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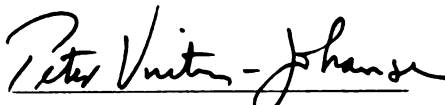
**THE CASE FOR HIV/AIDS EXECPTIONALISM
IN PUBLIC HEALTH POLICIES
BASED ON A COMPARISON OF
TWO STIGMATIZED EPIDEMICS**

presented by

Lynn M. Ross-Hermann

has been accepted towards fulfillment
of the requirements for

M.A. degree in Interdisciplinary
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**THE CASE FOR HIV/AIDS EXCEPTIONALISM
IN PUBLIC HEALTH POLICIES
BASED ON A COMPARISON OF
TWO STIGMATIZED EPIDEMICS**

By

Lynn M. Ross-Hermann

A THESIS

**Submitted to
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ABSTRACT

THE CASE FOR HIV/AIDS EXCEPTIONALISM IN PUBLIC HEALTH POLICIES BASED ON A COMPARISON OF TWO STIGMATIZED EPIDEMICS

By

Lynn M. Ross-Hermann

Since the problem of HIV/AIDS was recognized, there have been arguments as to how to solve the problem. Some legislators have advocated return to traditional public health methods, including testing and isolation of those infected. Others claim HIV/AIDS is a special case, and should be addressed with special policies. A case for exceptional policies can be made in comparing the current epidemic with the syphilis epidemic of the early twentieth century. Although similar in public reaction and modes of transmission, the epidemics have been dealt with in different manners. The policies of HIV/AIDS exceptionalism developed as a result of the differences in the role of public health during the two periods, as well as the current emphasis on individual rights allowing special interest groups to exert influence on law-makers. It is unlikely that health policies of the past would be useful in the current epidemic.

To Mom and Dad, who don't always
understand but still love me
and to Tom, who does understand
and still loves me

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My roommates Kris and Jodie have put up with my piles of papers and books spread across the floor for the good part of this

year. They deserve a special thanks for not throwing me (or my stuff) out.

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Preface

My interest in HIV/AIDS dates back to an undergraduate immunology class where I studied how HIV devastates the body's immune system and develops into Acquired Immunodeficiency Syndrome. In the course of my graduate studies, I began working at the HIV/AIDS surveillance unit of the Michigan Department of Public Health. It was during this time that I began reading some of the literature dealing with the many aspects of the nation's AIDS epidemic, as well as learning about many of the policies relating to HIV/AIDS.

One of the books I read was Randy Shilts' "And the Band Played On." It was this book which first confronted me with the many aspects of the HIV/AIDS problem. Although it is written from a homosexual perspective, Shilts also lays out the role of other groups (hemophiliacs, blood recipients, drug users, and heterosexuals, both female and male) affected by the virus.

The problem of how to control the HIV/AIDS epidemic, even limited to a public health perspective, is multifaceted, and all of the issues could not be addressed within the scope of this thesis. I have chosen the actions of the most vocal and active special interest group, homosexual men, as the focus of my analysis. However, I do not want to convey that this is

the only group affected, nor the only one doing anything about the problem. As many officials try to emphasize, HIV transmission is not limited to a particular gender, color, age or sexual preference. Approximately 11 per cent of the reported AIDS cases in Michigan are female, 51 per cent black, and three per cent under the age of twenty. At least 30 per cent contracted the virus by means other than homosexual behavior. Their place in the current epidemic and their role in fighting the spread of HIV/AIDS is very important.

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INTRODUCTION

No word causes more fear in the heart of an American today than the word AIDS--Acquired Immunodeficiency Syndrome. Since recognized in the early 1980s, AIDS has killed 141,223 people in the United States--1886 in Michigan (MDPH 1992). Over one million are believed to be infected with the virus causing AIDS. With no cure or vaccine for the virus, the only way AIDS can be controlled is through public health prevention efforts. However, the preventive methods called on by both health officials and the public to monitor and control the epidemic are often controversial.

Current public health legislation in effect to control the HIV/AIDS epidemic has been termed by many "HIV/AIDS exceptionalism" (Bayer 1991). This refers to the legislation designed specifically to deal with HIV/AIDS, including the requirement for specific informed consent for any testing for HIV¹. These policies are very different from other current and past communicable/sexually transmitted disease legislation. It is the differences found in the policies which lead to the question of how the exceptional policies came about and if they are necessary to control the epidemic.

¹The HIV test consists of a simple blood test, similar to many other tests which do not require informed consent.

One approach to examining the question of how policies for HIV/AIDS came about is to compare existing policy with policy of a similar epidemic. The syphilis epidemic of the early twentieth century has several similarities to the current HIV/AIDS epidemic, especially in the areas of modes of transmission and social reactions to the problems (such as public hysteria, stigmatization of sufferers, and demands for government intervention by both those at risk and those not at risk.) However, the resulting syphilis policies² often were very different from current HIV/AIDS legislation. The differences in policies are possibly a result of 1) the differences in the role of public health during the two time periods, especially the early Progressive focus on community good³ versus the contemporary focus on individual rights; and

²Policies relating to syphilis were included in legislation for all venereal diseases, including gonorrhea and chancroid. The laws were very similar to those for other communicable and infectious diseases, with the main difference being added confidentiality of all records relating to the venereal diseases.

³A decision which exemplifies the stance of the courts during the early twentieth century is *Jacobson v. Massachusetts* (1905, cited in Parmet 1989, 745). In it, the court stated:

Although this court has refrained from any attempt to define the limits of [the police] power, yet it has distinctly recognized the authority of a State to enact quarantine laws and "health laws of every description;" indeed, all laws that relate to matters completely within its territory and which do not by their necessary operation affect the people of other States. According to settled principles the police power of a State must be held to embrace, at least, such reasonable regulations established directly by legislative enactment as will protect the public health and the public safety...the liberty secured by the Constitution of the United States to every person within its jurisdiction does not import an absolute right in each person to be, at all times and in all circumstances, wholly freed from restraint. There are

2) the current emphasis on individual rights allowing minority and special interest groups to exert influence on law-makers⁴.

An examination of the results of the syphilis policies show that many civil rights were infringed upon, and this lead to many sufferers and others at risk to avoid identification, treatment and possible prosecution (Nelson 1932). If a person does not seek professional medical help, it is more likely the disease will continue to be transmitted. Therefore, a policy of HIV/AIDS exceptionalism which ensures confidentiality and personal choice of testing is necessary to protect the civil rights of those infected or thought to be at risk, as well as to encourage early identification of those infected and prevention efforts. The syphilis policies did not protect individual rights in the same manner as current HIV/AIDS legislation does. Therefore, policies similar to those implemented for the syphilis epidemic of the early part of this century would not be politically or morally acceptable or useful in the current epidemic.

manifold restraints to which every person is necessarily subject for the common good. On any other basis organized society could not exist with safety to its members. Society based on the rule that each one is a law unto himself would soon be confronted with disorder and anarchy.

⁴Unlike the groups affected by syphilis, one of the groups affected by HIV/AIDS, homosexual males, has made use of their status as a recognized minority group to push forward legislation supporting their interests relating to the epidemic.

HIV/AIDS AND SYPHILIS IN CULTURAL AND SOCIOLOGICAL CONTEXT

The different viewpoints surrounding the issue of HIV/AIDS exceptionalism has been addressed recently in the New England Journal of Medicine. Ronald Bayer Ph.D., in a "Sounding Board" article (1991) examines the question of how HIV/AIDS exceptionalism was developed and identifies the impact of homosexuals in the policy-making process. He states,

public health officials must contend with a range of extraprofessional considerations, including the prevailing political climate and the unique social forces brought into play by a particular public health challenge. . . . In the first years of the AIDS epidemic, U.S. officials had no alternative but to negotiate the course of AIDS policy with representatives of a well-organized gay community and their allies in the medical and political establishments.

Because of outside influences, many of the traditional practices of public health that might have been brought to bear, such as those for syphilis, were dismissed as inappropriate and unlikely to aid in controlling the epidemic.

Two other articles in NEJM address different sides of the exceptionalism issue. The first, an editorial by Marcia Angell M.D. (1991), proposes a dual approach to the AIDS epidemic which would do away with exceptionalism. This approach would entail an "attempt to distinguish social from epidemiologic problems and deals with both, simultaneously but separately." To accomplish this goal, Angell emphasizes the

necessity for more widespread testing for HIV, including the routine screening of all patients admitted to hospitals and all doctors and nurses, as well as all pregnant women and newborns. To deal with social problems attendant the epidemic, Angell proposes protecting HIV-infected persons against discrimination and hysteria by social and political measures, mostly by statute, and to deal with economic consequences of HIV infection with a nationally funded program analogous to the end-stage renal disease program. Overall, Angell advocates a return to the policies of the past, but adding legal protection against discrimination.

A Sounding Board article (1991) by Drs. David Rogers and June Osborn (Vice-chair and Chair, respectively, of the National Commission on AIDS), is a response to the letter by Dr. Angell. They are alarmed at the signs that "AIDS is being routinized . . . and not being addressed decisively." Instead of the testing methods proposed by Angell, Rogers and Osborn endorse four changes needed to deal with this public health crisis. First, moral leadership⁵ is needed at the highest level (i.e. the President). Second, swift moves must be made to improve the financing that will make basic health care services available to all who now lack them. Third, there must be better programs to deliver explicit, culturally

⁵The authors do not explain in their essay what they mean by moral leadership. It is possible they believe the leaders of this country need to respond to the problem in a positive, well-timed manner. Then, the public would have an example to follow in response to the epidemic.

appropriate education so that all will know how AIDS is transmitted and, equally important, how it is not. Finally, voluntary testing should be extended aggressively, including thoughtful counseling and swift access to health care as part of an HIV/AIDS initiative. The hope with these proposals is that they will help to eliminate discrimination and make medical care more readily available. If these changes are accomplished, they conclude, most Americans at risk would step forward for HIV testing. Therefore the authors advocate continued HIV/AIDS exceptionalism policy.

This series of articles represent the different sides of the exceptionalism issue. Bayer describes how exceptionalism developed. Angell recommends returning to traditional communicable disease policy, and Rogers and Osborn endorse the current exceptionalism. In order to try to determine the efficacy of either of these proposals, lessons will be drawn from the similar syphilis epidemic of the early twentieth century.

The most recognized similarities between HIV/AIDS and syphilis are medical--mainly modes of transmission and prospect of treatment. Syphilis is a disease caused by the bacteria Treponema pallida. Its main mode of transmission is through sexual contact, but it also may be transmitted maternally at the time of birth or by blood borne routes such as transfusions and "needle sticks". During the early part of this century, there was no proven cure for the disease. However, several treatments, using heavy metals or salvarsan

(arsphenamine), relieved symptoms and were believed to cure the disease. Without treatment, syphilis progressed over the lifetime of the infected individual and could culminated in central nervous system involvement and finally death.

AIDS is a syndrome characterized by the presence of opportunistic infections which result from a compromised immune system. It is caused by the Human Immunodeficiency Virus (HIV), a retrovirus that attacks cells of the immune system. Several modes of transmission have been identified, with sexual contact and intravenous drug use the most common. Other modes include maternal transmission and blood transfusions. There is no current cure for AIDS, and the treatments (mainly AZT and pentamidine for opportunistic infections) offer little long-term improvement. AIDS sufferers usually die within a few years of the appearance of the first symptoms, which may occur from two to ten years after they are infected with the virus.

Non-medical similarities between the two conditions are found in the social reactions. Since the late nineteenth century, venereal diseases such as syphilis have "been used as a symbol for a society characterized by a corrupt sexuality" and as an "affliction of those who willfully violated the moral code, a punishment for sexual irresponsibility" (Brandt 1985, 5). The moral codes⁶ referred to by Brandt have evolved

⁶The moral code, which is the generally recognized moral standard of the community, should not be confused with moral leadership, as previously defined.

over the course of the twentieth century. The late Victorian era whispered about extra- or pre-marital affairs and visits to prostitutes much as the homophobic society of the 1980s whispered about gays visiting bathhouses. In each case, moralists of the day worked to prevent a large part of society from identifying personally with the disease. They convinced much of the public that if they did not commit the sins, they would not get the disease (fostering an "it could not happen to me" mentality).

During the rise of the epidemics (the early twentieth century for syphilis and the 1980s for HIV/AIDS), each was characterized by misunderstandings and uncertainty of how the diseases could be transmitted leading to public hysteria, stigmatization of victims, and demands for authorities to control the spread of the diseases. Once the severity of the diseases were realized by the public, they reacted to protect themselves as they best knew how. Often this included attempts to isolate those infected or believed infected by demanding officials to force an individual into isolation or if this were not possible, social ostracism leading to isolation.

It is possible that hysteria in both epidemics resulted from an initial lack of knowledge combined with a realization of the severity of the diseases by the public and misinformation on the transmission of the causative agents. Hysteria is defined in the sociological literature as "a belief empowering an ambiguous element in the environment with

a generalized power to threaten or destroy . . . The three components of a hysterical belief are an ambiguous situation, anxiety, and redefinition of the situation (Smelser 1963, 84-85). Lack of knowledge of how a contagion is passed, and the riskiness of behavior often lead to ambiguity and anxiety. Fear that casual contact would lead to infection is common to both epidemics. In an anonymous story in a monthly magazine (in 1912), a woman describing the agony and stress that accompanied an apparently innocently transmitted infection illustrates the lack of education as to the modes of transmission of syphilis.

At first it was unbelievable. I knew of the disease only through newspaper advertisements [for patent medicines]. I had understood that it was the result of sin and that it originated and was contracted only in the underworld of the city. I felt sure that my friend was mistaken in diagnosis. When he exclaimed, 'Another tragedy of the public drinking cup!' I eagerly met his remark with the assurance that I did not use public drinking cups, that I had used my own cup for years. He led me to review my summer. After recalling a number of times when my thirst had forced me to go to the public fountain, I came at last to realize that what he had told me was true. Every day I expected to be accused of unspeakable things and turned adrift . . . Even though I was not discovered I had perhaps a more direful possibility to face. Daily, hourly, momentarily, I was haunted by the dread of passing on the disease to another . . . Every act of my life was carefully weighed under the influence of that feverish fear . . . I was strained, tense-afraid, afraid. Night and day, day and night I bore my burden of fear (Brandt 1985, 21-22).

The belief that syphilis could be transmitted by casual contact likely contributed to the public's hysteria. If a

person could become infected so easily, a large proportion of the population would be at risk--the disease would no longer be reserved for the promiscuous and prostitutes.

Other situations illustrate reactions by individuals as well as physicians when a person not believed to be at risk was found to be infected. Long (1938, 373) describes a situation where

[a] respectable man and woman, with seven children ranging in ages from one to eighteen years, came for interpretation of the medical findings of the physical examinations at the family agency clinic. Both showed positive reactions to the Wassermann test. These people were stunned, the situation horrible and unbelievable to them, the source of infection unknown.

He tells of another case in which a young physician did not mention the positive results of a syphilis test because "the patient and wife were such well educated and sensitive people that the truth about the diagnosis would be too shocking and they had trouble enough." A psychiatrist agreed with the doctor about secrecy (1938, 381). The denial by the patients of knowledge of how they became infected in the first case and the withholding of diagnosis by the doctor in the second illustrate the negative connotations syphilis had as well as the naivete as to how and who could contract the disease. It appears that there was a definite idea, even among physicians, of what type of person could become infected with syphilis.

The same type of fear and hysteria has been seen in the first decade of the AIDS epidemic. In White Plains, a New York mail carrier refused to deliver mail to an AIDS Task

Force office for two weeks because he feared catching the disease (New York Times 7 April 1987, B:7). In Florida, a barber refused to cut the hair of three hemophiliac brothers who tested positive for HIV. The family minister suggested they stay away from Sunday church services (Robinson 1987). Several groups organized opposition to the annual National Gay Rodeo in 1983, held in Reno, Nevada, for fear that "all those homosexuals would spread AIDS throughout Nevada" (Shilts 1987, 351-352). Such fearful reactions still occur in 1992, several years after the modes of transmission were identified.⁷

Part of this continuing fear may be due to the general attitudes towards those whose behaviors place them at greater risk for becoming infected, causing them to be stigmatized. A stigma has been described as "a bodily sign that people view as evidence of something unusual and bad about the moral status of the individual possessing it . . . three types are physical deformities, blemishes of individual character and tribal stigma" (Goffman 1959, 87). Often, people who are stigmatized are treated as though they are not quite human. This has been true for both syphilis and HIV/AIDS, mainly due to character blemishes associated with individual's sexual preferences, although stigma relating to physical deformities also results at certain stages of the diseases.

⁷The May 13, 1992, NBC Nightly News featured a story on a small town in Oklahoma with one AIDS case. This one case has created hysteria, demands for isolation and the treatment of the man like a convicted murderer after it was discovered he had sex with several women in the town.

The stigma of having syphilis follows the belief that only a certain type of person should get the disease, and when someone not considered to be at risk became infected it was terribly degrading. According to Stokes (1920, 145),

But 98 persons in 100 who know that there is such a disease as syphilis are alive to the fact that it is considered a disgrace to have it, and to little else. Such a feeling naturally chokes all but secret discussion of it. . . . What made syphilis terrible to the many really fine and upright spirits . . . was not the fear of paresis, or of any other consequence of the disease. It was the torture of disgrace, unearned shame, burnt into their backs by those who think syphilis a weapon against prostitution and a punishment for sin (1920, 142, 145).

This sentiment is echoed over sixty years later by one homosexual AIDS sufferer who comments, "mostly we talk about what it feels like to be treated like lepers who are treated as if they are morally, if not literally contagious." (Altman, 1986). Another comments,

The pain, suffering and despair of the disease alone are dreadful enough. The added stigma makes it virtually unbearable. You lose not only your life, but also your pride, your job, your insurance, your friends and your family. Posterity remembers you for dying of AIDS, not for having lived (Rogers and Gellin 1990).

Obituaries for those dying from either disease rarely mentioned syphilis or AIDS by name, but rather cited a blood disease or other long term illness as the cause of death. This change was to protect the reputation of the surviving family members and prevent further suffering. Once diagnosed, a person likely could never remove the stigma placed upon

them.

Stigmatization often carried over into the workplace, where being found infected with syphilis was commonly grounds for job dismissal or discharge from the military. Although presently there are anti-discriminatory laws (most often covered in legislation addressing handicapper issues; see Leonard 1987) against such treatment in the workplace, many employers in the 1980s tried to fire people with HIV or AIDS (Altman 1986, 61). A positive HIV test will still lead to military discharge. Other forms of stigmatization include refusal of physicians and other health care workers to treat those with the disease, refusal of the public to allow clinics that treat such diseases in their neighborhood, protests by parents not wanting infected children to attend school, and even instances of burning down the homes of sufferers (Robinson 1987, 1; Herek and Glunt 1988).

The stigmatization of those with AIDS has been largest against the gay population. In 1987, 1,042 incidents of harassment against gay people were reported to the National Gay and Lesbian Task Force (NGLTF) that involved references to AIDS; two thirds of the local groups who reported incidents to NGLTF expressed a belief that fear and hatred associated with AIDS fostered antigay violence (NGLTF 1988, in Herek and Glunt 1988). In 1988, one survey reported that one in five Americans was unwilling to have contact with people with AIDS in workplaces, schools, and communities (Blendon and Donelan 1988).

Although most of the focus of stigma has been on those who are regarded as "responsible" for their disease, even AIDS patients who have acquired the virus "innocently" (i.e. through blood transfusion or maternal contact) have faced ostracism. Speaking before a congressional hearing, Alan Brownstein, executive director of the National Hemophilia Foundation, testified:

In many respects excess fear of AIDS has presented more risk of death and disability than AIDS itself . . . How sad it was the other day when I learned from one of our chapters that their hemophilia camp enrollment was down 75% this year because parents of hemophiliac children had fear of their children being exposed to other children with hemophilia. We are now beginning to get reports of instances in the workplace where fear of contracting AIDS is expressed by those working side by side with hemophiliacs (cited in Altman 1986, 70).

Ryan White, a young hemophiliac, gained nationwide fame when identified as an AIDS sufferer. His classmates' worried parents attempted to prevent him from attending school through legal measures. His is one of many instances of children who are HIV positive, many of whom have become the center of court battles outlasting the lives of the children. Stigmatization has been extended to those who have done nothing which could be defined as morally wrong in becoming infected with HIV.

Hysteria, fear of disease, and stigmatization of sufferers has lead to demands for the government to take charge of the situation and provide resources (including leadership, personnel and money) to aid in controlling both epidemics. The public in both cases expected those in

leadership of this country to be at the front of the fight against the problems. The syphilis epidemic featured appeals to public health and sanitation (hygiene) officials to control its spread. Some believed that if syphilis could be properly diagnosed and effectively treated, it could be placed on the same footing by boards of health as other contagious diseases such as diphtheria and tuberculosis. This footing could lead the way for public health officials to take a more aggressive stand in the fight against venereal disease than was currently being taken (Brandt 1985). This concern echoed the sentiments of the American Medical Association's Committee on Prophylaxis of Venereal Diseases in 1903 (cited in Parran 1937, 79): "While other contagious diseases were controlled or combated by boards of health with great vigor and excellent results, venereal diseases are ignored by our sanitary authorities, and the morbidity therefrom is consequently not a matter of record; officially, there are no venereal diseases in the United States." In other words, until syphilis and other venereal diseases were regarded in the same category as other communicable diseases, they would not receive the same treatment from the health officials.

Unlike the syphilis epidemic, three-quarters of a century later appeals are directed to medical officials, especially scientists, to find a treatment, cure and/or vaccine for AIDS. Some of the first demands of the homosexual population involved in the fight against AIDS were for increased funding for research into the cause and possible treatments and cures

for the disease. Other demands were for the government to aid in financing treatment and support centers for those affected by the virus and their families.

Above, it has been demonstrated that the syphilis epidemic of the early twentieth century and the current HIV/AIDS epidemic have several similarities when comparing modes of transmission and the public's reaction to the epidemics. Because of these similarities, it is possible to compare the resulting policies for each of the epidemics, and to gain understanding of the complexities of the problems concerning the problems from the differences.

The subject of preventing the spread of contagious, particularly sexually transmitted, diseases is a highly controversial and emotional issue, especially when the disease has no cure and ultimately leads to a premature death. The problem becomes worse when the primary means of infection are defined by a large segment of society as socially unacceptable, but may be passed to "innocent" victims. Those who believe themselves unlikely to become infected often call for the protection of the innocent, sometimes desiring Draconian-type⁸ methods such as mass testing, identification and quarantine of those infected. However, those who believe themselves to be at risk for becoming infected oppose the Draconian policies. Rather, they desire laws which would

⁸"Draconian" refers to laws which are extremely harsh and restricting in nature, named after Draco's law code in Athens, 621 B.C.

protect their rights and privacy.

The policies for syphilis during the early part of the century and current HIV/AIDS policies represent different points on the line between Draconian and individual rights. The reasons for these differences are found in the philosophy behind public health policy and the extent to which that philosophy allowed for outside influences in policy-making.

During the early part of the twentieth century, public health focus was mainly sanitation-based, with policy generally formed for the community good, not necessarily taking individual rights into consideration. A common thought in twentieth century Progressivism was that the government could, and should, make the nation a better place to live and prosper. One of the ways to achieve this goal was for a community focus which would take all measures possible to achieve as large a population as could be maintained--"the more mouths, the more wealth." (Rosen 1974, 120). These extra mouths would help provide the country with more workers in the factories and farms, thus adding to the wealth and power of the country.

However, the rise of syphilis and other venereal diseases signaled to the Progressives a decline in the stability of the family unit. Brandt (1985, 17) comments that "as venereal disease became a focus for Progressive fears concerning the future of the family in the first years of the twentieth century, physicians increasingly considered it their responsibility to protect the institution of marriage from the

introduction of disease." In order to perform this duty, physicians and social hygienists turned to the government for aid. The government recognized the need to control the syphilis epidemic and used their power to enact what they saw to be the necessary public policy to meet their goals to protect marriage and positive population growth (Rosen 1974, 123).

This Progressive concept of government intervention to promote and protect health led to a notion of public health which emphasized the importance of community. Charles Edward Amory Winslow, professor of public health at Yale, defined public health in 1920 as:

the science and art of preventing disease, prolonging life, and promoting physical health and efficiency through organized community efforts for the sanitation of the environment, the control of community infections, the education of the individual in principles of personal hygiene, the organization of medical and nursing service for the early diagnosis and preventive treatment of disease, and the development of the social machinery which will ensure to every individual in the community a standard of living adequate for the maintenance of health (Winslow 1920 cited in Starr 1982, 180).

The enforcement of these goals within a community would undoubtedly restrict individual liberties at some point by forcing everyone to adhere to the government's standard of health. However, the Progressive philosophy allowed for the encroachment in order to accomplish their goals.

The policies enacted for the control of syphilis in the early part of the twentieth century illustrate the

restrictions placed upon people. In 1899, Michigan became the first state to make venereal disease (including syphilis) a bar to marriage, directing all men to swear to their health before taking marriage vows. This was to prevent syphilis from being transmitted to the innocent wife and children. Other laws passed in Michigan concerning the control of syphilis went into effect in 1919. Act 272 sec. 6631.1 declared venereal diseases including syphilis to be "dangerous, communicable and infectious, and therefore subject to all the laws of the state pertaining to such diseases, except as modified in this act" (Michigan Compiled Laws 1919). The modifications included provisions for the state health department to regulate the quarantining and isolation of infected persons and mandated the immediate reporting of any cases to the health department (Act 272 sec. 6632.2). It was possible for the health officials to isolate anyone infected, often resulting in the person being publicly identified. This could result in loss of employment and other discrimination.

Persons infected with syphilis (and other infectious or venereal diseases) were prohibited from employment in places where food or drink is manufactured, prepared, served or sold, or as cigar makers (Act 25 sec. 6635.1, Act 353 sec. 6637.1) because it was believed these were among the modes of transmission. People employed in these professions were required to submit to a physical examination by a health officer or physician whenever requested to by any local health officer. Pregnant women were required to have a syphilis test

by her attending physician as a result of Act 272 sec. 329.153 with hopes that intervention would keep the unborn from being infected. There were no provisions for informed consent before the test was administered, and a person could not refuse to take the test.

Not only were individual's liberties imposed upon by state officials, they also were bound by federal policy. These policies allowed for the U.S. government between 1918 and 1920 to promote and pay for the detention of more than 18,000 women suspected of prostitution (Brandt 1985, 89). Women were held against their will in state-run "reformatories" until it was decided by the officials they were no longer infectious. It appears that most of the health effort was focused on those people defined as immoral by the government.

Some have asserted that these early efforts of the government and social hygienists focused on the moral rather than scientific aspects of the epidemic. Dr. N.A. Nelson, of the Massachusetts State Department of Health, complains these moral approaches did little, if anything, to control syphilis. "What other disease would so long have been ignored in the face of so complete an armamentarium! Someone has said that if syphilis were only coughed and sneezed it would have been wiped out long ago" (1932, 165). Nelson seems to imply that the sexual nature of syphilis transmission has affected the government's treatment of the problem. One example of the moral approach by the government was in 1919 when Dr. Rupert

Blue, Surgeon General of the Public Health Service, asked the ministers of the country to set aside a day as Health Sunday and to preach sermons emphasizing the responsibility of the nation to protect returning soldiers and sailors and the community at large, and to take vigorous measures for combatting venereal diseases. His statement included "it is the social responsibility of the communities, of which the churches of every denomination are a part, to continue the work carried on in time of war in order that the world may be made safe not only for democracy, but for posterity" (New York Times 13 January 1919, 7:2). The work Blue refers to is that of fighting prostitution and extra-marital sex.

During the early 1930s, officials began to move away from a moralistic approach and called for "the extension of knowledge in the epidemiology of the disease and the better application of existing knowledge" as the steps needed in control of syphilis (Parran 1932, 141). Officials began to face the reality that syphilis is easily hidden and easily driven undercover with morality-based policy. Nelson emphasized this problem in his statement that "any law or regulation, therefore, which attempts to force the syphilitic into the open will succeed only in driving him to the cover of the drug store, the charlatan, the unscrupulous physician or to no treatment at all" (1932, 167). An argument could be made, therefore, for policy that would encourage individuals at high risk to be tested and treated, and protect them from being discriminated against.

Although the original policies enacted to control the spread of syphilis severely limited the freedom of some people, little has been written concerning the role those believed to be at highest risk for syphilis played in developing public health policy. It is unlikely they had any impact on the laws enacted to control the spread of the disease. As mentioned above, those seen most at risk for becoming infected were promiscuous men and prostitutes. Since the stigmatization of these groups was great, it was unlikely that individuals in these groups were able to organize themselves into politically relevant group or any type of community. Since nobody wanted to identify themselves as being infected, it was unlikely that one person would know if another was infected or at risk. Because of the general public's ostracism of these groups, as described above, any attempt by those infected to influence policy probably would have been ignored.

It is possible the Progressive philosophy of the government, as well as public health (a branch of government), also prevented those infected or at risk of becoming infected from influencing policy. Since the emphasis was on protecting the family unit and encouraging population growth, it is unlikely those accused of breaking down the family structure would be allowed to have a voice in policy-making.

Compared to the early twentieth-century focus on moral solutions to the epidemic, the current focus of public health policy is more medically-based with individual civil liberties

emphasized rather than community. The change to a medically-based policy has been partially a result of the shift from public to personal services as the public sources of illness were controlled⁹, as well as the strides forward in science and technology since the turn of the century. As science became more able to identify the causes of disease, and to cure and prevent disease, credibility in the courts and legislative chambers grew. With a focus centering on personal services, it follows that individual rights would become more emphasized than community rights.

However, the policy issues surrounding HIV/AIDS are not strictly scientific. They also involve the issues of individual civil liberties, rights of the community, moral and ethical questions, and allocation of funds. These issues have opened up the possibility of different interpretations of what is the best policy and demands for legislation to be enacted. In these situations, the medical experts are often pitted against the special interest lobbyists, each group sure their way is the one that will solve the problems. According to Parmet (1989, 766),

Cases of public health focus on the rights of the individual and whether medical science justifies particular majority-imposed limitations of those rights. Medical science, construed by the law as the servant of individual patients, thus serves as the mediator between

⁹The advances made in sanitation during the early part of the century greatly reduced the number of large-scale disease outbreaks, and allowed authorities to focus on personal services instead of community services.

well-recognized individual interests and the less developed, more inchoate conception of the public good.

It is necessary, then, for the special interest groups to have a solid medical backing for their demands.

One powerful interest group during the AIDS epidemic has represented the group hardest and earliest hit by the disease, homosexual males. Early in the epidemic, gay men realized the need to take action because the government was not taking steps to deal with the problem. They moved to become involved with controlling a disease threatening to attack many of them. At this time, gay men were most often associated with AIDS (then called GRID--Gay Related Immune Deficiency). The infectious agent was not yet identified and there was no treatment. With stigmatization and hysteria running high, especially towards homosexuals, gays believed that they had to stand up and demand their rights in order to avoid being discriminated against, and possibly quarantined (Bayer 1989, 195-197). With no cure for AIDS in sight, this proposed policy could mean a life sentence. Dr. Mathilde Krim of Sloan-Kettering Institute for Cancer Research emphasized the concern of gay men in a Congressional hearing in 1983, "The atmosphere of doom and total helplessness surrounding the problem of AIDS threatens to push us back into a medieval society complete with the equivalent of colonies of pariahs and lepers." (Altman 1986, 58). It is possible that the fear of being questioned and isolated drove these men to make use of the civil rights gained during the gay right's movement in

the 1970s and lobby against any legislation threatening to take away their rights.

Many of the demands of the homosexuals concerning HIV/AIDS policies can be traced to the philosophies surrounding the early gay rights movement which began with the 1969 Stonewall Street Riots in Greenwich Village, New York. The period from the riot through 1971 included the emergence of the modern gay movement, characterized by a willingness of gays to demand not just tolerance but a total acceptance of their way of life by government and the general public, and by a new militancy in making these demands. By the mid-seventies, a new type of gay politics had established itself in the United States, where a number of activists started using the traditional forms of American minority-group politics to make their demands to the legislatures (Altman 1982).

The political strength of the homosexuals at the onset of the HIV/AIDS epidemic was first felt in areas where gays had organized into coalitions, such as the Alice B. Toklas and Harvey Milk Gay Democratic Club in San Francisco, the Whitman/Stein Democratic and Log Cabin Republican Clubs in Washington, D.C., the National Gay Task Force, and the National Gay Rights Advocates. By making use of existing alliances, gays were able to influence several votes on early state legislation related to AIDS, and later on the federal level. Shilts describes one such occurrence which resulted in moving the San Francisco government to spend \$450,000 to

finance the world's first AIDS clinic, grief counseling and personal support for AIDS patients through the Shanti Project, and the first locally funded education efforts through the Kaposi's Sarcoma Foundation:

The supplemental appropriation sailed through the board of supervisors without a dissenting vote. Bill Kraus and Dana Van Gorder (gay activists) had timed the vote perfectly. Half the board was up for reelection in five weeks. Nobody would dare vote against public health money, given the fact that one in four city voters was gay. Mayor Feinstein personally felt the money should come from some other part of the health budget, but Bill Kraus knew her hands were tied as well. She was up for reelection next year and wouldn't dare veto an AIDS funding bill (Shilts 1987, 188).

The political power of the gays was well known to Mayor Feinstein and other politicians. They recognized that if they were to have a chance to be re-elected they would have to be supportive of the gay's demands. The same influence has been found in other states, as well as on the national level.

From 1986 to the present, several laws have been enacted by the Michigan Legislature which relate to HIV/AIDS. The Michigan laws are fairly representative of other state laws and generally follow the lead of the national legislation. Many of the issues addressed are similar to those addressed by syphilis and venereal disease legislation in the past, although the resulting laws differ.

Unlike the policies requiring a person to submit to a test for syphilis upon demand by a medical or public health official, an individual must give specific informed consent

before being tested for HIV (Mandatory Counseling and Informed Consent Act 1988.) The purpose of this Act is to ensure that an individual understands the meaning, outcomes and limitations of the test. The informed consent includes that the person tested be provided an explanation of the test including its purpose, the potential uses and limitations (including chances of false positive results) of the test, and the meaning of test results; explanation of the rights of the test subjects including the right to withdraw consent to the test prior to its administration, the right to confidentiality of test results, and the right to be tested on an anonymous basis; and a physical description (for identification purposes) of the person to whom the test results may be disclosed.

If the test for HIV is positive (usually meaning two reactive ELISA and one positive Western Blot confirmation), it is required that the result be reported to a local health department within seven days (HIV Reporting Act 1988). To protect the identity of the infected individual, the reports are confidential, with the option of anonymity. Next, according to the Partner Notification Act (1988), the person that administers an HIV test shall refer the test subject to the appropriate local health department for assistance with partner notification if the subject is HIV infected and the person administering the test determines that the test subject needs assistance with partner notification. The purpose of partner notification is to inform a person of their possible

exposure to HIV, and counsel them concerning their options. The identity of the infected partner is kept confidential.

Other HIV/AIDS Acts parallel policies for venereal disease. These attempt to balance the issue of individual rights verses public protection. The Health Threat to Others Act (1988) makes it a felony for a person who knows he or she is HIV infected to engage in sexual penetration with another person without having first informed the other person that he or she is HIV infected. The High Risk Crimes Act (1988) requires that upon arrest of a person for certain "high risk" crimes (e.g., prostitution, gross indecency, criminal sexual conduct, intravenous drug use), the court shall provide information about HIV and recommend HIV counseling and testing at a local health department. Upon conviction the court shall order HIV testing and counseling to be confidentially administered by a licensed physician or a local health department. The Correctional Facilities Act (1988) requires HIV testing of all incoming prisoners at state correctional facilities, segregation of HIV infected prisoners subject to discipline for high risk behavior, prisoner HIV testing upon blood or body fluid exposure of employees, free HIV testing of employees upon request and provision of equipment to implement universal precautions. These laws limit the rights of certain people, however, the limitations imposed have been justified as necessary to protect the public.

DISCUSSION

The public health policies concerning the syphilis and HIV/AIDS epidemics are characterized by different underlying philosophies. Although officials in both cases wanted to control the epidemics, the methods used to accomplish the goals were different. Public health at the beginning of the twentieth century implied a vast reserve of community authority and obligation to prevent illness. Syphilis policies were shaped by a Progressive philosophy that legitimated government intervention, especially with regard to preserving the family unit. Today, the rights of the public and of individuals and minorities are seen as being in opposition. HIV/AIDS policies are shaped by public health law which attempts "to demarcate or balance the conflict" between the interests of the individual on the one hand and the interests of the community on the other (Parmet 1989, 742).

The major differences in the resulting policies are found in how those infected or at risk were treated. The rights of people infected or believed to be infected with syphilis during the early part of this century were limited in that a person could be forced to submit to medical examinations and tests to prove or disprove their infection upon the demand of medical officers. A positive test for syphilis, especially for prostitutes, could result in institutionalization in jails, hospitals or camps until they were declared no longer infectious. HIV/AIDS policy of informed consent protects

people from this type of invasion upon individual rights found in syphilis policy. No one (except in limited situations) may be tested for HIV without specific informed consent. Those found to be infected are protected with confidentiality provisions.

These changes in the role of public health to allow input from individuals and minorities opened the door for special interest groups to influence new public health policy. As with most legislation, lawmakers take what their constituents desire for policy very seriously when considering what side they will endorse and vote for, especially when the experts cannot or will not endorse one plan. Until homosexuals began to voice their opinions on issues affecting them, there appeared to be little opposition to the vocal moral position of restricting the rights of those infected.

Unlike the promiscuous men and prostitutes of the syphilis epidemic, homosexuals have been able to gain legitimacy as a minority group, and to mobilize themselves as a social movement (a movement in response to a specific societal problem). Mauss (1975, 61-66) has described five stages in the natural history of a social movement. They are 1) incipency, 2) coalescence, 3) institutionalization, 4) fragmentation, and 5) demise. Homosexuals have been able to push the issues concerning HIV/AIDS into this movement. It is possible that the civil rights movements of the 1960s set the stage for a movement among homosexuals starting in 1969 to become a legitimate social group. According to Altman (1982),

"the seventies saw the beginning of a large-scale transition in the status of homosexuality from a deviance or perversion to an alternative life style or minority . . . along with this change, homosexuals were being cast increasingly in the role of the vanguard of social and sexual change, worthy of considerable media attention." The civil rights movement took the homosexuals through the incipency stage (characterized by "groping, uncoordinated efforts . . . unorganized, with neither established leadership nor recognized membership, and little guidance or control") and into the coalescence stage (formal and informal organizations developing out of segments of the sympathetic public that have become the most aroused by perceived threats to the preservation or realization of their interests). These occurrences during the seventies prepared the movement for the institutionalization stage in the eighties (government and other traditional institutions take official notice of a problem or movement and work out a series of standard coping mechanisms to manage it).

The happenings surrounding syphilis only partially fit into the social movement model. Although the problem of the epidemic was addressed by health and government officials, there was no movement with an organizational structure consisting of committed members and able leaders (of those affected by the disease). Without the leadership and membership similar to that found in the homosexual movement, no ideology was developed to help bring legitimation to the cause and maintain the movement's identity. Because of the

stigmatization of syphilis sufferers and lack of public discussion of the subject there was little chance for the necessary leadership and membership to develop.

The gay rights movement resulted in a highly organized interest-group which increased its influence on political issues throughout the 1970s and 1980s. When the AIDS epidemic was first perceived as a threat to their community, gay leaders quickly mobilized to pressure local and federal governments to respond to the problem (the institutionalization stage). The efforts of the homosexuals combined with the efforts of those attacking the epidemic from a public health approach to help develop policy that would protect both the rights of the individuals and of the public.

The differences in public health policy for syphilis and AIDS, and the examination of the reasons for the differences, lead to the question: should the public health policy for HIV/AIDS be different ("HIV/AIDS exceptionalism"), or should it be treated like other communicable and sexually transmitted diseases? Undoubtedly, disagreements over how policy should address the problem of HIV/AIDS will continue. As seen in the Angell and Rogers and Osborn essays, there is a wide range of possibilities, from mandatory testing to education to keeping policy as it is. Dr. Angell is correct in her idea that the social problems of HIV/AIDS are often confused with the epidemiological problems. However, her suggestion to combat discrimination and hysteria with political measures seems to miss an important part of the problem, that people cannot be

forced to like another person, or to treat others with respect. In many places, homosexuals and drug abusers were highly stigmatized even before HIV/AIDS. In order to combat HIV/AIDS discrimination, it would first be necessary to destigmatize responses to these two groups which are most highly associated with the epidemic. As Rogers and Osborn suggest, this problem cannot be combatted by legislation, but by moral leadership to counter discrimination and by more explicit, culturally appropriate education to alleviate fears.

Any time a health problem threatens to harm large numbers of people, the challenge is for health officials to develop, and for legislators to pass, laws to control the spread of disease while at the same time being sensitive to the civil rights issues concerning the epidemic. However, because of the circumstances surrounding different epidemics, even when there are several similarities, distinct policies are necessary. The argument for different policies is demonstrated in the syphilis and HIV/AIDS epidemics.

The Progressive philosophy of the early part of the twentieth century played a large role in the policies developed to control the syphilis epidemic. In retrospect, the policies appear to be violations of civil liberties for many individuals. Because of the current emphasis on individual civil rights, it is unlikely the same policies would be tolerated in the current epidemic. However, the idea of equal rights and protection for all is not the same as having specific legislation supporting the belief. Throughout

the twentieth century more minorities have been added by name (women in the 1920s, blacks in the 1950s, handicapped in the 1970s) to the list of groups which cannot be discriminated against, therefore protecting their rights in more than just theory.

It is possible the homosexual's belief that equal rights are often only true in theory that inspired homosexuals to start lobbying for policy favorable to their position on HIV/AIDS. Voluntary, anonymous testing, and more sensitive efforts to trace sexual partners arose from the concern that identification of those with AIDS would lead to loss of employment, housing and medical insurance, as well as to social ostracism. Their demand was for exceptionalistic legislation, specifically protecting a person's right to privacy, as well as ensuring that HIV status could not be the basis for discrimination.

While the concerns and demands of the homosexuals had a great influence upon the policies, they were not the only ones calling for exceptional policy. Many public health officials recognized the problems of driving people away from established medical care with the earlier syphilis policies. Bayer's claim that AIDS has become less threatening in the United States (in that the estimates of the level of infection put forth several years ago have proved to be too high) and therefore should not be treated as an exceptional disease, fails to address the problem of driving people underground. Although the numbers of those affected by HIV/AIDS may not be

as high as some other health problems, such as cancer and heart disease, few health problems have produced the same amount and level of public fear as AIDS. Without assurances of strict confidentiality (and possible anonymity in some states, including Michigan), it is likely that fewer people who believe themselves at risk will come forward to be tested. Lack of knowledge of one's HIV status prevents an infected person from avoiding high-risk behavior, informing partners, or receiving early medical intervention.

Policy enacted relating to HIV/AIDS must continue to ensure the protection of the identity those infected in order to encourage those who believe themselves at risk to come forward to be tested. Without knowing their HIV status, individuals cannot take the necessary precautions to prevent further spread of the virus. At the same time, policy issues must also address the protection of the community as a whole. In this regard, steps must be taken to discourage infected individuals from partaking in high risk behavior such as unprotected sex and needle sharing. This would not amount to a quarantine, unless knowingly passing the virus (or potentially passing) was regarded as a felony (possibly as attempted murder?) and the guilty person sentenced to jail.¹⁰

HIV/AIDS is an exceptional problem which must be addressed with exceptional policies to control its spread and

¹⁰A trial is currently in process in Michigan for a man accused of breaking Act 490 (1988). There is also precedent in the military for this type of case.

protect the rights of both those at risk of becoming infected and those with little risk. Returning to the public health policy of the early part of this century would not yield a fair or effective response to the current epidemic.

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