AIDS, Race, and the Law: The Social Construction of Disease

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Abstract

The existing literature on AIDS and the law has been largely silent on the issue of Acquired Immunodeficiency Syndrome (AIDS) in minority communities, despite the disproportionate impact of AIDS upon these communities, and despite the fact that the “literature on behavior change suggests the importance of considering sociocultural and psychological characteristics of a population in the promotion of certain health behaviors and practices.”

KEYWORDS: AIDS, race, law
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The existing literature on AIDS and the law has been largely silent on the issue of Acquired Immunodeficiency Syndrome (AIDS) in minority communities, despite the disproportionate impact of AIDS upon these communities, and despite the fact that the "literature on behavior change suggests the importance of considering sociocultural and psychological characteristics of a population in the promotion of certain health behaviors and practices." The question has been raised, "why is it now necessary to distinguish the impact of AIDS upon minority communities from non-minority communities?" The answer can be found in part in the Morbidity and Morality Weekly Report (MMWR) of the Centers for Disease Control; AIDS has had a disproportionate impact upon minority communities and AIDS also impacts differently upon minority communities. The answer also can be found in the complaint files of the San Francisco and New York City Human Rights Commissions; AIDS has given rise to a second epidemic, an epidemic of fear, stigmatization, and discrimination. This second epidemic has resulted in individuals losing their employment, housing, ac-


cess to medical care, insurance, and being subjected to harassment, intimidation, and even violence. Finally, the answer lies in the fact that the AIDS epidemic, and the accompanying epidemic of discrimination, have impacted most heavily upon minorities with the least resources to combat discrimination — I.V. drug users, women, homosexual and bi-sexual males, prison inmates, immigrants, and the poor.

Disease does not occur within a social vacuum. This essay examines the impact of AIDS upon minority communities within the context of the existing sociocultural, economic, and legal status of minority populations in the United States. AIDS makes explicit, as few diseases could, the complex interaction of social, cultural, and biological forces. The social construction of AIDS in minority populations is one of a pre-existing health crisis; scarce resources; economic, cultural, and language barriers to services; discrimination, including racism, prejudice towards I.V. drug users and homophobia; and an underfunded, overburdened public health care system. This social construction is also one in which, traditionally, the specific health care needs of minority populations have been unexamined, or discounted. "The historic failure of health research, policies, and programs to differentiate, and address in depth, the special needs of sub-groups within each racial/ethnic and sociocultural community is a major factor in the disproportionate burden of illness borne by minorities today."  

4. See sources cited supra, note 3; See also, Hammill, Employment and AIDS, in Acienberg, Sexual Orientation and the Law (1987); Schatz, The AIDS Insurance Crisis: Underwriting or Overreaching, 100 Harvard L. Rev. 1782 (1987). In addition to a rising tide of discrimination against persons with AIDS, a rise in AIDS related violence has also been observed. "David Wertheimer, executive director of the New York City Gay and Lesbian Anti-violence Project, said that the 249 individuals served by the project in 1985 represented a 41 percent increase over 1984. Of those cases, 28 percent involved violence against persons with AIDS or explicit use of AIDS related epithets by assailants." AIDS Policy & Law (BNA) (Oct. 22, 1986). AIDS related violence directed at minority groups perceived to be at high risk, e.g. Haitians, has been observed in New York; supra, New York City, note 3.


6. AIDS within minority communities occurs within the context of a pre-existing health crisis. See Report on AIDS and Ethnic Minorities, supra, note 2. The interaction of social, cultural, biological, and legal forces constitutes the social construction of AIDS in minority communities. Allan Brandt has characterized the "social construction of disease" as the "process by which social and cultural forces affect our understanding of disease." Brandt, supra, note 5.

7. Pasick, Health Risk in the Socio-Cultural Context, paper prepared for Health and Human Services, Office of Minority Health, for presentation at the conference on


9. Id. (The Report also found that a higher percentage of Blacks and Hispanics than Whites report that they have no usual source of medical care (20 and 19 percent versus 13 percent); proportionately fewer Blacks and Hispanics than Whites report that they use a physician's office as their usual source of care (46 and 54 percent versus 70 percent); proportionately twice as many Blacks and Hispanics than Whites report they use hospitals and health clinics as their usual source of medical care; and, proportionately twice as many Blacks and three times as many Hispanics as non-minorities have no medical insurance whatsoever (18 percent and 26 percent versus 9 percent)).


12. Centers for Disease Control, Conference on AIDS in Minority Populations in
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In a pioneering attempt to examine the factors that account for the disparity between the health status of minority populations and non-minority populations in the United States, the Secretary of Health and Human Services convened a Task Force on Black and Minority Health in 1984. The Final Report of the Task Force, released in 1985, revealed six areas of significant disparity between minority and non-minority health. These were cancer, cardiovascular disease and stroke, chemical dependency, diabetes, homicides and accidents, and infant mortality. The Final Report of the Task Force did not address the issue of AIDS, or even mention AIDS, even though the disproportionate incidence of AIDS in minority communities had been clearly documented at that point. It was not until the Fall of 1987 that Health and Human Services, through the Office of Minority Health, noted that “it has become clear that AIDS is also a serious minority health issue — in fact it is imperative that we understand that the number of newly identified cases of AIDS is growing more rapidly in the minority community than any other.” The failure of Health and Human Services to address the issue of AIDS in minority communities is matched by the Centers for Disease Control, which issued its first report on AIDS in the Black and Hispanic communities in the Fall of 1986, and convened its first conference on AIDS in Minority Populations in the United States in August, 1987. Finally, the failure of current AIDS

8. United States Department of Health and Human Services, Report of the Secretary's Task Force on Black and Minority Health, Volume I: Executive Summary (1983). (The Report represents the first comprehensive effort by the federal government to analyze the present state of knowledge in regard to the health status of Blacks and other minorities. The Report, released a year after the Secretary of Health and Human Services proclaimed AIDS the nation's "number one health priority," does not address the issue of AIDS.)
9. Id. (The Report also found that a higher percentage of Blacks and Hispanics than Whites report that they have no usual source of medical care (20 and 19 percent versus 13 percent); proportionately fewer Blacks and Hispanics than Whites report that they use a physician's office as their usual source of care (46 and 54 percent versus 70 percent); proportionately twice as many Blacks and Hispanics than Whites report they use hospitals and health clinics as their usual source of medical care; and, proportionately twice as many Blacks and three times as many Hispanics as non-minorities have no medical insurance whatsoever (18 percent and 26 percent versus 9 percent)).
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research and prevention efforts to address minority populations is reflected in the paucity of information on AIDS in minority populations represented at the Third International AIDS Conference, held in Washington, D.C., in June, 1987.34 Despite the lack of attention in existing research and prevention efforts, AIDS has had a significant impact upon minority communities. The devastating toll of AIDS upon minority communities must be viewed within the context of the unprecedented scope of the AIDS epidemic. The first cases of AIDS in the United States were diagnosed

the United States, Atlanta (Aug. 8-9, 1987).

13. The Third International Conference on AIDS brought together over 5,000 AIDS researchers, educators, and service professionals. An analysis of the presentations at the Conference, conducted by the Multicultural Inquiry and Research on AIDS (MIRA) of the University of California, found only limited research directed at minority communities. The study found that:

1) few of the leading figures in AIDS are Black or Latin (as suggested by the number of plenary speakers and session chair-people); 2) few of the scientists involved in AIDS research are Black or Latin (as suggested by the small number of scientific papers given by Blacks or Latinas); and 3) Blacks and Latins are more likely to be engaged in education and service-delivery (as indicated by their more significant involvement in roundtable discussions).

The study also noted that:

The impact of AIDS upon ethnic minorities has created a need for interventions that incorporate culture and language into prevention, education and treatment services. We are hampered in these efforts by our ignorance. For example, we need to know about minority sexual practices in order to design effective prevention messages. Yet there are few studies that look at those behaviors, and much of the research that exists is clouded in racial stereotypes and myths.

The contributions of ethnic minority researchers to the AIDS research effort can be invaluable in developing a knowledge base for prevention and treatment efforts. Perceptions, attitudes, and beliefs about AIDS, sexual practices, patterns of substance abuse, sexual lifestyles, grieving processes, changes in the community’s social norms and social policies are some areas where important differences can be found among racial and ethnic groups, differences which affect prevention and treatment efforts. And all are areas in which our understanding of the situation of minority communities lags far behind the research on majority communities.

Involvement of ethnic minority researchers in the AIDS effort is essential if we are serious about being effective in stopping this epidemic. The need for research with a multi-cultural perspective provides an opportunity to discover a variety of phenomena in ways that are specific to certain populations and in ways that are unusual.

Multicultural Inquiry and Research on AIDS, MIRA Newsletter (Summer 1987).


16. The World Health Organization has estimated that “as many as 50 to 100 million people may be infected by HIV by 1991, compared with the current estimates of five million to 10 million.” AIDS Policy & Law (BNA) (May 6, 1987).

17. Centers for Disease Control, supra, note 15.

18. Id.

19. Id.


21. Id.
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and reported to the Centers for Disease Control in June, 1981.\footnote{Centers for Disease Control, Kaposi’s Sarcoma and Pneumocystis pneumonia among homosexual men — New York and California, 30 Morbidity & Mortali-
ty Weekly Rep. 305 (1981).} Since then, AIDS cases have been reported from all 50 states, the District of Columbia, and four United States Territories.\footnote{Centers for Disease Control, Weekly AIDS Surveillance Report, (Dec. 7, 1987).}
The World Health Organization has reported cases from over 100 countries.\footnote{The World Health Organization has estimated that “as many as 50 to 100 million people may be infected by HIV by 1991, compared with the current estimates of five million to 10 million.” AIDS POLICY & LAW (BNAA) (May 6, 1987).}

While data on the prevalence of HIV infection in minority communities are not currently available, the reported incidence of AIDS reflects a disproportionate impact upon minority populations. Of the over 45,000 cases of AIDS reported to the Centers for Disease Control, as of December 1, 1987, over 40 percent are from minority communities.\footnote{Centers for Disease Control, supra, note 15.} While Blacks represent 12 percent of the population of the United States, they currently account for 25 percent of the reported cases of AIDS.\footnote{Id.} Hispanics represent 6 percent of the population of the United States, and yet they account for 4 percent of the reported AIDS cases.\footnote{Id.} Other minorities account for two percent of reported AIDS cases.

As a result of Centers for Disease Control reporting requirements, accurate data on the incidence of AIDS in the Asian, Native Ameri-
can, Pacific Islander, and other ethnic minority communities are not available.\footnote{See National Minority AIDS Council, supra, note 2.} It is the policy of the Centers for Disease Control to report these communities collectively as “Other”. This practice, which serves to mask the impact of AIDS upon these communities, has been criti-
cized by minority researchers and by the Final Report of the Secret-
tary’s Task Force on Black and Minority Health.\footnote{Id.} This has also served to slow the development of AIDS education and prevention programs in these communities.

A closer examination of AIDS cases reveals an even more pron-
nounced racial imbalance in the incidence of AIDS. Among women with AIDS, which comprises 7 percent of the currently reported cases,
Black and Hispanics account for 51 percent and 21 percent, respectively, of the diagnosed cases.22 Among children with AIDS, 57 percent are Black and 23 percent are Hispanic.23 Minorities account for approximately 80 percent of the inmates in correctional facilities with AIDS,24 and minorities are also disproportionately represented among I.V. drug users with AIDS.25

If allowed to continue unchecked, disease and death from AIDS and HIV infection will continue to mount into the next century. AIDS in minority communities has become an epidemic of unprecedented proportion in modern history, and the social, economic, and legal impact of this projected loss to minority communities in the United States is almost incalculable. Current projections by the Public Health Services predict that:

*By the end of 1991 there will be a cumulative total of more than 270,000 cases of AIDS in the United States, with more than 74,000 of these cases occurring in 1991 alone.

*By the end of 1991 there will be a cumulative total of more than 179,000 deaths from AIDS in the United States, with 54,000 of these occurring in 1991 alone.

22. Centers for Disease Control, supra, note 15.
23. Id.
25. A study of HIV infection among I.V. drug users in San Francisco found that:

HIV infection in San Francisco I.V. drug users is significantly more prevalent in Blacks and Latinos than Whites. This racial difference has also been reported in New York and New Jersey, though not in European surveys. There is no evident behavioral or demographic characteristics that readily explain the alarming prevalence of infection in this population. While needle sharing is no more prevalent among Blacks and Latinos than Whites, the risk of infection is clearly greater for individuals who share needles with minority group members due to the prevalence of infection in this group.

These data have several important implications. The potential for an epidemic of AIDS in I.V. drug users in San Francisco will necessitate changes in the city’s medical care system for AIDS and in AIDS prevention programs, both of which are oriented to a predominantly White, middle-income homosexual population.


26. United States Department of Health and Human Services, Public Health Service, Public Health Service Plan for the Prevention and Control of AIDS and the AIDS Virus: Report of the Coordinating Planning Conference, (1986). (While the Report notes the dramatic increase in the prevalence of AIDS in the heterosexual community, particularly among women and children, it fails to note that the vast majority of these cases will be in minority communities).

27. Researchers Say Vaccine Still a Few Years Away, AIDS POLICY & LAW (BNA) (June 3, 1987).
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*Because of the lengthy time period between infection and manifestation of AIDS, most of the people who will develop AIDS between now and 1991 are already infected.

*Dramatic increases will be seen in the prevalence of AIDS and HIV infection in the heterosexual population, particularly among women and pediatric cases.

In light of the large number of individuals currently infected with the HIV virus, which has been estimated to be 1.5 million individuals in the United States, and the projected number of AIDS cases for the next five years, it is unlikely that the rising incidence of AIDS in minority communities will slow or reverse within that period. The incidence of AIDS and prevalence of HIV infection in minority communities is likely to grow rapidly until some form of treatment and effective prevention is established. While initial attempts at the development of a vaccine have begun, numerous obstacles currently exist to the development of an effective vaccine. These include biological limitations not yet overcome by research, as well as legal, ethical, and funding limitations. An effective vaccine or treatment is not projected within the next five years. In the absence of an effective treatment or vaccine, the most effective avenue for reducing the spread of HIV infection is public education.

The goal of public education is to foster awareness about the transmission of AIDS, provide information on how individuals can protect themselves and others from infection, and promote behavioral changes for individuals engaging in high risk behaviors. In order to be effective, public education must be targeted towards a specific audience. This audience can be defined by behavior, e.g. men who have sex with other men or I.V. drug users. The audience can also be defined by community, e.g. individuals whose primary community is defined by their race, ethnicity, gender, or sexual orientation. Finally, the target audience may be defined by their setting, e.g. health care workers, prison inmates, or youth in school. Most existing AIDS-related public

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education programs have failed to target minority communities, or have failed to deliver a message that is culturally or linguistically appropriate.

The unwillingness of the Reagan administration to mount an effective response to the AIDS epidemic in minority communities has been evident from the start of the epidemic. In 1985 the Office of Technology Assessment issued a report sharply critical of the administration's handling of the AIDS epidemic in its first few years. The Centers for Disease Control (CDC) and the National Institutes of Health (NIH) were singled out for their failure to recognize the significance of the AIDS epidemic, and to mount an effective response.

Although CDC had identified AIDS in 1981, research at NIH did not begin in earnest until 1983. Bureaucratic procedures prevented a more timely response to this public health emergency. Second, when NIH did take up the problem of AIDS, research funding was inadequate. In 1982 and 1983 the administration did not budget any money for AIDS research; nevertheless, Congress allocated $35 million. The following year, the administration asked for $29 million, Congress appropriated $61 million. In 1986, Congress allocated $234 million, but the Reagan administration proposed cutting this to $213.2 million; this despite the fact that cases have been doubling every year.

The failure of the Reagan administration to adequately address the AIDS epidemic in its early years may well be remembered as the legacy of this administration. It was in this time period that the AIDS epidemic was allowed to establish a firm foothold within minority communities.

In the first five years of the AIDS epidemic, funding at the local, state, and federal levels has failed to address the impact of AIDS on minority communities, and has provided minimal incentives to already overstrapped minority public health programs. Many of the impediments identified by the National Academy of Sciences are even more acute for minority communities; communities faced by a pre-existing health crisis of drug abuse and chemical dependency, teen pregnancy and infant mortality, and high rates of sexually transmitted diseases.

One important obstacle to the development of AIDS prevention and education programs, in minority and non-minority communities, has been homophobia. Homophobia, the irrational fear of homosexual-

28. Brandt, supra, note 5, at 238.

29. Closely related to homophobia as an obstacle to the delivery of services has been the stigmatization associated with I.V. drug users. While services for the Gay community have been often hampered by homophobia, services for I.V. drug users with AIDS are often non-existent. I.V. drug users with AIDS, the majority of whom are minorities, present different needs than homosexual males with AIDS. The stigmatization associated with I.V. drug users has operated to slow the development and delivery of services to these individuals. This has included the lack of residential facilities for substance abusers with AIDS; the limited availability of treatment programs for I.V. drug users; limited access to medical care, including experimental drug trials; and, the limited response of the local community to the needs of I.V. drug users with AIDS.

30. Supra, note 5, at 234.

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edy as reflected in prejudice directed towards Gays and Lesbians, has operated to limit the availability of public funding for AIDS activities. Public agencies, and elected officials, have been hesitant to fund AIDS related programs for fear of being perceived as promoting homosexual activities, which may be in conflict with local legal or religious views. Homophobia serves to reinforce the false perception that AIDS is a "Gay, White, male disease". AIDS is not a Gay disease; particularly given the high rates of heterosexual transmission and pediatric AIDS within minority communities. AIDS is a public health crisis of unprecedented dimensions, and shortsighted public health policies that deny appropriate funding based on prejudice and stigmatization only serve to support the spread of the epidemic.

Despite the reality of AIDS in minority communities, AIDS is often portrayed as a "Gay, White, male" disease. Many legal service providers appear to share in this misperception. The misperception is dangerous in that it promotes discrimination against those perceived to be at risk, particularly Gay men and I.V. drug users.

Stigma goes beyond AIDS patients to anyone considered at risk of carrying the infection. Indeed, not only have AIDS patients been subject to discrimination but the public response to the disease has been accompanied by a rise in attack on homosexuals. Fire officials have refused to resuscitate men they suspected might be homosexuals. Police have worn gloves when apprehending suspects in some municipalities.

The AIDS epidemic has exacerbated existing societal discrimination against Gays and Lesbians, I.V. drug users, and prostitutes, and has provided new opportunities for discrimination. AIDS related hysteria
education programs have failed to target minority communities, or have failed to deliver a message that is culturally or linguistically appropriate.

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and fear have resulted in a rising tide of discrimination against Gays, I.V. drug users and others perceived to be at risk, and calls for repressive measures. "When the epidemic worsens, as it most certainly will, the social desire to identify and segregate those individuals who are infected will probably become more intense." Given the extent of existing societal discrimination against Gays, I.V. drug users, and prostitutes, and public perception about AIDS and homosexuality, it is likely that homophobia will remain a major obstacle to an effective public health response to the AIDS epidemic. Moreover, the social construction of this disease, in close association in much of the public's eye with violations of the moral code, could contribute to spiraling hysteria and anger. This cycle has already led to further victimization of victims, the double jeopardy of a lethal disease and social oppression."

Minority communities, and community leaders, have not been immune to homophobia. Even in light of the devastating impact of AIDS on minority communities there remain "prominent Black organizations who will not touch the subject of AIDS because of its association with the taboo topic of homosexuality, which is often viewed as some sort of white disease, and therefore alien to the Black community." The response of minority civil rights organizations to the AIDS crisis has often been one of silence. Homophobia remains an important part of the social construction of AIDS.

As a result of stereotypes about persons with AIDS, and the misperception that AIDS is a "Gay, White, male disease", some minority communities have developed a false sense of security. This misperception has also operated to mask the impact of AIDS on ethnic minority gay males. This false sense of security that these communities are not at risk, when they are in fact very much at risk, has operated to slow the development of AIDS education and prevention programs. The impact of these obstacles can be seen in the differing response of San Francisco and Los Angeles to the issue of AIDS in minority communities. San Francisco has actively addressed the issue of AIDS in minority communities. As a part of this process, the San Francisco Department of Public Health (DPH) has established a series of policy statements to address the concerns of racial and ethnic minority groups. These policies include:

1. DPH should insure that prevention education programs and intervention strategies are developed in San Francisco which will meet in a timely fashion the unique needs of racial and ethnic minority groups at risk for AIDS.

2. The design and content of AIDS education and intervention efforts among racial and ethnic minority groups should be shaped by information from epidemiological research as well as careful assessments about what targeted audiences already understand about AIDS and its transmission and of what stands in the way of their adopting or maintaining new behaviors.

3. The organizational basis from which AIDS education efforts in San Francisco are launched should be diversified. There should be a wide range of community settings and community-based organizations who educate the general and at-risk public about AIDS and its prevention. Particular attention needs to be paid to programs which will communicate effectively with people from racial and ethnic minority groups.

4. AIDS provider education must directly address attitudes that may distort the way in which information about AIDS is perceived by those professionals participating in training. Of particular concern, where AIDS is an issue, are attitudes about racial and ethnic minority groups.

5. DPH should insure that services are provided in a manner which

31. Id., at 236.
32. Id., at 241.
33. Speech by Gil Gerald to the Southern Christian Leadership Conference (May 31, 1986). (The failure of minority civil rights organizations to address the issue of AIDS appears to be a result of a number of factors. These include: lack of awareness of the problem, particularly in light of the media's portrayal of AIDS as a "Gay, White disease"; stigmatization of homosexuality and I.V. drug usage; and, the lack of adequate outreach to minority community leaders by government agencies and AIDS education and service organizations.)

34. San Francisco Dep't of Public Health, AIDS in San Francisco: Status Report and Plan for Fiscal Year 1987-88, (March, 1987). (These policies were developed after an extensive series of meetings with representatives from minority communities and minority AIDS education and service organizations. These meetings were held in the Fall of 1986 to address the failure of gay community-based organizations to reach minority communities. While these organizations have developed extensive services for their target audience, the city had not addressed the issue of AIDS in minority communities, particularly programs and services targeted toward substance abusers. The city has since developed education and prevention programs targeted toward minority communities, implemented surveys of the level of knowledge in regard to AIDS in minority communities; and, has begun to develop services targeted toward the I.V. drug community.) Conversation with Dr. Pat Evans, Associate Medical Director, San Francisco Department of Public Health, AIDS Office (Dec. 17, 1987).
and fear have resulted in a rising tide of discrimination against Gays, I.V. drug users and others perceived to be at risk, and calls for repressive measures. “When the epidemic worsens, as it most certainly will, the social desire to identify and segregate those individuals who are infected will probably become more intense.”

Given the extent of existing societal discrimination against Gays, I.V. drug users, and prostitutes, and public perception about AIDS and homosexuality, it is likely that homophobia will remain a major obstacle to an effective public health response to the AIDS epidemic. “Moreover, the social construction of this disease, the stigma attached to it, in close association with pedophilia, are a result of the public’s eye with violations of the moral code, could contribute to spiraling hysteria and anger. This cycle has already led to further victimization of victims, the double jeopardy of a lethal disease and social oppression.”

Minority communities, and community leaders, have not been immune to homophobia. Even in light of the devastating impact of AIDS on minority communities there remain “prominent Black organizations who will not touch the subject of AIDS because of its association with the taboo topic of homosexuality, which is often viewed as some sort of white disease, and therefore alien to the Black community.” The response of minority civil rights organizations to the AIDS crisis has often been one of silence. Homophobia remains an important part of the social construction of AIDS.

As a result of stereotypes about persons with AIDS, and the misperception that AIDS is a “Gay, White, male disease”, some minority communities have developed a false sense of security. This misperception has also operated to mask the impact of AIDS on ethnic minority gay males. This false sense of security that these communities are not at risk, when they are in fact very much at risk, has operated to slow the development of AIDS education and prevention programs.

The impact of these obstacles can be seen in the differing response of San Francisco and Los Angeles to the issue of AIDS in minority communities. San Francisco has actively addressed the issue of AIDS in minority communities. As a part of this process, the San Francisco Department of Public Health (DPH) has established a series of policy statements to address the concerns of racial and ethnic minority groups. These policies include:

1. DPH should ensure that prevention education programs and intervention strategies are developed in San Francisco which will meet in a timely fashion the unique needs of racial and ethnic minority groups at risk for AIDS.

2. The design and content of AIDS education and intervention efforts among racial and ethnic minority groups should be shaped by information from epidemiological research as well as careful assessments about what targeted audiences already understand about AIDS and its transmission and of what stands in the way of their adopting or maintaining new behaviors.

3. The organizational basis from which AIDS education efforts in San Francisco are launched should be diversified. There should be a wide range of community settings and community-based organizations which educate the general and at-risk public about AIDS and its prevention. Particular attention needs to be paid to programs which will communicate effectively with people from racial and ethnic minority groups.

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makes them as accessible as possible to patients being served. Sensitivity to differences in lifestyle, culture and language should be evident in all service settings.

6. DPH should make every effort to insure that staff in contract services and DPH settings in which services are planned or provided are culturally sensitive and, where monolingual clients are involved, language specific. Staffing patterns should reflect the populations targeted and served.

7. DPH should insure that each AIDS service contractor includes in their annual program proposal a plan for addressing the specific needs of the members of racial and ethnic minority groups as they relate to services concerned.

8. DPH should insure that racial and ethnic minority groups participate in the Department's periodic monitoring of contract services. These policies were developed as a result of an on-going dialogue between the Department of Public Health, AIDS education and service providers, and community based organizations. As a result of these policies, and the City's commitment to funding programs targeted toward minority communities, "San Francisco seems to have a unique opportunity to demonstrate that education and prevention programs, which are far less costly than treatment programs, can be effective in addressing the threat of AIDS among racial and ethnic minority groups."

In sharp contrast is the situation in Los Angeles, a city with approximately the same number of AIDS cases as San Francisco. In a suit filed by the National Minority AIDS Council, the Minority AIDS Project, the Southern Christian Leadership Conference of Greater Los Angeles, and the Los Angeles branch of the National Association for the Advancement of Colored People (NAACP), it was alleged that:

Officials of Los Angeles County responsible for the provision of health services have failed and refused to develop and implement any coordinated program of public education about AIDS, especially with regard to minority communities within the county. No plan for education has ever been drafted. Recommendations and proposals for effective education directed at minority communities have been ignored or turned down. County expenditures for education and minorities have not approached even a minimal level, averaging less than 3 cents per minority resident. County subsidized education about AIDS consists, and has consisted, of little more than printing of a few thousand pamphlets and presenting a handful of speakers and forums. By rough comparison, San Francisco now spends 10 times more on AIDS than Los Angeles County, although the caseload for San Francisco is only 15 percent larger.

The findings of the best available evidence regarding knowledge and attitudes about AIDS in minority communities within Los Angeles County as of July, 1986, summarized in the study "Minority Focus Groups/Final Report: Southern California Cares," are that "[t]here appears to be minimal awareness and concern about AIDS in minority communities . . . . Minorities do not feel personally threatened by AIDS and it has not impacted upon behavior." County officials participated in the study and are aware of its findings. The findings also state that there "appear to be low level of awareness and information, even among the high-risk groups within the Black community of Los Angeles . . . . The Black community appears to be where the gay white community was 2-3 years ago in terms of concern . . . . The epidemic has had no significant impact upon behavior, yet risk behaviors are prevalent, especially among IV drug users . . . . AIDS is perceived as a 'heterosexual disease' and a 'white disease.'" Within the Hispanic community, "[t]here is a low level of awareness and information, particularly among monolingual Spanish-speaking segments of the community . . . . Even among homosexual men, awareness and information levels are not what they should be . . . . As with the Black community, there is no perception of personal threat. AIDS is seen as a gay or white disease . . . . Monolingual Spanish speakers may not even know that AIDS exists and that it affects Hispanics. In this community, IV drug use is more acceptable than homosexuality . . . . The epidemic has had no real impact on behavior, except perhaps among gay-identified men on the West side. Public education about AIDS to minorities is insensitive or grossly insufficient in outreach to cultural, social, economic, literacy and language norms which impair necessary awareness and behavior change, nor have these issues been meaningfully addressed or addressed at all by County officials. Effective educational programs about AIDS requires attention to these issues."
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35. San Francisco Dep't of Public Health, supra, note 34 at 27.
36. Id., at 26.

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Public education about AIDS to minorities is insensitive or grossly insufficient in outreach to cultural, social, economic, literacy and language norms which impair necessary awareness and behavior change, nor have these issues been meaningfully addressed or addressed at all by County officials. Effective educational programs about AIDS requires attention to these issues.

37. Bean v. Board of Supervisors, Cal. Super. Ct., Los Angeles County, No. C640618 (March 18, 1987). (The suit charged the county of Los Angeles with having failed or refused to develop and implement education, prevention, and services programs in regard to AIDS in minority communities).
Unfortunately, and tragically for minority communities, the situation in Los Angeles is more common than the situation in San Francisco. A survey of existing AIDS service agencies conducted by the National AIDS Network, a national resource center for AIDS education and service agencies, revealed “limited success and many difficulties in providing AIDS education and services to People of Color.”\(^{38}\) Some of the reasons identified in this survey for the lack of success included:

1. lack of implementation of such programs;
2. limited success in involving minorities in agencies and programs;
3. lack of contacts in minority communities;
4. unsuitability of educational materials for use in minority communities; and,
5. lack of funds for these programs.\(^{39}\)

Many of the obstacles to the development of AIDS education and service delivery programs in minority communities are outlined in the National Minority AIDS Council Report on AIDS and Ethnic Minorities.\(^{40}\) This Report found that:

Ethnic minority populations, and other low income people, often rely on publicly funded clinics or hospitals for health care services. The high infant mortality rates, teen pregnancy rates, sexually transmitted disease, and substance abuse rates, reflect the inadequacy in the delivery of public education programs in these communities. In terms of AIDS education and prevention, this inadequacy is exacerbated by the lack of appropriate funding and other incentives. It is particularly alarming that teen pregnancy, substance abuse, and sexually transmitted disease rates in young adults are rising in minority communities. This indicates that these groups are at increased risk for AIDS, and that they are not being reached by current public health education programs.

The beliefs and attitudes of minority communities towards AIDS, and their receptivity to education and prevention programs, are affected by language, culture and stigmas associated with risk behaviors. The organizations that have been funded to date for

AIDS education and prevention were often established to reach a specific target audience: English-speaking, Gay, White males. These organizations are appropriate for their target audience, a group that currently represents the majority of the people with AIDS in the United States. However, these groups often lack the expertise to reach minority populations, homosexual or heterosexual.

Many of the groups represented in high risk categories lack effective community and political support structures. This lack of community and political organization, combined with social stigmatization, results in an inability to generate a political response. This is reflected in the difficulty in obtaining funding for high risk groups. The Gay community has been able to generate an effective political response, as reflected in funding, in those areas where it has been able to generate political pressure through community action. The community support structures within the Gay community have also been uniquely effective in responding to the demands of the AIDS epidemic. The response of the City of San Francisco, which offers the most comprehensive and cost effective services in the United States, is in fact premised on using support structures developed in the Gay community.\(^{41}\)

These constraints help to define the boundaries of the social construction of AIDS in minority communities. The social construction of AIDS in minority communities is one of a pre-existing health crisis: scarce resources; economic, cultural, and language barriers to services; discrimination, including racism and homophobia; and, an already overburdened, underfunded, public health care system. This social construction has profound social, economic, political, and legal consequences in terms of the way that AIDS impacts upon minority communities. While many of these consequences are outside the scope of this essay, the remainder of this essay shall focus on the interaction between AIDS, race and the legal system.

The wave of fear and hysteria that has accompanied the AIDS epidemic has resulted in widespread and systemic discrimination against persons with AIDS, AIDS Related Conditions (ARC), individuals who are seropositive to the HIV virus, and for those perceived to be in high risk groups. This discrimination has also encompassed individuals who are the families and loved ones of persons with AIDS, including heterosexual and Gay couples, employees of AIDS services or-

\(^{39}\) Id.
\(^{40}\) See, National Minority AIDS Council, supra note 2.

\(^{41}\) Id., at 10-14.
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41. Id., at 10-14.

Published by NSUWorks, 1988
organizations, and other care providers. This discrimination has resulted in individuals losing their employment, housing, insurance, and being denied access to medical services. Widespread and systemic discrimination has been reported through public hearings conducted in New York, Los Angeles, and San Francisco.48

This discrimination has also encompassed members of minority communities and has presented special challenges for them. The New York City Commission on Human Rights has issued two reports on AIDS discrimination and minority communities.49 The Commission found that discrimination does not occur in a vacuum. It has both a history and a social context. For people of color, AIDS related discrimination is the latest in a history of discrimination on the basis of race, gender and, in some cases, sexual orientation. As a result, people of color who for years have received little help or support in the fight against race, economic and sex discrimination are less likely to seek help when confronted with AIDS-related discrimination. This is particularly true for intravenous drug users whose activity has been criminalized for years. Race and class have often been important factors in determining who has access to education, health care and the media, resources which are vital to the fights against AIDS and AIDS-related discrimination.44

The New York City Commission on Human Rights has also documented the impact of AIDS discrimination on a particular minority community.

To cite just one example of the AIDS backlash on an identifiable group, consider the devastating impact of AIDS related discrimination on Haitians. Despite the fact that Haitians have been removed from the AIDS risk groups, the stigma remains. Reports from Haitian community workers indicate that in some areas the unemployment rate for Haitians is twice that of other Black workers. Why? Many Haitians feel that this situation is directly attributable to AIDS. Particularly hard hit have been domestic workers, who are generally female and undocumented. Haitian children have been beaten up (and in at least one case, shot) in school; Haitian store owners have gone bankrupt as their businesses failed; and Haitian families have been evicted from their homes. The problem of discrimination against this community is not news, but unfounded fears about AIDS have surely escalated the intensity of prejudice directed towards Haitians. The same is true for the various groups (gays, IV drug users, prostitutes, etc.) now linked with AIDS in the public's consciousness.45

Much has been written elsewhere about the legal protection that currently exists for persons who have been discriminated against on the basis of AIDS.46 However, the legal environment appears to be improving for persons who have been subject to discrimination. There is a growing consensus in the courts that individuals with AIDS are protected by the Federal Rehabilitation Act of 1973,47 that persons with AIDS are protected by state physical handicap or disability statutes,48 and an increasing number of jurisdictions are adopting local ordinances that prohibit discrimination against persons with AIDS. What is lost in these treatments of legal rights of persons with AIDS is the availability of the remedy — particularly the availability of the remedy for low income people, for I.V. drug users, for individuals who fear being iden-
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42. See, San Francisco Human Rights Commission, Hearings on Discrimination Against Persons with AIDS, (Feb., 1986); Los Angeles City/County Task Force, Public Hearings on AIDS, (Jan., 1986); New York City Commission on Human Rights, Report on Discrimination Against People with AIDS, (1986). As a result of these hearings and the documented discrimination, AIDS Discrimination Units have been established in the San Francisco and New York Human Rights Commissions, and in the Los Angeles City Attorney’s Office.


44. Id.

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tified as homosexual, and for individuals struggling to cope with the reality of AIDS in minority communities.

There are also sociological factors involved. One factor is that more Black and Hispanic persons find themselves unemployed or underemployed than Whites. People in this situation may not have access to workplace-funded medical insurance. There may be no regular family doctor and people in such a situation may thus find that they have to rely on hospital emergency rooms for medical care. Consequently many people of color are, for a variety of reasons, neither diagnosed nor treated for AIDS related conditions until the disease reaches an advanced stage. Hence, a historical problem — the absence of proper medical care for racial and ethnic minorities and the poor — has critical implications in the AIDS epidemic. 49

The social construction of AIDS in minority communities also has tremendous implications on the availability of effective legal remedies. In light of the significantly shortened lifespan for persons with AIDS, the New York City and San Francisco Human Rights Commissions have developed expedited mediation and investigation processes for the resolution of AIDS related disputes. This is even more critical for minorities with AIDS. A recent study of the survival rates of 5,833 AIDS patients in New York City, from diagnosis until death, revealed clear patterns of difference based on race and sex. “The probability of survival, particularly during the first year of illness, is most strongly influenced by the particular manifestations of AIDS, but is also affected by age, sex, race, and the route of acquisition of the virus.” 50 This study found the highest rates of survival among homosexual white men, and the lowest rate of survival among Black women with a history of intravenous drug use. “Early survival was substantially better among whites than among Blacks or Hispanics.” 51 This study also suggests that Blacks and Hispanics seek treatment at a latter progression of the illness, as reflected by the larger number of Blacks and Hispanics who were diagnosed at the time of death.

The rapid spread of AIDS within the intravenous drug using population has also presented special problems in combating AIDS related discrimination. 52

Despite the modern official acceptance of narcotics as an illness and not a crime, the public’s attitude of needle users continues to be marked by moral condemnation, assumption of character weakness and fear. This attitude is heightened by the fact that a majority of needle users in treatment are members of ethnic minorities, as are over 80 percent of needle users with AIDS. The combination of poverty, addiction, racism, fear and moral approbation leaves needle users without the political or economic power to command attention to their plight. 53

These factors also make it less likely that legal service organizations, and private attorneys, will be responsive to their needs.

For many I.V. drug users with AIDS their principal interaction with the legal system is with the criminal justice system. A demographic study of 177 inmate deaths from AIDS in the New York State correctional system revealed that 92 percent of these inmates admitted to intravenous drug use; 40 percent were Hispanic, and 39 percent were Black. 54 It is not insignificant that the first person convicted of assault with a deadly and dangerous weapon on the basis of his positive antibody status, was a Black federal prison inmate with a history of I.V. drug use. 55

Many correctional systems have implemented, or proposed, mandatory screening programs for HIV infection. 56 Because of the large numbers of seropositive I.V. drug users within minority communities, these policies will have a disproportionate impact upon minority inmates. The effects of these policies will not be limited to just within the facility.

If actual or inferred test results become known to the correctional population at large, seropositive inmates may face intimidation, threats, or actual violence from others concerned about the possible spread of AIDS. Moreover, revelation of positive test results could

49. New York City Commission on Human Rights, supra note 43.
51. Id.
53. Id.
55. United States v. Moore, United States Dist. Ct., Dist. of Minn., No. Crim. 4-87-44.
56. See United States Dep’t of Justice, supra, note 24.
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subject inmates to serious discrimination in employment, housing, and insurability after they are released from the institution.97

Inmates with AIDS have been subjected to isolation and segregation. This has included denial of participation in work release programs, exercise programs, visitation programs, and other activities that would place them in contact with other inmates.98 This has occurred despite the fact that the Centers for Disease Control have issued strong regulations against such segregation in health care facilities.

The trend away from segregating inmates with ARC and HIV positivity may reflect concern that segregation will be insufficient to accommodate increasing numbers of such inmates. However, these policy changes undoubtedly reflect a growing awareness that segregating inmates with ARC and seropositivity may be unnecessary and inappropriate and may lead to inmate lawsuits raising difficult legal issues.99

One of these difficult legal issues may be the racial imbalance in these segregated facilities.

The plight of Black and Hispanic inmates with AIDS also raises serious questions in regard to access to medical services. The medical challenge posed by AIDS may require careful monitoring and surveillance of inmates with AIDS, ARC and other forms of HIV infection because of the many opportunistic infections that can develop quickly. In addition, because AIDS is an extremely serious psychological as well as physical problem for those with the disease, counseling and support systems are also an essential element of care. Proposals for mandatory HIV screening in correctional settings raise serious issues in regard to counseling, follow-up care, and other support services. Some of these issues were raised in Cordero v. Coughlin, a suit brought against the New York State Department of Correctional Services.100 The inmates involved alleged that New York's policy of medical segregation constituted cruel and unusual punishment and deliberate indifference to their serious medical needs. It was further alleged that their segregation un-

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constitutionally fostered depression and deterioration of their medical condition. Finally, the inmates alleged that as a result of their segregation they were unconstitutionally deprived equal access to rehabilitation programs, exercise, visitation and other benefits. The court found in favor of the Department of Corrections, holding that inmates have no constitutional right to freedom from segregation instituted to advance a reasonable correctional objective. Numerous other suits are currently pending challenging the quality of medical care afforded inmates, and other areas including inadequate and discriminatory medical care; insufficient medical information provided to inmates; insufficient diagnostic services; failure to identify and respond to medical needs in a timely manner; discrimination in admission to hospitals in the community; and, discrimination in parole decisions.101

Prisoner rights advocates in California have identified numerous deficiencies in the provision of services to inmates with AIDS. They found that

the consequences of segregating prisoners who test positive are drastic. They have little or no programs and facilities in the prison. They also have no access to the prison's law library. Although laundry is supposed to be delivered weekly, there is never enough for all prisoners. The AIDS wings do not have separate kitchen facilities so that the food must be transported to the wing and often arrives cold. AIDS prisoners have no access to the main exercise yard and instead must use a tiny yard adjacent to the AIDS wing. The yard is filthy because inmates from the upper floor throw objects and food at the AIDS prisoners.102

Other deficiencies include restricted access to prison industries, which


97. Id. at 35.
98. Id. note 24.
subject inmates to serious discrimination in employment, housing, and insurability after they are released from the institution.**

Inmates with AIDS have been subjected to isolation and segregation. This has included denial of participation in work release programs, exercise programs, visitation programs, and other activities that would place them in contact with other inmates.** This has occurred despite the fact that the Centers for Disease Control have issued strong regulations against such segregation in health care facilities.

The trend away from segregating inmates with ARC and HIV positivity may reflect concern that segregation will be insufficient to accommodate increasing numbers of such inmates. However, these policy changes undoubtedly reflect a growing awareness that segregating inmates with ARC and seropositivity may be unnecessary and inappropriate and may lead to inmate lawsuits raising difficult legal issues.**

One of these difficult legal issues may be the racial imbalance in these segregated facilities.

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Other deficiencies include restricted access to prison industries, which

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57. Id. at 35.
58. Id. note 24.
offer job training and money; ineligibility for work furlough programs, the only opportunity to work outside the facility; ineligibility to conjugal visits; lack of educational programs for inmates and staff; denial of access to condoms, needle cleaning solutions or other AIDS prevention tools; limited access to compassionate release programs; and lack of access to experimental treatments and drugs.  

The lack of access to experimental drug treatments and drug trial programs also has serious consequences for low income persons, I.V. drug users, and children with AIDS. As a result of past abuses by drug companies, who often utilized inmate populations for experimental drug trials, most correctional systems have barred inmates from participating in drug trials. This had the unintended effect of denying treatment and care to inmates with AIDS, as most of the currently available AIDS treatments, including azidothymidine (AZT), are classified as experimental. In addition, protocols for experimental drug trials usually exclude individuals who are current or former I.V. drug users. Finally, experimental drug trials are usually offered through large university hospitals, or other settings that are inaccessible to low income, minority populations. For example, when Burroughs-Wellcome, the manufacturer of azidothymidine, released its initial protocol for the distribution of AZT it required the administration of AZT through a private physician; the effect of this was to deny access to low income individuals with AIDS, primarily minorities, who were often seen in clinic settings. The protocol has since been modified to allow the administration of AZT in hospital and clinic settings, although the availability of AZT for inmates, I.V. drug users and low income persons remains an unresolved issue. The only AZT research trial for children with AIDS is being conducted by the National Institutes of Health in Bethesda, Maryland; the effect of this has been to exclude most Black and Hispanic children with AIDS, who are generally the children of low-income I.V. drug using mothers, from participating in these drug trials.

AIDS has not occurred in a vacuum, it has occurred within the context of the social construction of minority communities within the United States. AIDS has presented unique challenges for minority communities, and for legal service providers. The failure of the legal community to recognize and address these challenges will operate to limit the availability of AIDS related services for these communities. AIDS is more than a public health challenge, it challenges the ability of our legal system to deliver compassionate and necessary services, and it challenges our commitment to provide services to those who have the least resources to combat discrimination. AIDS has demonstrated how economics and race cannot be separated from disease, it has also demonstrated how the social construction of minority communities in the United States cannot be separated from law.
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63. Id.