in general rather than on what we now know “really” spreads the disease. In accounting for the scientific bias of the time, however, neither historical narrative seems to fit. There was a concerted effort, once the patterns of the disease were recognized, to shift scientific thought into a more ‘correct’ category. Perhaps the most pronounced example of this is the active name-changing of the disease to AIDS by the CDC in early 1983 to accommodate that perspective.

 This is inexplicable within the standard historical explanations for initial problems with HIV/AIDS research. Active homophobia on the part of scientists through neglect is clearly inaccurate, since there was heavy interest and research in the area. If homophobia was the driving factor, it is unclear why the CDC, or the scientific community at large, would have investigated at all. On the other hand, no fact or piece of evidence existed to prompt the linking of HIV and homosexual identity other than that gay men seemed to have it. Indeed, modern science has actively disproven the “innate” connection between HIV and homosexuality, instead locating transmission in specific behaviors. Moreover, extensive documentation supports the premise that the attribution of the disease “innately” to the Haitian population was both unsound science and public policy (House Committee on Governmental Operations 1983, 41-44) What, then, prompted the characterization of HIV as an innately “gay” disease rather than an immune disease that happened to affect gay men more?

To answer that question, an understanding of the structure of scientific investigation is necessary. Thomas Kuhn asserts the “primacy of paradigms” in scientific activity. What that means, he argues, is that, “[a]t a level lower or more concrete than that of laws and theories, there is […] a multitude of commitments to preferred types of instrumentation and to the ways in which accepted instruments may legitimately be employed” (Kuhn 40). Kuhn is largely concerned with the ways scientific activity accounts for “anomaly” and the possibility of unexpected realizations about the natural world. That part of the analytic is less relevant here, since political issues are not “natural” in the same sense, but the byproduct of individuals, groups, or the state making claims on themselves or each other. What is relevant, however, is Kuhn’s argument that “since nature is too complex and varied to be explored at random, that map is as essential as observation and experiment to science’s continuing development” (Kuhn 108). Simply put, since a starting point, or some theoretical assumption, is necessary, a paradigm is unavoidable. Even if those assumptions can be “justified”, that assumes in itself a justificatory system to produce that status.[[5]](#footnote-5)

This problem, however, is fundamentally unavoidable, particularly with regards to exceptionally complex scientific problems. The structure of the HIV problem required importing *some* set of assumptions to begin the research process. It exemplified this kind of scientific structural agenda setting insofar as it relied on assumptions that could not be reliably tested at the time. As Sandra Panem notes, as a physician writing in the mid-1980s,

the problem was further complicated by the complexity and interdisciplinary nature of AIDS; it is a medical mystery that raises fascinating virologic, immunologic, epidemiologic, and oncologic questions. This very complexity-and the eventual appreciation that cracking its solution would provide fundamental insight into the as yet poorly understood processes of immunology-has engaged the attention of so many scientists. Yet ironically, the complexity of AIDS affected the ability of the establishment to initially target a research response (Panem 24).

 The scientists at the time operated within a certain bureaucratic structure, namely the CDC, and within a given research structure. More importantly, there is absolutely no way those scientists *could* have understood the actual biological processes at work. Some guess work was necessary because a structure for investigation was necessary.

With regards to HIV, however, the structures chosen turned out to have problematic impacts both on addressing the problem in question as well as in gathering data on that problem. As Treichler notes, in commenting on the procedures used by various scientists, particularly those associated with the federal government,

[O]nly in late 1986 (and somewhat reluctantly at that) did the Centers for Disease Control expand upon their early "4-H list" of high-risk categories […] The original list, developed during 1981 and 1982, has structured evidence collection in the intervening years and contributed to a view that the major risk factor in acquiring AIDS is being a particular kind of person rather than doing particular things. Ann Giudici Fettner pointed out in 1985 that "the CDC admits that at least 10 percent of AIDS sufferers are gay and use IV drugs. Yet they are automatically counted in the homosexual and bisexual men category, regardless of what might be known --or not known-about how they became infected." So the "gay" nature of AIDS was in part an artifact of the way in which data was collected and reported.

The very research methods involved in initial understandings of HIV, then, were contaminated with a latent bias that placed homosexuality as a more primary factor in HIV acquisition than other behaviors, such as intravenous drug use, that we now know are far *better* predictors of HIV acquisition than sexual identity. Moreover, there was an embedded misunderstanding of the intersections between the groups “at-risk” for infection. For example, perceptions of masculinity among Haitian-Americans in the early 1980s generally precluded admission to either homosexual conduct or drug use. Indeed, the result was a generalization of “HIV” into “Haitian,” with little understanding of the actual mechanisms of transmission (House Committee on Governmental Operations 1983, 45-61).

Now, it is unclear why the assumptions and paradigms imported to understand HIV went in this particular direction. Again, active homophobia seems incomplete because the scientists in question were actively concerned with understanding the nature of the disease to save the lives of homosexuals who had it. On the other hand, scientists clearly came, eventually, to understand the nature of the disease correctly, so the assumptions in question were clearly not absolutely *beyond* some kind of rational examination. Indeed, Pierre Bourdieu argues that, in the context of scientific investigation,

Academic interrogation inclines [one] to take up a point of view on his own practice that is no longer that of action […] encouraging him to shape his explanations in terms of a theory of practice that meshes with the juridical, ethical or grammatical legalism to which the observer is inclined by his own situation […] His remarks convey this primary truth of primary experience only by omission, through the silences and ellipses of self-evidence […] This language, which recognizes only particular cases and details of practical interest of anecdotal curiosity, […] which minimizes the vague generalities and *ad hoc* explanations appropriate for strangers, leaves unsaid all that goes without saying (Bourdieu 91).

So, in engaging in any academic investigation, the scientific necessity of reducing and generalizing may omit the “fringe” assumptions embedded in the investigation. With regards to HIV, however, why *these* particular academic assumptions about the nature of sexual identity went unnoticed despite the scientific interest in the area. This question of *what* the logic was which informed what we would now call ‘mistakes’ in the early 1980s has been explored at length in academic literature. A good articulation of the general theme, however, can be found in Mirko Grmek’s *History of AIDS*, where he notes that

In America the press gave broad coverage to the subject […] The tone was at once reassuring and alarming: a new scourge has descended on humanity […] Journalists avoided the term ‘epidemic’ and emphasized the paucity of the victims and the fact that they were confined within certain ‘risk groups’ or ‘target populations’. Since it was no longer certain that homosexuals alone were at risk, commentators strove to insinuate that all the risk groups were in some way ‘marginal’ (Grmek 31).

While now such a description seems remarkably homophobic to the modern reader, what is important to note is that while the prevailing mindset may well have been homophobic, the scientists in question, given the narrowness (relatively) of their question, were not in a position to see that. So, in some capacity, the initial research into HIV proceeded according to a set of assumptions that dually affected the outcome of the that research while simultaneously not being the kind of research which would immediately disprove those assumptions. For, as Kuhn argued, “If there were some higher authority by recourse to which his vision might be shown to have shifted, then that authority would itself become the source of his data” (Kuhn 113). Scientists in the early 1980s were not, in this sense, deliberately homophobic, but still imported homophobic “background” knowledge into their study.

 To further illustrate the point, the reaction from organizations dealing with hemophilia was decidedly *not* like that of groups dealing in issues pertaining to race or sexuality. In its report before Congress in 1983, the National Hemophilia Foundation stated that “The Centers for Disease Control has kept us informed of all new AIDS cases and hemophilia related developments. They have been sensitive to the needs of our constituents by providing background information in a timely ay so that we have ample time to communicate to treatment centers, chapters and patients” (House Committee on Governmental Operations, 1983, 55). In forming the knowledge base necessary to engage the disease, then, it seems that hemophiliacs were engaged much earlier and more directly than other groups, despite having identical illnesses.

All of this, however, merely speaks to a sort of epistemological agenda setting informed by what was, by all accounts, the savage homophobia of the time.[[6]](#footnote-6) Indeed, this analytic explains why a large amount of advocacy on the part of people with HIV has targeted the epistemic presumptions associated with the disease. Groups like ACT UP, or the AIDS Coalition To Unleash Power, emerged in the 1980s specifically to engage in that kind of project. Their struggle was explicitly and directly epistemological, in that the call was not for a particular action from any agent, but rather a generally increased concern with HIV that would, ideally, motivate a larger knowledge base (Brier 156-171). Their “grassroots epistemological warfare” was an attempt to challenge what they saw as the structure informing the terms of the agenda setting debate.

The background knowledge, even in the most rigorous circles, was clearly influenced to some extent by prevailing attitudes about homosexuality and its place in American society. Agenda setting as a political process, uniquely, is concerned with the evaluation of existing social problems as important or unimportant, and their associated placement on the national agenda. As such, what remains to be seen is exactly how and to what extent, if at all, the epistemic “background” of HIV/AIDS influenced its placement on the national agenda, and what that analytic says about the agenda setting process as a whole.

**II. Federal Action**

 The history of federal response to HIV/AIDS in the 1980s is extensive and, with good reason, highly critical. From June 1981 to June 1982, the federal government spent approximately one million dollars on AIDS research and treatment, as opposed to nine million on the comparatively trivial problem of Legionnaires disease. In late 1982, Congress appropriated 2.6 million for the same purposes, yet was heavily opposed by Reagan, who claimed the money was simply unnecessary (House Committee on Governmental Operations, 1983, 1985, Rimmerman, Shilts). Already, the agenda setting process seems to be leaving something out, insofar as nearly five years collapsed before the idea of increased funding, beyond that provided for other, far less threatening problems, made its way onto the national agenda. Indeed, President Reagan, in office for nearly all of the relevant time period, did not mention AIDS publicly until 1987, years after both the introduction of the disease *and* wider international recognition.[[7]](#footnote-7) What accounts for the delay?

 The story begins to get interesting with the arrival of 1983, with the Reagan administration continually refusing to advance funding for AIDS research. The summer of 1983 saw the first notice of HIV penetrating the executive branch, with several gay activists meeting with low level members of the Department of Health and Human Services, at HHS headquarters. That meeting was quickly followed up by a second meeting, this time involving members of the Moral Majority, and largely focused on how the administration should react to the “homosexual” element of the crisis (Brier 82-4). The next such meeting was in August of 1985, where officials (including then Secretary of Health and Human Services Margaret Heckler) were told that “only” the risk groups acquired AIDS, and a conservative, family, heterosexual-oriented response was planned, emphasizing abstention from homosexual conduct as a way to fight HIV (Brier 82-87, Behrman 13-20). As a byproduct, the President generally did not talk about HIV to void the “political risk” involved with doing so, little money was funneled into research, and as such legislator’s had little idea how to shape policy. Indeed, President Reagan actively opposed expansion in funding to address HIV while in office. The effects of that delay are widely documented. In 1989, President George Bush appointed a federal commission to refine and target the federal response to the crisis. In their initial reports they documented that

Our nation’s leaders have not done well. In the past decade, the White House has rarely broken its silence on the topic of AIDS. […] Articulate leadership guiding Americans toward a greater response to AIDS has been notably absent. We are accustomed to hearing from the “bully pulpit” about national problems and how we should address them, so perhaps the public cannot be blamer for assuming that such a silence means that nothing important is happening (National Commission on AIDS 1991).

This delay, however, is mysterious in its origins. The scientific evidence, while structurally influenced as described previously, still supported a greater administrative response, if only with regards to funding apportionment. The absolute failure of President Reagan, however, cannot be purely attributed to even budget concerns, or any countervailing issue, since the problem was not only a lack of funds, but also of leadership. The lack of even rhetorical leadership by the President thus had an influence not reducible to scientific ignorance and had harms not confined to simply keeping AIDS off the agenda. Rather, it qualitatively changed the nature of public perception of AIDS such that it *could* not get on the agenda.

The President is not simply thought of in America as another political officer. In some sense, he personifies the nation. He is a leader, and not just an officer. Jeffrey Tulis, in *The Rhetorical Presidency*, outlines many of the reasons why the President has been able to take on such a unique popular role. Indeed, his analysis of the rise of the rhetorical presidency, and the ways it takes power, illustrate its dependency on structure in the sense conceptualized here. Tulis argues,

It is increasingly the case that presidential speeches themselves have become the issues and events of modern politics rather than the medium through which they are discussed and assessed […] the terms of discourse that structure subsequent ‘sober’ discussion of policy are altered, reshaping the political world […] By changing the meaning of policy, rhetoric alters policy itself (Tulis 179).

This understanding of Presidential power somewhat illuminates Tulis’ claim, elsewhere, that a “political common law” is important and desirable. The reason it is desirable is because it helps to make apparent the implicit structural modifications the President makes to the agenda setting process when s/he exercises their rhetorical prerogative (Bessette and Tulis 246).

 President Reagan’s non-discussion of AIDS whatsoever is thus not simply another move in the agenda setting game. Rather, recognition by the individual conceptualized as the *leader*, not merely as another player, of national politics prevented the issue from being recognized *as an issue*. He did not use the “bully pulpit” necessary for political ideas to gain the coherency necessary for consideration.

 The structure that led to such an omission was alluded to earlier. President Reagan’s primary source of political power, and his particular rhetorical focus, was consistently exclusive of much of the population for whom HIV was an important concern. The administration simply did not want to associate itself with the populations in question. Sills explains that, “the Reagan administration was reluctant to turn to Congress for funds to support AIDS research and services because of the root causes of the disease as it manifested itself in the U.S., that is, in dangerous sex practices and in infection through drug injections” (Sills 157). In this context, HIV was never placed on the agenda, at least via the executive, not because of a lack of knowledge about the crisis nor as the result of a robust public dialogue about the issue. There was never a public debate about the importance of acting on the issue or a reason offered why the federal government was not acting on it; it was simply not mentioned. Such an absolute lack of presidential leadership on the issue thus preemptively prevented issue from even getting the opportunity to be rejected from national agendas. Indeed, its eventual presence on the Presidential agenda, around February 1987, was largely a byproduct of a decision by Reagan’s advisors that AIDS education should “*not* be neutral between heterosexual and homosexual sex” (Brier 90-95).

 This lack of response caused a particular problem for the Food and Drug Administration under Reagan. In large part, the FDA did not see the President as exercising any kind of organizing prerogative with regards to the issue, and as such was delayed in doing research into the area. According to Associate Commissioner for Policy and Planning William Hubbard, it was thought “within the FDA that the Reagan administration didn’t want to talk about AIDS for a long time […] AIDS activists concluded that the agency was sitting on lifesaving AIDS drugs and refusing to let patients have them, sort of a ban by the social conservatives” (Hubbard 31). Indeed, the lack of Presidential leadership was not just felt publicly, but within the administration itself. Don Francis, a CDC official during the emergence of the disease, claimed before a congressional committee on March 16, 1987 that “Much of the HIV/AIDS epidemic was and continues to be preventable. But because of the active interference with scientifically designed programs, the executive branch of this country has caused untold hardship, misery, and expense to the American public” (Rimmerman 2002, 89). A similar sentiment was echoed by Congress in 1985, with testimony from AIDS specialists arguing that

We also need besides information, we need information coming from people that have some leadership qualities and that have believability quotients. We have not seen up until this point moral leadership coming from our elected officials […] If President Reagan has not spoken on it, the message that comes across loud and clear is it is not important and it is peripheral to American life (House Committee on Governmental Operations 1985, 219)

 For that reason, Congress was far less able to organize a coherent response to the HIV crisis within the time needed to have a real effect. The attempts to do so, however, did occur, and far before the executive branch recognized the disease at all. Three particular Senators, Barbara Boxer of San Francisco, Henry Waxman of Los Angeles, and Ted Weiss of New York, began advocating for increased federal attention to AIDS, the latter two most importantly doing so in late 1983 (Rimmerman 2002, 2008). That advocacy consisted primarily in urging a Congressional response to the pandemic in general. Specifically, proposals were offered to increase funding for AIDS research\, education and outreach campaigns to at-risk populations, and social research into patterns of transmission (House Committee on Governmental Operations 1983; House Committee on Governmental Operations 1985). While the funding for research steadily increased with time, little headway was made on the other issues, with the Senate heavily resisting such proposals. Ultimately, the final goal was accomplished in 1987, when President Reagan created the Watkins Commission, an agency designed to plan the federal response to a medical crisis nearly a decade old (Brier, 92-7; House Committee on Governmental Operations 1985). In that year, a cogent federal response began to emerge. There were limits, however, to the Presidential response to the findings of the Watkins Commission. Indeed, according to the House Committee on Government Operations, the President virtually ignored the report of the committee, produced in June 1988, for an extended period of time (Richert 469-70). Additionally, the efforts of the executive branch, specifically Surgeon General Koop, to respond appropriately were hindered by the emphasis Koop wanted to place on sex education and other policies out of sync with prevailing conservative attitudes at the time (Brier 98).

 What accounts for this delay? By 1983, the medical community had altered the name of the disease from “GRID” to AIDS, and had begun to change its mechanism of response from identity-based to behavior-based activity (see the preceding section). In this context, the form the opposition to such federal action took within the legislature is particularly interesting.

 The opposition was spearheaded by Senator Jesse Helms, a Republican who actively opposed the perceived “homosexual agenda” of the time. Helms proposed, and succeeded in getting passed, regular amendments to the federal appropriations bills concerning AIDS that prohibited the spending of federal money on AIDS education materials that “promote or encourage, directly or indirectly, homosexual activities”. The Senate overwhelmingly passed the amendments. Indeed, this opposition crystallized with the first Presidential recognition of HIV in 1987. On October 14, 1987, Senator Helms delivered a Senate address adamantly opposing various increases to HIV research funding by denouncing a safer-sex comic book published by the Gay Men’s Health Crisis Center of New York.[[8]](#footnote-8) The thrust of his criticisms, that typified legislative concerns with the funding and support of HIV prevention programs, was that they encouraged “sodomy” and other perceived parts of the so-called “homosexual lifestyle.” Indeed, this kind of advocacy is specifically rooted in the mindset, identified in Section I, of perceiving homosexuality and other “degenerate” behaviors as the “actual” threat, not the disease itself (Rimmerman 2008).

 The legislative response to the crisis, however delayed by such homophobic opposition, was ultimately much faster than the executive response. That speed, however, is still only comparative. Government scientists, within the CDC, recognized the crisis as significant enough to warrant further attention as early as 1980, poorly understood as it was. Recognition in Congress was still later than scientifically prompted, just earlier than the executive. So, while active homophobia explicitly attempted to push the issue off the agenda, via Senator Helms’ platform of concern for ‘spreading’ homosexuality, some factor kept the issue from crystallizing enough to even elicit such a response. Simply put, the question is why it took so long *for there to be a debate* about whether or not, and how, the federal government should respond that provided the context for Helms’ opposition. Moreover, why did this initiate take place within Congress and not originate with the President, with the latter being empirically much more capable of assuming these kinds of leadership roles?

 Several events that interceded from 1983 to 1987 are particularly enlightening on this point. First, the possibility of heterosexual transmission was specifically documented in 1983, the same year that Congress began to really discuss the disease at all. This realization had two interestingly opposed impacts. It opened up the possibility that HIV could, theoretically, be transmitted to any person, including every member of every constituency. As such, public advocacy for research into the disease could, and did, take the form of public health concerns that included *everyone*. It was not a “gay” concern, but an unqualified public health matter. Additionally, though, the possibility of heterosexual transmission generated an overwhelming backlash against those groups thought to be the tipping points for infection in the “general population”. As Grmek describes, “Heightened consciousness of the possibility of contamination by heterosexual activity and by blood transfusion, moreover, fanned the hatred of certain minorities. This unexpected plague, divine retribution, placed the mark of infamy on homosexuals […] and in general the ‘marginals’.” (Grmek 39)

Second, in 1985, Rock Hudson publicly acknowledged his infection, as a heterosexual male and via heterosexual sex, with the HIV virus. This event marked a radical rhetorical shift in the way HIV was discussed in the media. The incident expanded the scope of the possible ‘infected’ beyond sexual orientation to sex in itself. A similar incident occurred with the public disclosure of Ryan White’s HIV status as a white, heterosexual, middle class teenager who contracted the disease via a blood transfusion, and of “Magic” Johnson’s HIV status in 1991. According to Philip H. Pollock III,

The symbols and values associated with Johnson’s situation, particularly his proclaimed (and unchallenged) heterosexuality, were fundamentally at odds with the connection between AIDS and homosexuality […] Johnson did not explicitly say that government funding AIDS treatment should be increased, or that the AIDS problem has gotten worse, or that the disease can be contracted through heterosexual contact. But he did say that ‘it can happen to anybody, even me.’ that he is ‘far from being homosexual,’ that he endorsed ‘safe sex,’ and that he would become a ‘spokesman’ for the disease […] citizens would tent to take his case as typical of a large class of cases. And the mental picture of his predicament would not be readily available in public memory for future reference […] It […] produced a change in the *structure* of opinion, a durable shift in the type of values people use when deciding where they stand on policies dealing with the disease (Pollock 429-30).

The public disclosure of the HIV status of individuals who did NOT conform to pre-existing notions of who the disease affected thus marked a qualitative shift, obvious in the rhetoric used at the time, in public and political perceptions of the disease.

 Third, the political situations of Senator Helms and Senator’s Boxer, Weiss, and Waxman were profoundly different, with the former building a political career on explicitly homophobic and conservative Christian constituents and policy, while the latter represented areas with significant gay populations. Indeed, all three democrats represented areas, New York and California, with significantly higher numbers of constituents in at-risk populations. Importantly, though, their advocacy did not begin, despite those populations, until the year heterosexual transmission was officially recognized as possible. These issues are all extensively documented via letters sent to Senators Boxer, and others, from queer organizations specifically advocating in such a way (House Committee on Governmental Operations 1983, appendices).

 Thus, the historical trend is generally that the issue got attention on the agenda as it became more and more identified with the heterosexual population, and only once it was absolutely clear that the heterosexual population was implicated whatsoever. Indeed, it became no less lethal to at-risk populations, such as IV drug users, that it did affect during this time. It was also not a problem of those groups, such as homosexuals, lobbying Congress for activity in the early years and Congress failing to respond. Simply, no attention was given at all, in terms of a substantive federal response, until 1983.

 Indeed, it was this specific strategy adopted by the three aforementioned democratic senators in advocating for federal attention. As Rimmerman argues, “One way that congressional Democrats attempted to force the administration to increase funding and other forms of support for people with HIV/AIDS was to publicly highlight the large numbers of people affected by the epidemic. This strategy helped to concretize AIDS for the public” (Rimmerman 2008, 38-9). This kind of strategy largely aligned with the publishing of Rock Hudson’s HIV status, and the eventual creation of World AIDS Day. Moreover, this progression aligns perfectly with the progression in the scientific community regarding the disease. The adoption of “AIDS” over “GRID”, the recognition of heterosexual transmission, and the surfacing of cases of infection of “innocent” victims such as hemophiliacs all made this recognition possible.

 So far, this aligns, or at least does not contradict, typical models of the agenda setting process. Standard models see agenda setting as a series of decisions and non decisions that determine what does and does not receive political attention. Bachrach and Baratz view the agenda setting process as a series of “decisions and non-decisions” by relevant political actors, that culminate in particular acts by sovereign bodies. The reason their analytic was important, as opposed to preceding designs such as Dahl’s[[9]](#footnote-9), is that they tracked the occurrence of non-decisions, defined as “a decision that results in suppression of thwarting of a latent or manifest challenge to the values or interests of the decision-maker” (Bachrach and Baratz 44). The standard methodology, not unique to Bachratz and Barach, is to identify the relevant areas of conflict first and foremost, and to analyze how they are handled. As they argue

If grievances there are, the investigator’s next step is to determine why and by what means some or all of the potential demands for change have been denied an airing. Which of the change-seekers’ complaints, he must ask, were denied access to an area of conflict, which were branded as violative of predominant values and therefore nullified, and which were sidetracked and eventually squashed by referral to a hostile committee or other dilatory tactics? (Bachrach and Baratz 49)

 What this model, and others like it, share in common is a start at the raised claims made in a given conflict, and proceed to analyze how they are treated. Clearly, the “agenda setters” within the federal government that pushed for the inclusion of HIV on that agenda were Senator’s Boxer, Waxman, and Weiss, as well as others enlisted by them. What is missing though, and cannot be accounted for by Bachrach and Baratz, is the *delay*. Given the knowledge of the disease, why were there no concrete decisions *or nondecisions*? Such an evaluation is, fundamentally, the key distinction between the two historical narratives mentioned earlier. Was the barrier to action active resistance to those who needed it, involving a series of active decisions and non decisions, or an unfortunate byproduct of inadequate awareness? The latter, as has been shown, is simply historically not true, certainly not as late as 1983-1985. Within the former option, though, no such agenda setting events are easily found. So, how are we to understand the place of HIV within the scope of possible political decisions and attention at the time?

Heclo argues that a full understanding of political choice, “also means being aware of how socially embedded norms, symbols, cultural scripts, and the like can shape strategic interactions. As something more than the formal rules of the ‘game’, such contextual factors provide resources, signals, and focal points in those interactions, thus *limiting the purely theoretical range of likely outcomes*” (Heclo 59, emphasis added). This kind of perspective is critical, though, not just as applied to institutions, but to individual sovereign choices or individual or group claims made on the state. Those “contextual factors” seem best discerned by analyzing those groups advocating for given political goals. According to available scientific knowledge at the time, the groups who had to fear HIV included Haitians, homosexuals, IV drug users, and some others. So, how these groups responded is critical to understanding that that “theoretical range” was, and thus understanding the structure in which that political discourse was occurring.

Several aspects of that discourse are particularly striking. First, the initial efforts were to *deny* the existence of the disease, arguably to the extreme detriment of those communities. In the summer of 1981, the press’s of New York, San Francisco, and Los Angeles all, at some point, claimed that the ‘gay cancer’ was the invention of explicitly ‘homophobic’ physicians (Berhman, Brier). Indeed, efforts surfaced to distance gay interests from HIV as much as possible. Gay rights groups resisted efforts, as late as 1989, to discern the true extent of the epidemic by claiming that the money should be more focused on treatment rather than research. Indeed, the general theme of the political activities of this sector were to resist the perceived “medicalization” of homosexual identity (echoing its then recent declassification as a mental illness) by physicians and the government. There were widespread perceptions that homosexual males constituted a kind of “brotherhood” or “fraternity,” to which frequent sexual activity was not simply promiscuous or dangerous, but a necessary sign of solidarity against an otherwise oppressive government hostile to their interests (Brier 12-27).

Second, even if HIV had turned out to be somehow strictly confined to the “four H’s”, it was still recognized as serious and lethal far before getting put on the agenda in Congress, and even further before recognition by the President. Indeed, deaths are documented as early as May 1980. The only explanation for such deliberate ignorance of an issue that was still serious to a large population (if only the ‘degenerate’ population) is that the relevant sovereigns did not consider the affected populations as within their political backdrop. While it makes sense that those Senator’s who initiate Senate advocacy had a political incentive to do so, it does not make sense that such an incentive was not recognized as such until heterosexual transmission was possible. Indeed, as the chair of the AIDS Medical Foundation testified before Congress, “In New York, the public is now astounded to lean suddenly that over 30 percent of AIDS patients are heterosexuals, whether drug abusers are not” (House Committee on Governmental Operations 1985, 329-31). The populations recognized as at risk in the early 1980s did not waiver; they were merely insufficient to attract attention.

Third, foundations and private organizations concerned with public health issues were largely reluctant to discuss the issue. Gay advocacy organizations, as indicated previously, were extremely reluctant to take up the mantle to do so. Health organizations not doing so, however, is far more striking, given that they would ostensibly have an interest in the disease outside its identity politics. The normal private channels of advocacy, however, were equally compromised. Susan Chambre argues that

Initially, AIDS was of little interest to foundations and advocates […] As with the mass media, where coverage was contingent on journalists’ having a personal connection to the story, foundations and advocates became interested in AIDS when they had a concerned staff member who lobbied to have the issue placed on the foundation’s list of funding priorities. Some gay staff members were in a difficult position, since directing attention to AIDS might lead to a loss of privacy about their sexual orientation (Chambre 68).

The idea of privacy also intersected with early AIDS activism in a particularly unusual way, because individuals were afraid, entirely, to work with state entities at all to address the crisis out of a lack of confidentiality and fear of “outing” (House Committee on Governmental Operations 1983, 213-223).

In sum, a fear of association with particular groups connected with HIV actively prevented its recognition within groups whose *explicit focus* was public health. Obviously, this effect was not universal, and private advocacy for AIDS research did emerge over time. Rather, the point is simply that public health concerns could not be expressed as such for reasons completely disconnected from any issue related to public health itself.

 The distinction between this kind of process and that which can be described by the typical agenda setting models described previously is crucial. The homophobia which impeded the process of eventual recognition was not manifested in any specific decision, at least prior to 1985. Rather, it followed preexisting “rules of the game” which implicitly excluded homosexuals, and the other “4-H” categories, from political consideration. The wariness on the part of the gay community was specifically a byproduct of the then-recent recognition of homosexuality as not a mental illness. Indeed, the connection of HIV with homosexuals was itself an importing, explicit in scientific methodology, of prejudicial attitudes towards gays and lesbians. That connection, in turn, tainted any consideration of the issue of HIV itself. In short, the entire structure implicitly excluded homosexuals such that *no one* could raise the “disagreements” that agenda setting models center on to analyze political power. The “non-decisions” that might be analyzed within normal models would be President Reagan’s sidetracking of the report of the Watkins Commission in 1988, or Senator Helms opposition in 1987. What is missed is the actual delay for any of those discussions to occur, during which people were dying and the infection spreading.

 Moreover, the harm of HIV, even in its early stages, was still recognized as at least applicable to a large segment of the population, they were merely all thought of as the “4-H degenerates.” The coinciding of political attention and the possibility of heterosexual transmission shows how that possibility did not just make the harm bigger, but prompted the recognition of the issue as harmful at all. An exclusively “minority” harm was not just a small harm, but not seen as worthy of attention at all.

 In this context, the idea of a “logic of sovereignty” begins to take shape. The existing federal government was not seen by the populations in the most need as *possibly* responding to their interests by virtue of their active persecution, in other ways, of that population. Indeed, the perceptions of the interaction, on all sides, between the government and sexual minorities, among others, was extremely hostile. Indeed, two physicians writing about their experiences in the 1980s collecting data on HIV recall that

We were to find that any study focusing on AIDS and HIV infection would have to confront not only the legacy of this epidemic, but also the history of gay and minority groups’ negative experience with the health care system. Homosexuality had for generations been classified as a mental disease […] and gays had suffered discrimination in immigration policy and housing that was sanctioned by the Public Health Service. The black community’s mistrust of the public health establishment as a result of the Tiskegee experiment, a PHS study that withheld treatment for 40 years from 400 black men with syphilis, is documented […] We were to experience how suspicions deriving from many sources affect all our efforts to gain and to disseminate knowledge about the HIV epidemic (Hurley and Pinder 608-9).

And, critically, the lack of Presidential response and the nature of the legislative debate all indicate how hostility towards the gay community, and other at risk populations, was the norm for the medical establishment, and the federal government in general.

 Here, at last, we find the resolution of the two competing historical narratives of federal responses to HIV mentioned previously. Active homophobia cannot account for the delay, since what characterized the delay was simply omission. Nobody was raising the (we now know) “scientifically accurate” claims that would have saved lives. The reason nobody was doing so, however, was not simply random chance. It was the result of specifically anti-gay social attitudes that were read into scientific research and the public mind with regards to the disease. As was noted before Congress in 1985, in an unusually prescient manner

Prejudice and legally condoned discriminatory practices against homosexuals constitute today a direct threat to public health because they force people into avoidance of disclosure of HLTV-III infections. […] It is therefore urgent that our society abolish all laws and regulations that discriminate against homosexuals and that individuals with moral authority, including the President, lead the final struggle for equal protection under the law for all” (House Committee on Governmental Operations 1985, 330).

Indeed, that is why heterosexual transmission changed the entire structure. As Reagan said in his address, in 1990, to the Pediatric AIDS Foundation annual dinner, “I’ve learned that all kinds of people can get AIDS, even children” (Behrman 26).

The issue was not simply amassing enough people, but rather for the *relevant* kinds of people to be affected. The initial scientific research, by importing the same prevailing homophobic social attitudes, made the initial connections to degenerate populations that was reflected in the non-politics of early HIV. This cannot be accounted for by analyzing points of conflict in themselves, because those conflicts already assume existing social and political standing to make those claims, and thus reflected political structures of value. What Bachrach and Baratz, and other structurally similar theories, assume is that existing harmful social conditions, such as HIV prevalence, will translate into claims on the state in the form of their “points of conflict.” What they miss are preexisting political structures that influence how those claims can be made. As Heclo noted, they miss the theoretical constraints on political possibility.

In their famous work, Baumgartner and Jones explore this possibility, noting that “social conditions do not automatically generate policy actions,” but rather that “the image of the issue [must change] from that of a private misfortune to a public problem amenable to government solutions” (Baumgartner and Jones 25-31). This logic, properly understood, presents deep challenges to the notions of “decisions” or “nondecisions” in studying political agendas, because the deciding factor cannot be reduced to how much “power” one agent can use, but rather how they can frame a given issue against the “backdrop” of the public on which they depend.

Other theories explicitly concerned with “events” and “structure” as opposed to individual decisions are equally blind to this characteristic of agenda development. Birkland’s characterization of “policy communities” is telling, because he seems to presuppose the existence of such communities, and ignores the possibility of a policy communitys’ formation being prohibited by the “structure” of the policy in question. He argues that “the degree to which political conflict overcomes any advantage or disadvantage provided by a focusing event[[10]](#footnote-10) is a function of the visibility and tangibility of an event and of the degree of polarization in the policy community” (Birkland 37-48). The problem, then, is that policy communities are still seen as individual agents “responding” to a particular problem. This perspective cannot account for the AIDS pandemic’s place in agenda setting history, since it provides no account of how policy communities come to see certain harms as harms whatsoever. Moreover, he presupposes an established knowledge of the harms and mechanisms of certain phenomena, as in the case of oil spills, or an ability to investigate the problem free of widespread ideological bias, such as in nuclear meltdowns. Homosexuality, however, as has been seen, had such a pronounced social meaning in shaping policy framing and research as to entrench a particular mindset that was not questioned for far too long a time.

 These constraints, however, are not just the product of random chance. They have their specific origins, as we have seen, in a social value structure that placed no value on the lives of sexual minorities, IV drug users, and others. Indeed, those with political power were incredibly disposed to simply not care about those populations. In this sense, the issue of HIV/AIDS policy appears to have had a constitutive “background” insofar as the federal government not only did not support, but did not interact with, entire segments of its population stricken with a fatal disease, with official CDC involvement to boot.

 This “background” is the network of social and political attitudes that decide what scientific and material events, such as the deaths of people from AIDS, translate into political concern and attention at all. In short, there must be some shared ground to make claims on the state for action that give those claims force. That common ground is usually provided by various markers, such as citizenship, that require governmental response. In this case, however, the “rules of the game” were extremely clear, as described previously, that the government did not exist *for* those with HIV, at least not until 1983 (Brier 41-76).

 This alludes to a fundamental “disjunct” within agenda setting, and models thereof, in itself. Agenda setting can never simply be the analysis of different actors in a community making claims on the state, because that presupposes that all the relevant actors are considered to have standing, and are generally situated to make claims on, that state. Individuals, scientists, and others can come and *claim* a problem exists, but, for the state, there are no ‘problems’ outside those recognized in the first place. As Schmitt describes “as long as the sovereign state exists, this state decides for itself, by virtue of its independence, whether or not such a reservation (self-defense, enemy aggression, violation of existing treaties […] and so on) is or is not given in the concrete case” (Schmitt 51). Agamben extends that idea, noting that it is really the *only* characteristic mark of sovereignty, because it lies at sovereignty’s limits. He terms this the ‘state of exception’, and argues that, “The state of exception is not a special kind of law (like the law of war); rather, insofar as it is a suspension of juridical order itself, it defines law’s threshold or limit” (Agamben 4). The reason, then, that this is problematic for agenda setting modeling is that such models cannot analyze the limit by looking at individuals, decisions, or non decisions, but rather must look at the content of political discourse and see what is and is not being left out. An active resistance on the part of the state is at least a recognition of the legitimacy of the claimants to raise those claims. Senator Helms never said that Senators Boxer, Waxman, and Weiss were doing anything illegal. Rather, the delay involved with the HIV pandemic was a glimpse of the “edge” of sovereignty, since it was and is an issue that affects the entire population, yet only initially surfaced in populations insufficient for political action. Because there is no external channel to inform the state of what is and is not ‘really’ worth political attention, the terms of value must be set somewhere. The state alone decides when a problem obtains, and must do so according to some metric usually, in the United States, rooted in who politicians think of as their constituents or their support, who they are *really* responsible to. What Bachrach and Baratz, and others, miss via their focus on individual events is the larger network of attitudes that made conflict within the state conceivable whatsoever.

 The emphasis on structure, focus on what Bourdieu referenced earlier as the “unspoken” or the “presumed,” and a decreased emphasis on individual political decisions of events is, interestingly, put quite well by authors writing about strategic agenda denial. As they write,

Most prior work stressed the perspective of those working for the active consideration of new issues. Although it has certainly acknowledged the importance of opponents’ strategies, the perspective tended to present opponents in one-dimensional terms. It is important to emphasize that opposition is often rooted in the deeply felt fears that new proposals engender and that the intensity of opposition is tied to the specific material interests at stake, as well as to the deeply held threats to identity that the worldview of initiators and their proposals embodies” (Cobb and Ross 42-49).

Indeed, the relevant modification is that these identities in play are not always explicit, to any party involved, and are certainly not “officially” recognized by a state body. So, a focus on individual events, individual actors, and conceptualizations of agenda setting as a game with certain agents having more power than others misses the “logic” of sovereignty itself, alluded to in the previous quote. The “symbols” of policy, the connections they draw to other symbols, and all the other characterizations of agenda setting criticized here all share in common a lack of discussion of the logic, the mechanism, that governs the final outcome. Moreover, these theories cannot account for circumstances that lack a full, or even remotely adequate, scientific understanding of the issues in question. The political elements of scientific research that frame the possible policy outcomes are entirely absent. That structure is the proper object of agenda setting study, and no such study can be complete without it, since the *meaning* attached to the game becomes obscure.

**III. Normative Implications**

In the context of the federal government’s response to the start of the HIV/AIDS pandemic, structural agenda setting influenced policy in such a way that not only harmed numerous individuals at the time, but created the conditions for a national “crisis”, to use Congress’s terminology. Indeed, this is not surprising, given that the role of structure is far easier to see after the fact. Additionally, as was seen in Section II, the questioning of assumptions is often not politically expedient, since groups advocating for state attention often try to portray their interests as within the scope of what the state is already concerned with, or is not very far outside it.[[11]](#footnote-11) This one empirical study seems, then, to suggest that some mechanism should exist for understanding how structural agenda setting might operate currently or in the future.

 Given that the reason public policy should be concerned with its paradigm or structural agenda-setting role is the potential harm not being so concerned could incur. This seems to imply that individuals that do not share the social or political experiences of the harmed groups, for some reason, can or will not take the concerns of that group adequately into account. Iris Marion Young offers a compelling account of this process, noting that

Where some structural social groups have dominated political discussion and decision-making, these social perspectives have usually defined political priorities, the terms in which they are discussed, and the account of social relations that frames the discussion. At the same time these perspectives are not experienced as only one way to look at the issues, but rather often taken as neutral and universal (Young 2000, 144)

Indeed, the universality component of this perspective is not surprising. The danger structurally embedded agenda setting assumptions pose is that they prevent a certain group or groups from articulating an important political demand, with real consequences on those groups (such as death from HIV).

 Young’s solution to this problem, though, is equally intuitive. If the issue is the conceptual exclusion of certain groups from public space, an appropriate solution would seem to be the direct representation of those groups themselves. Indeed, when Rock Hudson publicly proclaimed his positive status in 1985, which expanded the group of “AIDS victims” to heterosexuals in the popular mind. But, conceivably the reaction prior to such political changes would have been different had there been, for example, an openly homosexual member of Congress, or someone with a more direct connection to the medical and social realities of HIV.[[12]](#footnote-12) As Young describes

The concreteness of individual lives, their needs and interests, and their perception of the needs and interests of others […] are structured partly through group-based experience and identity. Thus full and free expression of concrete needs and interests under social circumstances where some groups are silenced or marginalized requires that they have a specific voice in deliberation and decision making (Young 1989, 263).

This voice is ultimately what prompted the Congressional hearings in 1983 on HIV, though indirectly through the relevant Congressmen who had comparatively large constituencies affected by HIV. If anything, more direct participation in those kind of process would both allow policy problems to be recognized faster, and with a higher degree of political acceptance.

 Kuhn provided good reasons why seeing outside a paradigm, or without a paradigm, is impossible. A sovereign act always must presuppose some internal logic that is not immediately transparent. That is probably unavoidable. The harms of this inevitability, though, can be counteracted through an increased degree of self-reflexive awareness of assumptions. That awareness, in turn, is best provided through hearing the voices of those actually affected by policy. There is no unmediated access to what social problems “really” warrant placement on the agenda, but some attempt can be made to mitigate the problem through a policy of full inclusion in social and political life for those likely to be negatively affected by state ignorance so as to increase the chances that such claims will be made at all. Now, the ability to determine who those groups are, or to have a full degree of awareness of such policy implications, is probably limited. But, as Young shows, history suggests that an effort to try is better, and more socially responsible, than no effort at all.

**Conclusion**

Theoretically and empirically, agenda setting is an extremely relevant and constantly evolving area of policy development. Conceptualizing that process, however, in terms of a series of distinct actors making transparent decisions based on stable, scientific foundations masks the true role of the process, and the external forces that shape it. More importantly, the implications are not simply an academic adjustment of a model. Rather, the influence of structure has real, concrete impacts on policy decisions, as well as the everyday lives of typically marginalized individuals. The idea of a structure subtly influencing agenda setting in an imperceptible naturally seems to imply that nothing can be done about it. As Young illustrated, though, steps can be taken to gain a better understanding of what or whom structural assumptions may be excluding. And the impacts on those who are excluded, as the AIDS pandemic has shown, are too important to be ignored.

**References**

Agamben, Giorgio, and Kevin Attell. *State of Exception*. Chicago: The University of Chicago, 2005. Print.

Bachrach, Peter, and Morton S. Baratz. *Power & Poverty: Theory & Practice*. New York: Oxford UP, 1970. Print.

Bardhan, Nilanjana R. "Accounts from the Field: A Public Relations Perspective on Global HIV/AIDS." *Journal of Health Communication* 7 (2002): 221-44. *JSTOR*. Web.

Baumgartner, Frank R., and Bryan D. Jones. *Agendas and Instability in American*

*Politics*. Chicago: University of Chicago, 1993. Print.

Behrman, Greg. *The Invisible People: How the U.S. Has Slept through the Global AIDS*

*Pandemic, the Greatest Humanitarian Catastrophe of Our Time*. New York: Free, 2004. Print.

Bessette, Joseph M., and Jeffrey K. Tulis, eds. *The Constitutional Presidency*. Baltimore: The Johns Hopkins UP, 2009. Print.

Birkland, Thomas A. *After Disaster: Agenda Setting, Public Policy, and Focusing*

*Events*. Washington, DC: Georgetown UP, 1997. Print.

Bourdieu, Pierre. *The Logic of Practice*. Stanford: Stanford UP, 1980. Print.

Brier, Jennifer. *Infectious Ideas: U.S. Political Responses to the AIDS Crisis*. Chapel

Hill: University of North Carolina, 2009. Print.

Chambre, Susan M. *Fighting For Our Lives: New York's AIDS Community and the Politics of Disease*. New Brunswick, New Jersey, and London: Rutgers UP, 2006. Print

Cobb, Roger W., and Marc Howard. Ross. *Cultural Strategies of Agenda Denial:*

*Avoidance, Attack, and Redefinition*. Lawrence, Kan.: University of Kansas, 1997. Print.

Grmek, Mirko D., *History of AIDS: Emergence and Origin of a Modern Pandemic*. Trans. Jacalyn Duffin, Russell C. Maulitz. Princeton: Princeton UP, 1990. Print.

Heclo, Hugh. *On Thinking Institutionally*. Boulder, London: Paradigm, 2008. Print.

Kuhn, Thomas S. *The Structure of Scientific Revolutions*. Chicago: The University of Chicago, 1962. Print.

National Commission on AIDS. *America Living with AIDS: Transforming Anger, Fear, and Indifference into Action*. Washington, D.C. : The Commission.

Panem, Sandra. "AIDS: Public Policy and Biomedical Research." *The Hastings Center Report* 15.4 (1985): 23-26. *JSTOR*. Web.

Pollock, Richard H. “Issues, Values, and Critical Moments: Did “Magic” Johnson Transform Public Opinion on AIDS?” *The American Journal of Political Science* 38.2 (1994): 426-446.

Richert, Lucas. “Reagan, Regulation, and the FDA: the US Food and Drug Administration’s Response to HIV/AIDS, 1980-1990.” *Canadian Journal of History* XLIV (2009): 467-487.

Rimmerman, Craig A. *From Identity to Politics: The Gay and Lesbian Movements in the United States*. Philadelphia: Temple UP, 2002. Print.

--------------. *The Lesbian and Gay Movements: Assimilation or Liberation?* Westview, 2008. Print.

Schmitt, Carl. *The Concept of the Political*. Chicago: The University of Chicago, 2007. Print.

Shiltz, Randy. *And The Band Played On: Politics, People, and the AIDS Epidemic*. New York City: St. Martins, 1987. Print.

Sills, Yole G. *The AIDS Pandemic: Social Perspectives*. Westport: Greenwood, 1994.

Treichler, Paula A. "AIDS, Homophobia, and Biomedical Discourse: An Epidemic of Signification." *October* 43 (1987): 31-70. *JSTOR*. Web.

Tulis, Jeffrey K. *The Rhetorical Presidency*. Princeton: Princeton UP, 1987. Print.

United States. Cong. House. Committee on Government Operations. *Federal and Local*

*Governments Response to the AIDS Epidemic Hearings before a Subcommittee of the Committee on Government Operations, House of Representatives, Ninety-ninth Congress, First Session, July 3; September 13; and December 2, 1985.* 99th Cong., 1st sess. H. Bill. Washington: U.S. G.P.O., 1986. Print.

--------------. House. Committee on Government Operations. *Federal Response to AIDS:*

*Hearings before a Subcommittee of the Committee on Government Operations, House of Representatives, Ninety-eighth Congress, First Session, August 1 and 2, 1983.* 98th Cong., 1st sess. H. Bill. Washington: U.S. G.P.O., 1983. Print.

William Hubbard Interview, FDA Oral History Collection

Young, Iris M. *Inclusion and Democracy*. Oxford: Oxford UP, 2000. Print.

-------------- "Polity and Difference: A Critique of the Ideal of Universal

Citizenship." *Ethics* 99.2 (1989): 250-74. *JSTOR*. Web.

1. The argument here is not that scientists directly excluded anyone outside that group, but that the definition of AIDS victims via that generalization had unintended and unseen impacts on future research in the area. [↑](#footnote-ref-1)
2. Interestingly, fewer and fewer individuals are willing to make this claim. [↑](#footnote-ref-2)
3. Kuhn’s comment that any change in paradigm always imposes another paradigm, that it is impossible to be without a paradigm, is significant here. No one, much less someone making a decision in a sovereign capacity, can make a paradigm-less or truly ‘neutral’ decision without employing some unspoken calculus. [↑](#footnote-ref-3)
4. These articles were of particular important, since they mark the appearance of a discussion of the disease in a major, mainstream medical journal. [↑](#footnote-ref-4)
5. This argument is similar to one made by Richard Rorty in the first chapter of *Contingency, Irony, Solidarity* about the inability of the ‘world’ to ‘disclose’ truth directly to people, since those truths can only take the form of symbols, propositions, or some structure that is human-created. [↑](#footnote-ref-5)
6. If not already a pretty widely accepted historical fact, the prevalence of government restrictions on homosexuality and the lack of political organization among gay people should support this claim about the time. [↑](#footnote-ref-6)
7. The first World AIDS Day was created in 1985, and involved numerous other nations with public policy priorities typically closely connected with those of the United States, such as many in Western Europe. [↑](#footnote-ref-7)
8. For the documents in question themselves, see Brier, 41-91. [↑](#footnote-ref-8)
9. Robert A. Dahl, *Who Governs?* (New Haven, 1961) [↑](#footnote-ref-9)
10. To be clear, this kind of “event” is something like, for Birkland, a hurricane or nuclear plant meltdown, that draws public attention and “focuses” it on a particular social issue. [↑](#footnote-ref-10)
11. In this light, it makes sense that ACT UP rarely targeted specific elected officials in a lobbying capacity, but rather engaged in much more sporadic, “guerilla” tactics involving numerous levels of the political process. [↑](#footnote-ref-11)
12. This would also engage another issue Young discusses, namely the “disillusionment” with the political process experienced by groups whose needs are glossed over. Representation in the state by members of marginalized populations would likely make those groups more willing to work with the state. In the context of AIDS policy, this would have at least affected the initial feeling by many that AIDS was a fabrication of a homophobic medical or political regime. [↑](#footnote-ref-12)