Stemming the Tide of HIV Infection:

A Multidimensional Analysis of Risk and Prevention for Acquired Immuno-deficiency Virus

by

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In time of darkness, that is the time to love.

- Elie Wiesel

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ABSTRACT

This thesis uses a feminist analytic framework to examine sources of HIV risk and means of HIV prevention, within three different "waves" of the AIDS epidemic as they have evolved in the United States, from 1981 to the present. The waves are 1) gay men, 2) intra-venous drug users, and 3) women and children.

The author uses a multi-disciplinary approach to examine sources of HIV risk at many different levels of people's lives -- the interpersonal, the economic, the political, the social and the religious. In analyzing the effectiveness of various prevention efforts, the author employs a distinction used within feminist scholarship, namely those interventions which are practical and those which are strategic. Practical interventions are intended to address the concrete needs of AIDS prevention and strategic interventions are intended to address the more over-arching obstacles to behavior change and seek to transform the conditions of meaning in people's lives.

After analyzing each "wave" of the epidemic in considerable detail, the author concludes that both practical and strategic interventions are needed if we are to effectively STOP further transmission of HIV. The author argues that through a combination of practical and strategic efforts in the gay community, transmission of HIV was virtually ground to a halt. Although the specific socio-economic conditions of the second and third waves differ enormously from the first, the lesson learned from the gay community's experience is that transformation is possible with the appropriate combination of practical and strategic interventions. Practical public health interventions alone, if they are intensified, may be able to slow down the rate of HIV transmission in the second and third "waves," but it is only through simultaneously employing both practical and strategic intervention techniques that true behavioral transformation to reduce risk of HIV can take place.

Thesis Supervisor: Frank Jones, Ford Professor of Urban Affairs

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Countless people have asked me how I could work on something as depressing as AIDS. I have definitely had many moments of feeling sad and despairing. But, what always picked me up, were the people I interviewed who are working so seriously and compassionately to relieve the human suffering this epidemic has wrought. The doctors, the nurses, the drug counselors, the shelter directors, the educators, and people with AIDS themselves -- they are all truly remarkable human beings. Most spent twice as much time with me than their busy schedules really allowed, and encouraged me every step of the way. In particular, Dr. Jim O'Connell and Sister Margaret Leonard deserve my special gratitude, for the way in which they both approached their work with so much love and wisdom, deeply inspired me.

Frank Jones, my advisor, my ally and my friend, never failed to support me in any way he could. Frank paved the way for me to develop a new perspective on the epidemic -- one that had historical depth and social relevance. Melvin LaPrade and especially Paula Schnitzer, helped me think through my analysis and further develop that perspective. Lang Keyes did me the service of critically but gently questioning that perspective, sending me and my thesis into a tailspin that could only be calmed around Carl Koechlin's kitchen table, going round and round, trying to figure out a new approach. In Carl's kitchen, where frustration was interspersed with humor and herbal tea, my thesis took a new shape and asked a new question -- all that was left was to write.

My writing process had its peaks and valleys, but the final product would look very different than it does today if it were not for my roommate Rachel who selflessly allowed me to abuse her computer and for my fantastic thesis support group which included myself, Carl Koechlin and Helen Cohen. Carl and Helen read draft upon draft of each chapter, telling me what was clear and what was foggy, and editing my writing at points when I had lost all perspective. Helen in particular kept reminding me, "You're thesis is great, Twersky!" and without their support, I still might be stuck back in chapter two...

I cannot in good conscience leave off talking about the writing process without at least mentioning the consistent inspiration provided by Marge Piercy's poetry. Her poetic elegance and eloquence was where I turned during all those late night blocks. When reality was too forbidding, her poetry offered me the sublime world of the imagination and reawakened me to the infinite possibilities of the written word.

Through it all, my family and my friends never stopped believing that I would write the best thesis ever. Carol sent me love, Alice sent me my favorite coffee, Sharon sent me music and kinship, Debbie and Joan sent me wonderful pictures of their

daughter who is my favorite baby in the world and Esther always gave me some necessary distractions.

Most of all, I want to thank Helen for helping me make my mind, my heart and my soul all work together.

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INTRODUCTION

"STOP AIDS." A few months ago, a banner with these words was stretched across three lanes of halted midday traffic on the Golden Gate Bridge in San Francisco. "STOP AIDS" - a message to those in their cars and to the nation that we need to feel rage at the havoc AIDS has wreaked on communities across the country and that we need to stop the epidemic now. Crying out to everyone who would listen and underscoring the grief, frustration and anger at losing loved ones on an almost daily basis, the message was meant for our hearts and minds, and perhaps even for the virus itself. Over 50,000 people have died, over 88,000 people have been diagnosed with AIDS,[1] between 1.5 - 2 million more are infected with the virus nationwide -- this epidemic has to be stopped. The question is, how?

With no cure or vaccine expected within the next 20 - 25 years, we cannot stave off the inevitable progression of those currently infected with Human Immuno-deficiency Virus (HIV) to "full blown AIDS" and ultimately, death. But we can prevent further spread of AIDS/HIV infection. In fact, it is imperative that we do so before a whole generation of people is wiped out as a result of AIDS-related mortality. And the people affected are no longer just concentrated in major metropolitan areas of the East or West Coast. Whereas in 1986, New York and San Francsico accounted for 40% of the nation's AIDS cases, in 1991 these two

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[1]Centers for Disease Control. HIV/AIDS Surveillance Report, March 1989: 1-16. Unless otherwise noted, all surveillance data used will be from this report.

cities are expected to account for 20%. Every city and town in the nation will most likely be affected. It is believed that soon, everyone will personally know at least one person who has been diagnosed with AIDS.

The real tragedy of this epidemic is that AIDS is in fact preventable. It is not a genetic disorder. It is not a contagious disease which can fester in water or be transmitted through air or insect bites. Despite persistent popular beliefs to the contrary, AIDS is NOT spread through casual contact. Rather, there are very specific ways that the virus is transmitted, namely through blood and semen, and our knowledge about transmission routes has not altered since 1985. Thus, if sex partners practiced "safe sex" and if intra-venous drug users (ivdus) stopped sharing needles and other drug "works," we could virtually halt the spread of the epidemic in this country. But information and resources have been slow to trickle down to the people who most need them. And, the national response has been sluggish -- full of condemnation instead of compassion.

This thesis explores issues of AIDS risk and AIDS prevention. Using a feminist framework of analysis for thinking about the multiple forces contributing to different people's risk of AIDS, I propose a broader, more comprehensive approach to prevention than has heretofore been advocated by those working in the public health arena. The specific theoretical framework I employ, is explained in detail below.

I examine each of the three "waves" of the epidemic as they have been articulated by epidemiologists. The first wave has consisted of gay/bisexual men, the second wave is categorized as intra-venous drug users, and the third wave, women and children. There are also smaller waves which have surfaced at different times such as hemophiliacs and transfusion recipients early on in the epidemic, and health care workers who have become infected with HIV due to occupational exposure. Relative to the growing numbers of Persons With AIDS in this country, however, these smaller waves are comparatively tiny and will not be directly addressed in this thesis.

Although none of the three primary waves are mutually exclusive -- there are iv drug users who are gay, women who use iv drugs, and so on, this distinctive breakdown has nevertheless been useful in tracking the spread of the virus. The breakdown also underscores a critical and disturbing pattern of transmission. What seemingly began as an epidemic among gay men has become a broader epidemic hitting those who have been marginalized by our society. The number of ethnic minorities contracting AIDS through intra-venous drug use, primarily Black and Latino men, women and children, is growing exponentially and is highly disproportionate to the percentage of Blacks and Latinos in the general population.[2] Furthermore, Black and Latina

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[2]According to Centers for Disease Control Surveillance data, March 1989, Blacks comprise 26% and Latinos 15% of the total diagnosed AIDS cases. In contrast, according to the 1980 U.S. Census, Blacks make up approximately 12% of the U.S. population and Latinos are only 4%.

women and children are the fastest growing subgroup to be infected in this epidemic. Whereas gay men typically had their own economic and political resources with which to seek care and develop strong community support services, those in the second and third waves are poor, inner city residents who have traditionally been excluded from economic and political power in the U.S.

Those who have been principally affected by AIDS are members of already socially outcast groups. They are therefore easy targets for stigmatization and discrimination. As Alan Brandt, an historian of medicine and science has noted, "People With AIDS are at risk not just from a serious, terminal disease but from a series of social perceptions and attitudes that encourage discrimination and isolation."[3] Because of these prejudicial attitudes, many People With AIDS have lost their jobs, their housing and their social supports. Proposals for quarantine still hang heavy in the air as do Lyndon Larouche's calls for mandatory testing and public disclosure of HIV status. As Brandt also acknowledges, "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 attacks on homosexuals."[4]

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[3]Brandt, Alan M., No Magic Bullet: A Social History of Venereal Disease in the United States Since 1980, Oxford University Press, New York, 1987.

[4]ibid.

The tendency to blame disease on a particular group of people and to view disease as a punishment for imprudent behavior has a long and rather hideous history. This holds true whether one is looking at periods in history before or after "germ theory" became an accepted scientific notion. As Charles Rosenberg, an historian and sociologist of science has observed, "A disease is no absolute physical entity but a complex intellectual construct, an amalgam of biological state and social definition."[5]

Venereal diseases, for instance, have consistently been used as a rallying point for social conservatives to express the decay of family values in the face of what they perceived to be a corrupt and degenerative sexuality. Women were often blamed and shamed for their "unnatural inclination to suppress the maternal instinct" by engaging in sexual relations outside the bounds of marriage and the nuclear family.[6]

Similarly, the stereotyping moralism that went on around syphilis had a particularly pronounced affect on Blacks. Physicians in the South believed Blacks to be a "syphilis soaked race", making them a seemingly ideal population on which to conduct a study about the impact of syphilis if left untreated.[7]

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[5]Rosenberg, Charles E. The Cholera Years:The United States in 1832, 1849 and 1966, University of Chicago Press, Chicago, 1962, 1987.

[6]Brandt, Alan M. No Magic Bullet, referring in part to comments made by President Roosevelt in 1911.

[7]Jones, James, Bad Blood, The Free Press, New York, 1981.

Hence, in 1932, the Public Health Service undertook the infamous Tuskegee experiment which actively sought to prevent Black men from receiving treatment for their syphilis while leading them to believe that they were being treated for their condition by government doctors. Before the experiment was finally called to a halt in 1972, it is estimated that approximately 100 Black men in the study had died from tertiary syphilis.[8]

Blacks were also scapegoated during the nineteenth century cholera epidemic in the U.S. "Whether he was free or slave, Americans believed, the Negro's innate character invited cholera."[9] Because cholera was able to proliferate in conditions of gross sanitation, poor Irish immigrants who were living in the "foulest slums of America's cities" also suffered disproportionate premature deaths as a result of the epidemic.[10] Instead of advocating for measures to relieve poverty, most Americans believed that the Irish themselves were to blame, "being exceedingly dirty in their habits, much addicted to intemperance" and in short, "miserable foreigners."[11]

This history is not just restricted to an American context. In the 14th century, during a period of grave anti-Semitism in Europe, Jews were blamed for causing Black Death (one of the most serious outbreaks of Bubonic Plague) and thousands of Jews were

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[8]ibid.

[9]Rosenberg, Charles E., The Cholera Years.

[10]ibid.

[11]ibid.

subsequently killed in over three hundred and fifty massacres in Europe.[12]

History is rife with examples of blaming marginalized communities for diseases from which members of that community may suffer. In the case of AIDS, despite all advances in science and medicine, our society has been constructing all the classic prejudices all over again. This time the stigma is attached to gay men, iv drug users, young Black and Latina women, Haitians, or Central Africans, but it is playing out as the same script by another name, in another place in time. Indeed, the social constructions of the AIDS epidemic are so frighteningly reflective of tragedies past -- one would think we would have learned better by now.

Theoretical Framework for Analysis

The central question of this thesis is, how can we stop this epidemic? AIDS is preventable through behavior change but in order to employ effective prevention measures, one first needs to recognize what it is that is putting different people at risk of HIV transmission. One of the big lessons of the AIDS epidemic, is that it is difficult for people to change patterns of behavior to which they have become accustomed. Public health "risk factors" have been identified as "unsafe sex," i.e. sex without condoms

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[12]Simpson, Michael A., "The Malignant Metaphor: A Political Thanatology of AIDS" in AIDS: Principles. Practices & Politics, I. Corless and M. Pittman-Lindeman, eds. Hemisphere Publishing, WA 1988.

and "unsafe drug behavior," i.e. needle sharing, the idea being that any behavior which allows for the exchange of blood or semen, is potentially a behavior which puts one at risk for AIDS (see Appendix A for explicit details on AIDS and HIV transmission). I propose that one needs to probe deeper, beneath the identified public health risk factors, to deeply embedded social sources of risk.

One must ask why people are engaging in unsafe sex and still sharing needles in the age of AIDS? Is it because they are not aware of the risks associated with their behavior? If so, why has AIDS information not reached them? Is it because they feel no compulsion to change behavior? If so, what is causing this resistance? Is it because they are not <u>able</u> to change behavior? If this is the case, what are the obstacles? In short, what is it that is preventing behavioral transformation? One must be able to pose and answer these questions in order to develop effective intervention strategies for making behavior change both possible and desirable.

In examining the three waves of the epidemic, I explore the multiple factors contributing to people's risk for AIDS/HIV. I draw specifically on Julie Matthaei's framework of a unitary feminist analysis "which takes all dimensions of oppression into account simultaneously"[13] for one cannot constructively think about or plan for AIDS prevention unless one considers the

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[13]Matthaei, Julie "Marxist-Feminism and Marxist Economic Theory: Beyond the Unhappy Marriage" November, 1988.

obstacles embedded in the dynamic relationship between sexual preference, race, class, gender, religion, and culture. One must carefully look at how forces at the micro level, i.e. personal, family and community relations, interact with forces at the macro level, i.e. the larger institutional, economic, political and religious structures. When taking into account "the structure and exercise of power at various levels of society,"[14] one is able to identify how these different forces work to both create and reinforce conditions which put people at risk for AIDS.

Because such an analysis necessarily requires discussions which are context-specific, I discuss each wave of the epidemic within its particular social, political and economic context. As 73% of diagnosed AIDS cases among gay men are white and mostly middle-upper class, and 80% of intra-venous drug use (ivdu) related cases and 81% of cases through heterosexual contact are ethnic minority and poor, it is clear that the elements of risk and measures taken for prevention will vary considerably from one context to the next.

Within each social context, I identify two distinct but interconnecting levels of prevention which are either already in effect, such as in the gay community, or still need to be further developed, as in communities of color. The two levels of prevention are intended to respond to the multiplicity of obstacles to behavioral transformation and as such take the form

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[14]Hart, Gillian "Disaggregating the 'Household': Gender Inequality and the Dynamics of Agrarian Change," Unpublished.

of "practical interventions" and "strategic interventions." For these practical and strategic formulations, I draw on the work of Maxine Molyneux[15] and Caroline Moser,[16] but have adapted and expanded upon their theoretical frameworks in order to confer relevance to their conceptions with regard to AIDS prevention.

Practical interventions are those which address a person's practical, concrete needs with regard to AIDS risk reduction. These interventions may include the dissemination of accurate information, the distribution of condoms, bleach or needles, and so on, depending upon who the targeted audience is for a given intervention. Practical interventions offer an individual the basic means of how and why he/she should change behavior.

Strategic interventions, on the other hand, are intended to address the more over-arching barriers to behavioral transformation, i.e. those barriers which make responding to practical interventions difficult or impossible. Strategic interventions are "derived... from an analysis of...subordination and from the formulation of an alternative, more satisfactory set of arrangements to those which exist."[17] Because the interventions must be effectively context-specific, each will

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[15]Molyneux, Maxine, "Mobilization Without Emancipation? Women's Interests, The State, and Revolution in Nicaragua" Feminist Studies 1986.

[16]Moser, Caroline. O.N., "Women, Human Settlements and Housing: A Conceptual Framework for Analysis and Policy-Making" Women, Human Settlements and Housing, C. Moser and L. Peake, eds. Tavistock, New York, 1987.

[17]Molyneux, Maxine, op. cit.

take a different form. For example, gay men face different obstacles to transformation than do Latina women and strategic interventions must be formulated accordingly.

Sometimes, the obstacles to change may be a result of a general lack of access to resources which affects whether or not one has incentive to change. Often, however, strategic interventions are concerned with changing consciousness, with altering power relations at the community level and between the community and larger economic and political structures, and with paving the way for new relationships of meaning to develop at many levels of people's lives.

A unitary and interdisciplinary analysis of risk is what informs my discussions of coherent and viable intervention strategies. In addressing the question of how the AIDS epidemic can be effectively stopped, I hope to provide a new and broader way of thinking about both risk and prevention than has heretofore been proposed by those in public health. In the conclusion, I address some of the problems which may arise when translating this framework of analysis into actual planning practice and some of the obstacles to simultaneously pursuing both practical and strategic interventions.

I. THE FIRST WAVE: GAY MEN

Many view the experience of AIDS in the gay community as the "success story" in this epidemic. They argue that effective intervention in the form of education and information is what allowed a once exponential HIV infection growth rate, to be reduced to a current rate of nearly zero.[1] Indeed, studies have shown that whereas in 1984, 74% of gay men in San Francisco practiced unsafe sexual behaviors, by 1987, only 10% were engaging in unprotected sex.[2] When looking more closely at the gay male community's experience, however, a number of other factors begin to emerge as instrumental in making behavioral change both possible and desirable. These factors, outlined below, represent developments on many different levels of gay men's lives, some of which were in response to forces external to the community and some which were responding directly to behavior patterns internal to the gay male culture. Taken together, these instruments of change have all contributed to a transformed community consciousness including a reevaluation of what it is

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[1]These observations relate to those who identify themselves as gay, not just men who have sex with other men. Thus, in my discussion of the gay community's experience, I focus on the self-identified gay population. In chapter three I address the issue of those who engage in homosexual activity but do not identify as gay, and the problems which that lack of identification engenders, particularly with regard to women.

[2]Fineberg, Harvey V., "Education to Prevent AIDS: Prospects and Obstacles" AAAS Conference Papers, 1988. Other cities, such as New York and Los Angeles have documented similar changes in behavior among gay men.

that gives meaning to gay men as individuals and as a collectivity.

Background: Gay Men's Risk for AIDS

After the Stonewall riots of 1969, an historic event in New York City where gays fought back against indiscriminate police raids on a popular Greenwich Village gay bar, homosexuals began to struggle openly for gay liberation. During the 1970's, many gay men migrated to urban centers like San Francisco, New York and Los Angeles, and developed a community infrastructure in which they could express their new-found sexual freedom. Gay legal and political organizations were formed to advocate for gay rights on an institutional level. Gay newspapers proliferated, as did bookstores, clothing stores, movie theatres and restaurants catering to an almost exclusively gay clientele. A "gay pride week" was established, highlighted by an annual gay pride parade. Most popular among many gay men, were the bars and the bathhouses. In the bars, men could meet, "cruise" and initiate sexual encounters. Bathhouses offered anonymous sexual contact and men went to these establishments for the sole purpose of sexual activity, often with many different partners during the span of a few hours time. For many, the bathhouses symbolized a hard fought for freedom of expression and a response to a repressive homophobia which had haunted gay men for most of their lives.

The types of sexual activity that went on in the bathhouses and more generally among gay men, often involved frequent exchanges of blood and semen. Thus, it was precisely these sexual activities which allowed HIV to spread so rapidly through the gay male population in these urban centers. But, because sexuality had become so central to the gay male identity, gay men were initially very reluctant to relinquish these sexual freedoms.

The Legacy of Homophobia and Institutional Neglect

Shortly after the causative agent for AIDS began to look more and more like a transmissible virus, one which was passed through blood and semen, some public health professionals proposed strategies for preventing further spread of this new disease -- strategies of education as well as regulation. These attempted interventions were initially rejected by gay men who deeply distrusted the motives of public institutions which for so long had ostracized homosexuals. The attempted closure of the bathhouses in San Francisco, for example, demonstrated this deep distrust. Many gay men viewed the bathhouse closure as a threat to their new-found liberation. They regarded the rumors of a new gay-related disease as a fantastic "theory designed to attack gay life-styles."[3] As a result, the bathhouse battles were feverish and highly politicized. As San Francisco Mayor Diane Feinstein once remarked in a moment of frustration with the bathhouse battles, "If this were a heterosexual problem, these

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[3]Fitzgerald, Francis, Cities on a Hill, Simon & Schuster, New York, 1986.

establishments would have been closed a long time ago. But because this has been involved in politics, they haven't closed."[4] Ultimately, the gay male community took the necessary steps to ensure the bathhouse closures, but it was only after gay men themselve were able to recognize the dangers which the bathhouses posed to the health of those who used them as well as to the larger gay male population.

Hence, institutionally initiated alternatives, however well intentioned, were initially rejected by gay men because of a long history of institutional oppression on the basis of sexual orientation. If this mistrust had not existed, it is likely that the spread of HIV infection could have been quelled long before 50 - 60% of gay men in San Francisco (and elsewhere) became infected with the deadly virus, as is now estimated to be the case.[5]

Ironically, the lack of institutional response, particularly on a national level, also let HIV transmission go unchecked for far too long. Because AIDS was first identified as Gay Related Immune Disorder, or G.R.I.D., and as affecting a group of people who were marginal to mainstream American concerns, resources and information necessary for quelling transmission, were not considered to be a priority by those setting the national agenda.

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[4]ibid.

[5]San Francisco AIDS Plan, Fiscal Year, 1987-88. Boston AIDS Consortium Report, February 1989. Confronting AIDS: Update 1988, Institute of Medicine, National Academy of Sciences.

In contrast to the national concern for Legionnaires Disease which killed 29 men who attended a Philadelphia Convention, or the national compassion and immediate investigation in response to Chicago's Tylenol poisoning scare, no such rapid mobilization was authorized for AIDS. By the time Ed Brandt, the Assistant Secretary for Health of the U.S. Department of Health and Human Services, declared AIDS to be the "number one health priority," in 1985, 1,450 Americans had already been diagnosed with AIDS and 558 people had died.[6] Underscoring the sluggish national response, is the startling and unconscionable fact that Ronald Reagan did not publicly utter the word "AIDS" until five years into the epidemic. Had the first people to contract AIDS been Legionnaires, or suburban heterosexuals, one can imagine how different the national response would have been.

Thus, the legacy of institutionalized homophobia asserted itself at the national level by neglecting to mobilize resources to protect gay citizens of this country, and also tried to overcome itself in some instances on the local level such as in the bathhouse controversy. In both cases, however, the legacy clearly contributed to exacerbating the tragedy that has befallen so many gay men.

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[6]Randy Shilts, And the Band Played On: Politics, People and the AIDS Epidemic, St. Martins Press, New York, 1987._

Successful Community-Initiated Interventions

In the early 80's after gay men acknowledged the reality of AIDS, they began raising money and organizing grassroots prevention campaigns. Through the initial efforts of community-based organizations like the Gay Men's Health Crisis in New York City and the San Francisco AIDS Foundation, gays soon began to identify AIDS as being the most important problem facing the gay community.[7] In an unusual display of solidarity, many lesbians also joined the struggles around AIDS because they saw the epidemic as threatening the survival of the gay community; not only was the virus taking the lives of so many gay men, but many gay community leaders were dying and the backlash against gays for being the "bearers of a new modern plague," was manifesting in increased incidence of violent "gay bashing" around the country.[8] People feared that AIDS might become the justification for turning the clock back twenty years in relation to gay civil rights. Thus, a mixture of community-initiated practical and strategic interventions and what I term, "incidental" motivating factors, were instrumental in bringing about individual and collective transformation.

Community-Based Practical Interventions

Practical interventions were designed to change individual behavior. These interventions included: 1) widely disseminating

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[7]ibid.

[8]Brandt, Alan M., op. cit.

explicit information and education about AIDS prevention, through any and all available media, 2) distributing condoms with which to practice safe sex, often encased in packages containing safe sex guidelines, 3) prevention messages suggesting ways for gay men to consciously eroticize safe sex, thereby making safe behavior sexier, 4) developing alternatives to unsafe sexual practices, such as the increasingly popular enterprise of "telephone sex," and 5) establishing formal and informal support groups for men to learn about behavior change and to reevaluate accepted community norms.

All of these interventions proved to be critically important in making behavior change possible. Support networks in particular, appear to have played a significant role in sustaining behavioral changes. Those who are hooked in to support networks are likely to changed their sexual behaviors whereas those who have detached themselves from community supports are those who reportedly know the least about AIDS and are the least likely to change behavior.[9] Rather than coping with AIDS through a supportive problem-solving approach, these men who have detached themselves from the community, seemingly few in number, are denying the imminent impact the AIDS crisis is having on their lives, a pattern clearly repeated in the epidemic's second and third waves.

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[9]Montgomery, Susanne and Jill Joseph, "Behavioral Change in Homosexual Men at Risk for AIDS: Interventions and Policy Implications" New England Journal of Public Policy, Winter/Spring, 1988, Vol 4, No 1.

A pre-existing community infrastructure and informal network of relationships, provided accessible paths for these practical interventions to take root. Gay businesses and organizations of all sorts, actively supported AIDS prevention campaigns with generous monetary contributions and in kind donations. Volunteers flooded to the cause, each adding his/her own energy and creative touch to the process of prevention. These practical interventions would very likely never have been as successful as they were, however, without the compliment of strategic interventions and other incidental motivating factors.

Community-Initiated Strategic Interventions

Strategic interventions designed to help facilitate behavior change were focused much more on pressuring institutions to respond to the legitimacy of the gay community's needs and on collective community transformation. These interventions served as building blocks towards formulating an alternative set of relationships, both within the community and between the gay community and the institutions with which it was contending. The strategic interventions within the gay community context in many ways take on a different tone from those required for prevention in other impacted communities. The barriers which gay men needed to break down were based less on material obstacles and more on internal notions of what it meant to be a gay man. Thus, the subordination gay men were striving to overcome, derived partly from institutional shunning and partly from identities which gay men themselves had constructed.

In order to respond to institutional neglect, already existing national gay organizations such as the Lambda Legal Defense Fund and the National Gay and Lesbian Task Force, joined forces with newly formed local, state and national level AIDS coalitions, to promote effective political action around AIDS issues. In addition, ACTUP, the AIDS Coalition To Unleash Power, now has a national network of activists performing frequent acts of civil disobediance in places like congresspeople's offices, the White House, city halls, and outside of insurance companies. ACTUP's motto is "Silence = Death" and through its nonviolent direct actions, it hopes to shatter the silences and denial which have for so long surrounded the AIDS epidemic, and force the power sources of the nation to unleash their resources and help prevent further deaths.

Despite strong initial resistance from most local, state and national authorities, this political mobilization influenced governmental decisions to more liberally allocate resources towards alleviating the growing AIDS crisis. In time, governmental bodies such as the Presidential AIDS Commission and various governors' and mayors' task forces, sought out the gay community's cooperation, and its knowledge and experience about a whole host of issues related to AIDS prevention, treatment and care. Thus, gays were able to exert such enormous political pressure, not only because they were well organized, but also because members of the community had amassed vast amounts of knowledge about AIDS, thereby becoming recognized as experts in

the subject. This valued expertise helped in making some inroads towards evening the balance of power between homosexuals and the state, although as demonstrated by the federal government's refusal to adopt anti-discrimination measures to protect gays, or People With AIDS, clearly, there is still a long road ahead.

To compensate for a national lack of compassion, the gay community has fashioned its own ways of coping and of redefining what it is that gives meaning to relationships. I have identified four strategic avenues in this regard.

The first is art. Literature, theatre, and other visual media have provided an outlet for the emotional turmoil deeply brewing within so many who are grappling with issues of their own death or the death of loved ones. Artistic expression, generally highly valued in the community, has been an important means of breathing life into an overwhelming experience of death.[10] Creativity is a source of vitality, and as such, offers hope and validation that AIDS is as much about love as it is about loss.

A related second avenue of coping and of redefining meaning, is the noticeable shift among gay men towards religion and spirituality. Although no systematic study of this phenomenon has yet been undertaken, signs of transformation are evident in the gay press and through anecdotal reports from gay men

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[10]The "Names Project," an internationally acclaimed patchwork quilt, now with tens of thousands of panels dedicated to remembering the lives of those who have died from AIDS, is perhaps the most eloquent expression of grief, allowing memories to live on forever. As the project's motto explains, "See it and understand."

themselves.[11] It is unclear how much of this shift has taken place among People With AIDS/HIV and how much of a role it has played as an actual preventative behavior change mechanism. Nevertheless, the fact that many gay-identified AIDS organizations put a premium on spiritual counselling, indicates that there is a growing general acknowledgement of the need to nurture the spiritual part of one's self.

The third avenue, namely, a growing preference for more sustainable and/or monogamous relationships, most overtly supports practical prevention, as fewer partners generally decreases ones risk of HIV transmission. Again, no systematic study has yet been conducted on this development, but indications of this shift are evident in the gay press where it is now very common to see personal ads which read "HIV negative man seeking same for warm, safe, companionship."

The fourth avenue has meant bridging the gap between gay men and lesbians. Traditionally, gays and lesbians have had very little to do with one another. They each had their own organizations and tended to lead very different kinds of lives. Today, lesbians make up a high proportion of the people working in AIDS organizations.[12] A little over a year ago, a national gay and lesbian quarterly magazine went into circulation, marking the

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[11]See, for example, Monette, Paul, Borrowed Time: An AIDS Memoir, Harcourt Brace Janovich, Orlando, FL, 1988.

[12]In January 1989, a conference was held in San Francisco for lesbians involved in all facets of AIDS work. This was the first conference of its kind and was attended by hundreds of lesbians.

first time that a national publication has explicitly and successfully catered to both groups. Although this new solidarity is not 100%, as gays and lesbians continue working together under conditions of crisis and compassion, mutual respect is growing. Thus, gay men have in part redefined their collective identity by embracing the support of their sisters within the community.

None of these four "strategic interventions" were cooked up in any kind of conspiratorial manner by some people sitting around in leather swivel chairs drinking steaming black coffee trying to figure out what alternative set of relationships would work to transform community consciousness. Rather, these coping mechanisms evolved over time, in their own time, as responses to needs for new meaning and for identities which were not just tied to active sexual expression.

Incidental Motivating Factors

Fear. Grief. Loss. Compassion. When one has experienced the loss of so many loved ones, when everyone in a community personally knows at least ten people who have died or are dying of AIDS, when one has personally cared for and supported people in their effort to live and die with dignity, -- fear, grief, loss and compassion, prove to be powerful motivating forces for transforming personal and community norms. These forces represent neither practical nor strategic interventions but they influence all levels of transformation. They are byproducts of an epidemic that has taken the lives of tens of thousands of gay men. They

are the byproducts of compassionately and heroically caring for those who are ill. They are the sad result of an unbelievable and unforgettable tragedy.

Conclusion

It is difficult to view the experience of AIDS in the gay community as a "success story." Fifty-nine thousand, five hundred and forty-two gay men have already died of AIDS in this country and thousands more are infected with HIV.[13] Many of these deaths could likely have been prevented if there had been immediate national mobilization. Because those initially affected were "only homosexuals," AIDS was typically viewed as just punishment for sinful and aberrant behavior.

The gay community has been able to organize itself, however, utilizing its own economic and political resources to ultimately stem the tide of infection and make behavior change both possible and desirable. This change was brought about through a combination of factors, including practical interventions focused on the individual, strategic mechanisms focused on the institutional and on transforming community consciousness, and other motivating factors resulting from confronting the sorrow and honesty of death and dying.

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[13]Centers for Disease Control, HIV/AIDS Surveillance Report, March 1989:1-16.

II. THE SECOND WAVE: INTRA-VENOUS DRUG USERS

When confronted with seemingly intractable social problems, the frequent tendency of policy-makers is to propose quick-fix mechanisms of social control. With the AIDS epidemic, this tendency has been all too frequent. Past proposals for quarantine, mandatory testing and public disclosure of HIV status, may be just the tip of the iceberg, particularly as the number of AIDS cases among ethnic minorities and intra-venous drug users (ivdus) continues to rapidly increase. For example, at a May 1987 meeting sponsored by the National Institute on Drug Abuse, participants debated whether or not involuntary commitment to drug treatment for ivdus might help to stop the spread of AIDS.[1] How such "involuntary commitment" might take place is unclear, but the very fact that it was considered is a frightening indication of potential future policy proposals.

The intention of this chapter is to explore what it is that is putting ivdus at risk for AIDS, from both practical and strategic points of view and to evaluate current prevention policies being used to address risks presented by this "second wave." This includes examining who are the ivdus contracting AIDS, what are the forces behind their drug-related behaviors, and inquiring as to whether public health interventions have had an impact on ivdus' willingness or ability to transform their

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[1]Watters, John K., "Preventing HIV Contagion among Intra-Venous Drug Users: The Impact of Street-Based Education on Risk Behavior" Presented at III Intl Conference on AIDS, WDC June 1987.

drug-related risk behaviors. While the focus of this chapter is on ivdus as a whole, the specific concerns of female ivdus are addressed in detail in chapter three.

Who are the Intra-Venous Drug Users Contracting AIDS?

Intra-venous drug users comprise 27% (N = 24,406) of the total number of AIDS cases diagnosed in the U.S. since the beginning of the epidemic. (N = 90,990)[2] Seventy-four percent of the ivdu-related cases are in heterosexual men and women and 26% are homosexual/bisexual male ivdus. Of all the heterosexual ivdu AIDS cases, 77% are male and 80% are ethnic minority, almost entirely Black and Latino. Some of the ivdus are homeless, most are extremely poor, living in urban ghettos where drugs are often seen as the only escape from an otherwise bleak reality.

Thus far, in major East Coast cities like New York and Newark, New Jersey, it is estimated that 50% - 60% of the ivdus are HIV+.[3] Cities such as Boston and Philadelphia are not far behind, as it is estimated that approximately 40% of the ivdus in these cities are HIV+.[4] Estimates from other cities around the country range from 5% on up. Even though HIV infection rates do

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[2]CDC AIDS/HIV Surveillance data April 1989.

[3]Confronting AIDS: Update 1988, Institute of Medicine/National Academy of Sciences, National Academy Press, WDC, 1988.

[4]"The Boston AIDS Consortium: Task Force Reports and Preliminary Recommendations," November 1988. Interview with David Fair, Assistant Deputy to the Commissioner of Public Health for the City of Philadelphia.

vary from region to region and coast to coast, ethnic minorities are consistently overrepresented in the numbers of AIDS cases. Blacks and Latinos on the West Coast, for instance, are three times more likely to contract AIDS than whites, whereas on the East Coast, they are twelve times more likely to contract the virus.[5]

Many of the studies to determine HIV prevalence among ivdus have thus far used ivdus who are in drug treatment programs as the subjects for study. Because no more than 20% of the estimated 1.2 million ivdus in the nation are receiving drug treatment at any given point in time,[6] there are self-selection biases inherent in all of these studies. Thus, there is no way of accurately assessing HIV prevalence among those not receiving treatment and it is indeed possible that the rates are actually higher than those cited above. Since the other 80% are actively using drugs, it is probable that HIV prevalence among ivdus as a whole, will continue to increase.

Sources of Risk Associated With Intra-Venous Drug Use

The conditions for drug use are constructed by forces at many different levels of society. As Bateson and Goldsby have noted in their book, Thinking AIDS,

> ...disease and drug use thrive on poverty and inequality. In America, the [AIDS] epidemic developed in a period when government was withdrawing from social programs,

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[5]Confronting AIDS: Update 1988.

[6]ibid.

> cutting budgets in all nonmilitary areas, and using the machinery of regulation to promote economic productivity rather than individual welfare.[7]

The exclusion of ethnic minorities from mainstream political, economic and educational opportunities has led minority communities, particularly Black and Latino urban communities, to alternatively develop an entrenched underground drug economy. Drugs have become the substitute for economic opportunity and the antidote to despair. Consequently, they have become a most significant source of AIDS transmission among the poor.

When average welfare entitlements for individual adults are under $300 per month and only one-third of the unemployed are eligible to receive unemployment compensation benefits,[8] it is no wonder that people in poverty are increasingly entering the "drug market." Dealing drugs is much more lucrative than a dead-end minimum wage job -- it pays enough to provide those who work in the drug trade a status otherwise unachievable. Drug dealers have thus carved out their own segment of the current U.S. segmented labor market.

Using drugs is also often appealing to people who suffer the daily vagaries of poverty. When no brighter options are available than enduring the indignities of welfare, insufficient employment options, inadequate housing, or no housing at all, using drugs is

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[7]Bateson, Mary C. and Richard Goldsby, Thinking AIDS: The Social Response to the Biological Threat, Addison Wesley, New York, 1988.

[8]Homelessness, Health , and Human Needs, Institute of Medicine, National Academy Press, WDC, 1988.

not just an escape, but rather, is often a rational choice given the circumstances. Therefore, it is not surprising that as the number of people in poverty increases, so does the number of poor people addicted to drugs. And as the number of poor people addicted to drugs increases, so does the number of poor people diagnosed with AIDS. Somehow, conditions of poverty must be transformed so that using or dealing drugs is NOT a rational choice. Thus, public health interventions alone cannot fully address AIDS risk reduction because public health does not have the capacity to facilitate the transformation of conditions of poverty.

The longer such conditions of poverty and exclusion exist, the more entrenched do drug behavior patterns become. Young boys, eleven or twelve years old, have become "runners" in the drug trade, meaning they act as decoys to pick up and deliver drugs for the dealers. Based on my interviews with people in different cities, this seems to be a phenomenon common in the Black communities of Harlem, the South Bronx, and East Oakland, CA, the Puerto Rican communities in Philadelphia, and poor communities of color in Boston. Throughout much of the nation, poor children are growing up in environments where the only opportunity to make money is through the drug trade. When faced with the choice of making a couple of hundred dollars a week running some drugs around the neighborhood, or going to school, which offers seemingly little opportunity for success, these kids frequently choose the more adventurous, more materially gratifying, and

importantly, the circumstantially sanctioned drug-related activities.

The fact that drug-related activities are sanctioned by many within urban ghettos is critical because it means that community norms have developed such that drugs are often viewed as an accepted, and sometimes, even preferable way of life. When parents, friends and other role models in the community are using drugs, young people tend to follow the pattern. Thus, while 23% of the diagnosed AIDS cases among Blacks and Latinos fall within the 20 - 29 years of age range, because of the average ten year incubation period for the virus, the majority of these People With AIDS now in their twenties, were infected with HIV while still in their teens.

Economic and social conditions have thus created patterns of behavior which serve to encourage continued use of drugs within poor communities of color. Because it was public institutional neglect which in part allowed these destructive community norms to develop, members of these communities have been understandably distrustful of institutional motives designed to protect them from AIDS. As articulated by Sister Margaret Leonard, director of a homeless shelter in Boston, poor communities are now contending with a "crisis of meaning," a crisis which has manifested after long and bitter battles with poverty and discrimination. As Leonard explained, lack of affordable housing, inadequate education and unemployment, are problems which have snowballed over time to create a sense of utter powerlessness over ones

life. For people in poverty, this powerlessness goes hand in hand with feelings of despair and frustration. According to Leonard, poor people are increasingly turning to drugs because they have lost their sense of meaning, of purpose, and of hope that the conditions of their lives can indeed improve.

Behavioral transformation in poor communities is thus going to take more than the traditional approaches suggested by conventional public health wisdom. Health education techniques alone are clearly insufficient to affect sustained behavior change, because knowledge or awareness of risk does not translate into actual transformation unless one believes that he/she has some incentive to change patterns of behavior.

In the wake of the national "Just Say No" campaign, federal efforts have proposed little more than abstinence to affect drug-related behavior change. The "Just Say No" approach is misguided regarding severe drug addiction, however, for one cannot simply say no and miraculously rid him or herself of an intense physical dependence. In the age of AIDS "Just Say No" is an especially mean-spirited approach for it implicitly punishes addiction with the likely consequence of death.

Rather than treating addiction as a disease, where each addicted individual may require a different mode of treatment or medication, many choose instead to debate the morality of different treatment methods, i.e. methadone maintenance versus going clean and sober through the cold turkey method. As Dr. Deborah Prothrow-Stith, MA Commissioner of Public Health, has

astutely pointed out, we do not debate the morality of treating diabetes patients with insulin versus nutritional monitoring or some other kind of intervention -- why should we do so with people who suffer from addiction? Yet as a society we continue to treat drug addicts as criminals unless they happen to be in the upper classes and/or are addicted to the arbitrarily legal drug of alcohol.

Although iv drug use has led to many people contracting HIV, it is really the way people shoot drugs which puts them at risk for AIDS. When ivdus are shooting up, they frequently do not have more than one set of drug paraphernalia and share that set between them. Not only is there blood on the needle from another person's usage, but in order to get the last bit of the drug into the body, ivdus often do a "rinse" of the syringe. This involves drawing ones blood back into the just emptied syringe to wash all the heroin or cocaine off the sides, and then shooting the blood and drug mixture back into ones own veins or giving the mixture to somebody else to shoot. These practices of sharing and rinsing have been enculturated as standard practices and some claim it contributes to ritualizing and eroticizing the act of shooting up.[9] Therefore, when intervening in addictive behavioral patterns, AIDS prevention also encounters drug rituals in a drug culture which has developed over time.

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[9]Beny Primm, President of the Urban Resource Institute, Brooklyn, New York and member of the Presidential Commission on AIDS, described these drug practices in detail in an M.I.T.-sponsored AIDS conference, March 1989.

Prevention Strategies

Intra-venous drug users are frequently referred to as a "hard to reach population." For this reason and because HIV is spreading so rapidly through poor communities of color, the AIDS Activities Oversight Committee sponsored by the Institute of Medicine/National Academy of Sciences, identified that:

> the gross inadequacy of federal efforts to reduce HIV transmission among iv drug abusers, when considered in relation to the scope and implications of such transmission, is now the most serious deficiency in current efforts to control HIV infection in the United States.[10]

To date, there have been three practical methods proposed to help stem the tide of HIV infection among iv drug users. These include: 1) education regarding safe behavior, 2) supplying ivdus with the materials they need to ensure they are using clean drug works, and 3) persuading ivdus to "go clean" by entering drug treatment programs. Below, I discuss the potential for success of each of these practical methods of intervention, outlining strategic obstacles which will be necessary to overcome.

Education

Informing iv drug users about AIDS and about how to reduce risk of transmission, is a critical component of AIDS prevention. Without knowing what the virus does or how it can be passed from one person to another, there is no chance at all that an

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[10] Confronting AIDS: Update 1988.

individual will change his/her behavior. There are a number of obstacles to the effectiveness of education, however.

Reaching ivdus with information is a major obstacle. Health educators have not traditionally reached out to active drug users, nor has health education been conducted within the shooting galleries of urban ghettos. It is therefore essential that people or institutions that are trusted by members of poor communities and have the ability to communicate with people at risk, be the ones who disseminate information.

Churches in both the Black and Latino communities could play this role as they often serve as powerful and authoritative forces which counterbalance despair with spiritual hope and guidance. Typically, however, churches shy away from actively dealing with drug issues in their communities. They also, not surprisingly, have been reluctant to acknowledge the AIDS epidemic in their midst. The few parishes which have become involved in charitable undertakings for People With AIDS, are tremendously reticent to explicitly tackle the drug and sexual behaviors putting people at risk for AIDS.

One method currently being used in many cities, is to employ ex-users to do street outreach regarding AIDS prevention. Ex-users are street-smart, know when they are being conned, know the language and the practices associated with drug use, and are more likely to be trusted by active users. Such has been the experience with "ADAPT," a group of volunteers, many of whom are former addicts, who visit shooting galleries in New York with

prevention materials. Similarly, the Midcity AIDS Consortium in San Francisco and Project Trust in Boston, both of whom employ ex-users for intensive street-based education efforts, report increased AIDS awareness among ivdus in these cities.[11]

Although street outreach and education has met with some success in terms of addicts' knowledge about HIV transmission, this knowledge has not always translated into behavior change. For instance, according to Dr. Jim O'Connell, Director of Boston's Health Care for the Homeless program, all of the fifty homeless iv drug using People With AIDS who he has treated are extremely knowledgeable about AIDS and are given viles of bleach from O'Connell with which to clean their needles.[12] Nevertheless, when they are out with their buddies shooting up, O'Connell says, if the others are not interested in using bleach or not sharing needles, then the PWA just goes along with the general consensus and gets his/her fix along with the rest of them. These PWAs figure they are almost sure to die within two years, they need their fix and don't want to buck the tide of the general ivdu culture such that they will be ostracized and not get their drugs. They themselves have nothing to gain by changing their behavior and they risk losing one of their primary pleasures in life if they do attempt change.

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[11]Feldman, Harvey W. and Patrick Biernacki, "The Ethnography of Needle Sharing Among Intra-Venous Drug Users and Implications for Public Policies and Intervention Strategies," National Institute on Drug Abuse Research Monograph 80, 1988. Also, interview with Fred Felch, Director of Project Trust, April 1989.

[12]Interview with Dr. Jim O'Connell, March 1989.

This raises the issue of whether ivdus are more or less likely to change behavior if they know their HIV status. Dr. O'Connell does not encourage HIV testing. He feels that by keeping open the option that an individual may be HIV-, that individual may be more prone to alter drug and sex practices. Particularly with regard to homeless ivdus, for whom there are little or no better options available than the conditions under which they currently live, the knowledge that they were HIV+ would provide absolutely no incentive to change behavior. If there is still a chance that the person is not infected with HIV, however, fear of transmission may provide an incentive to transform drug practices.

This same approach towards testing was, in fact, adopted very early on by the gay community. The reasoning was that all gay men needed to alter their sexual practices, regardless of their HIV status. They needed to protect themselves and their partners. Since early treatment methods have yet to be proven effective, one does not lose any medical benefits by delaying HIV testing.[13] On the other hand, one might benefit a great deal from not knowing ones HIV status -- by retaining a sense of hope in ones life.

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[13]Lately, the question of whether early treatment will be effective in treating HIV, has been the subject of some debate and controversy. Some advocate for early treatment of AZT or other experimental drugs in the hopes of delaying onset of opportunistic infections. It is unclear, however, whether such early treatment will really prove successful and how early during the incubation period one should begin taking those drugs, particularly given the harmful side-effects of drugs like AZT.

Whether this approach will work with ivdus is not yet known, but it seems unlikely that the experience of the gay community will repeat itself among ivdus. People who shoot drugs are in need of their fix the moment they are shooting up. Fear of what might happen to them five to ten years down the road when HIV infection progresses to full blown AIDS, may not be the priority at the moment. Furthermore, death has always been a reality for drug addicts. Although AIDS is a much more painful and protracted death than overdosing, people who shoot drugs do so with the understanding that at some time, their drug use may kill them.

AIDS education also comes late in the game considering the social processes that lead to iv drug use. By the time a person has become addicted to intravenous drugs in this day and age, it is likely that the individual is a poly-drug user, that he/she may have started with smoking crack or popping pills, and then began to experiment with the more extended highs one can get from shooting heroin or cocaine.[14] It is therefore insufficient to intervene just at the stage of intra-venous drug use, because by that time, addictive behaviors are often already embroiled in one's physical and social realities.

Educational efforts are thus hampered by a variety of factors, including the problem of reaching ivdus with information, lack of institutional trust, problems of incentives to change, enculturated patterns of drug use behaviors and the powerful force of addiction itself. Education as a means of AIDS

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[14]Beny Primm, March 1989.

prevention is by its very nature, reactive. That is, through the dissemination of information, educational interventions are intended to undo all of the forces which have contributed to the complex nature of drug use practices. Clearly such a task is too great for educational interventions alone.

Distributing Materials for Clean "Works"

Much of the AIDS education targeting ivdus, exhorts them to not share needles or other drug works. To help facilitate this change in practices, street outreach often includes distributing bleach which has been demonstrated to effectively kill HIV on contact. Outreach workers explain how to clean needles with bleach and then rinse with water, and often supply literature with graphic details showing the process from start to finish. As indicated by Dr. O'Connell's comments noted above, there is still reluctance on the part of ivdus to clean with bleach each time they are about to shoot up. They are not accustomed to the practice and often don't want to be bothered by what they see as a burden on their regular practices.

The other method of ensuring that ivdus have clean works, is to distribute clean hypodermic needles. However, the now infamous needle-exchange controversies are fraught with moralizing and partisan politics. Needle-exchange programs are vehemently opposed by law enforcement officials because they view such an enterprise as encouraging criminal behavior. Lately, they have also been opposed by some Black health-care and drug treatment

advocates who claim that needle-exchange is a quick-fix solution which does not respond to the pressing need for more and better drug treatment alternatives.[15] Advocates of needle-exchange, on the other hand, argue that addicts will continue to use drugs whether or not they have clean needles and that denying them the availability of clean needles, amounts to unnecessarily putting drug users at increased risk for AIDS/HIV infection.

Although it seems to me that needle-exchange programs would serve as good practical interventions in reducing the spread of HIV infection, there are inherent obstacles to be reckoned with in order for the programs to be effective. The first obstacle concerns the way the programs are designed. The demonstration projects currently being tried are designed in such a way as to ensure their failure. The needle-exchange pilot program in New York, for example, is located in a mid-town government office building. Not only are addicts disinclined to exchange their needles in a government building, but they would need to take a bus in order to even get to this non-residential location. New York's pilot program has thus been able to enroll only 80 ivdus, hardly significant considering that there are an estimated 200,000 drug users in New York City.[16]

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[15]Boston Globe, April 29, 1989.

[16]Drucker, E. "AIDS and Addiction in New York City," quoted by Donald Craven in "HIV in Intravenous Drug Users: Epidemiology, Issues and Controversies," New England Journal of Public Policy, Winter/Spring, 1988.

The second obstacle concerns public policies which regard the possession of hypodermic syringes to be a criminal offense. Addicts who have been incarcerated are often so bitter about their experiences in jail that they will go to great lengths to avoid repeating that experience. One heroin addict, in response to a question about why she refused to keep new, uncontaminated needles on her person, replied, "I would rather get AIDS than go to jail."[17] Thus, in some instances, the illegality of hypodermic needles encourages addicts to be more concerned about avoiding the immediate threat of jail instead of the more distant threat of AIDS.

The final obstacle to needle exchange concerns people's use of them. That is, supplying clean needles does not ensure that people will always use clean needles. Needles can still be shared and they can still be re-used. It is therefore essential that educational campaigns be continuous and that serious attempts be made towards transforming the meanings which addicts associate with drug sharing practices.

Drug Treatment

The third practical intervention proposed to reduce ivdus' risk of AIDS/HIV infection is to persuade addicts to enter drug treatment programs. The reasoning is that if they "go clean," their risk of infection through needle-sharing has been eliminated. For those ivdus who know that they are already

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[17]Feldman, Harvey W. and Patrick Biernacki, see note 11.

infected with HIV, however, the appeals for a clean and sober life may fall on deaf ears. For those who are not HIV+ or are unaware of their HIV status, there are still other obstacles to entering drug treatment programs.

A primary obstacle concerns the sheer unavailability of treatment slots. In New York, about 100 treatment programs care for 30,000 persons, which accounts for about 15% of the total number of addicts in the city. In Boston, there are approximately 900 treatment slots and 16,000 addicts.[18] Hence, even if prevention efforts could persuade addicts to enter treatment, there are simply not enough slots available. Funding is limited, treatment sites are limited and as noted above, the moralizing that goes on around drug treatment, severely limits the types of treatment alternatives which are available to addicts.

A deeper obstacle to drug treatment is that there is nothing better waiting for people at the back end of treatment. There is still poverty, still no affordable housing, still discrimination, still inadequate education, and no wonderful jobs are right around the corner. In short, none of the conditions which have in part created and in part reinforced patterns of drug use, have been transformed. What is the incentive to go clean if the future is no brighter when you're sober?

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[18]Craven, Donald, op. cit.

Conclusion

In order to stem the tide of HIV infection among intravenous drug users, interventions must be constructed on both the practical and strategic levels. All of the practical prevention methods, i.e. disseminating accurate and accessible information, distributing bleach and needles, and improving both the quantity and quality of drug treatment programs, encounter obstacles in the path of sustainable transformation. Practical interventions, in true reactive mode, can only treat the symptoms of drug behavior patterns -- they can't treat the source. In the context of AIDS, such palliative measures are inadequate and have fatal consequences.

Some Black community leaders are just beginning to openly express their fears about a lost generation as a result of AIDS. The threat is a real one and it cannot be stopped just by providing information, bleach, needles or drug treatment. These practical interventions are by all means essential, but in order to seriously promote AIDS prevention among ivdus, one must deal with why and how drugs have become so entrenched in poor Black and Latino communities and one must confront political mechanisms of exclusion. This necessitates strategic planning for poverty alleviation, economic development, community development, and establishing real and effective anti-discrimination measures. It requires confronting, in a serious way, the crisis of meaning which has evolved over time in poor communities of color. In

short, eliminating risk of AIDS requires addressing deeply embedded, complex, and unequal power relations in our society.

III. THE THIRD WAVE: WOMEN AND CHILDREN

Currently, women and children are the fastest growing subgroup to be infected in this epidemic. Over half of the current cases among women are caused by their own iv drug use, but the proportion of female AIDS cases where women contracted AIDS from their male sexual partners is 30% of all female AIDS cases and is growing.[1] The overwhelming majority of these women are Black and Latina (together comprising 72% of all women diagnosed with AIDS), and approximately 80% are of child-bearing age. Many of these women were infected while in their teens or early twenties, unaware of the risks associated with their behavior. Some have passed the virus on to their babies through perinatal transmission and it is often only when the child is born with symptoms[2] that these mothers first discover they are infected with HIV.[3]

Conventional public health measures are proving particularly inadequate for women, and those at risk often do not have the information or resources they need to effectively change their

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[1]Women currently comprise 9% of the 86,000+ AIDS cases nationwide, CDC Surveillance data, March 1989, Report from the San Francisco Dept of Public Health Perinatal AIDS Project, November, 1988

[2]Very few studies have been conducted on perinatal transmission and current estimates are that between 20% - 65% of children born to HIV-infected mothers, will go on to develop "full-blown AIDS." San Francisco Perinatal AIDS Project Report.

[3]Dr. Janet Mitchell, Director of Perinatology at New York's Harlem Hospital Center reported on this phenomenon at a conference sponsored by Boston's Black Women's Council on AIDS, October 1988.

behavior. This is in part the case because AIDS has been largely identified as a male disease, initially affecting gay men and then iv drug using men. This negligence on the part of the state has allowed infection rates among women to reach a critical stage with explosive potential.

The intention of this chapter is to examine women's risk of Acquired Immuno-deficiency Syndrome (AIDS) in the United States and to offer a broad understanding of the multiple forces contributing to their risk. Even though the third wave is articulated as consisting of women and children, this chapter focuses primarily on women's risks for it is through diminishing a woman's risk of HIV infection that risks to newborns will also be mitigated. In analyzing women's risks and the pros and cons of different prevention mechanisms, I look specifically at how personal, cultural and institutional forces reinforce each other, to put women at greater risk of transmission. Using such an approach, one is able to probe beneath the identified public health risk factors of "unsafe sex" and "needle-sharing," to issues of unequal power relations and to the deeply embedded social sources of risk. This deeper understanding then provides a coherent and viable base upon which to construct practical and strategic interventions for AIDS prevention with specific regard to women.

DECONSTRUCTING WOMEN'S RISK OF AIDS/HIV

In deconstructing women's risk factors, I concentrate on the conditions of Black and Latina women's lives, for they comprise

the overwhelming majority of AIDS cases as a result of needle sharing and sexual contact.

Drugs as a Risk Factor

In both Black and Latino communities, it has usually been men who control the drug economy.[4] Men are the ones who buy and sell drugs in quantity, rarely allowing women to enter the entrepreneurial aspects of the "drug market." Thus, women are usually "turned on" to drugs by men in their lives and once addicted, are reliant on men to supply their habit. Thus, this underground economy, created by broad political and economic forces, has provided an arena in which men can play out their role of dominant provider at the community level. It allows men to give expression to a culturally favored macho mentality and maintain gendered relationships of dependence. In the context of AIDS, these relationships can and do have fatal consequences for women.

These relationships of dependence are further fostered by the phenomenon known as the "feminization of poverty." Black and Latina women represent some of the poorest populations in this country. They tend to bear more children on average than do white women, and often cannot afford to support their families single-

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[4]Dr. Beny Primm, member of Presidential Commission on AIDS, discussed this in relation to the Black community in M.I.T. lecture, March 1988. Men's control over drugs is even more prevalent in the Latino community, according to an April, 1988 interview with Carmen Paris, Director of AIDS Education program, Congreso de Latinos Unidos, Philadelphia.

handedly. Also, since 1970, Aid to Families With Dependent Children (AFDC) benefits declined by about one-third in real dollars[5], thereby exacerbating poor women's economic insecurity, and contributing to another growing phenomenon, namely, the "feminization of homelessness." In the face of seemingly impenetrable class barriers, women seek relief where it is accessible, and often find it in the temporary haven of drug-induced pleasures. Public health injunctions to not use drugs are often not viable, for when no brighter options are available, there is little incentive to "go clean."

As more women have become addicted to drugs, they have begun to enter the drug market through a desperate form of barter -- by selling sex, not in exchange for money, but for the drugs themselves. These women represent a new breed of prostitutes. They are in their early twenties, many have children, and they are often homeless.[6] Because they cannot find lucrative employment in the formal sector of the economy, they have managed with the only resources left to them, their bodies. In this case, it is women's exclusion from mainstream wage-earning jobs that gives way to the personal indignities of prostitution.

As a group, prostitutes tend to be well informed about AIDS. They will usually practice safe behavior unless they are "dope hungry" -- when the need to feed their addiction overpowers their

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[5]Homelessness, Health, and Human Needs, Institute of Medicine, 1988.

[6]"The Invisible Girls: Homeless and Hooking in the Neighborhood" The Village Voice, March 14, 1989.

self-protective will. This has been observed among prostitutes in New York.[7] If they are addicted and they need their fix, they will often consent to sex without using a condom if their male clients insist.

For women to get off drugs is extremely difficult. Not only is there little incentive to go clean, but there are very few treatment options available to women. The treatment that does exist is often woefully inadequate and caters significantly more to men than to women. Women with dependent children have perhaps the hardest time getting off drugs as there are very few residential drug treatment centers which serve families. In the entire State of Massachusetts, for example, there is one such program with the capacity for only 25 adult women and their children. Thus, the shortage of accessible treatment limits women's possibilities of recovery, thereby sustaining women's addiction as well as their susceptibility to AIDS.

When there are children in an addicted woman's life, additional conflicts arise between her drug-related activities and her child-rearing responsibilities.[8] These women want to, and believe they should, take care of their children, especially as they are often the sole parent in their children's lives. In addition, as sociologist Beth Schneider has observed, "It is through motherhood that many Latin women affirm their status as

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[7]ibid.

[8]Schneider, Beth "Gender and AIDS" AAAS Conference Papers, 1988.

women, and...female drug addicts reveal that children and motherhood are their singular claim to a sense of self-worth." Thus, the lifestyle associated with drugs, insofar as it negatively affects a woman's capacity to be a good mother, diminishes her self-esteem. Mothers who have been diagnosed with AIDS, appear to be experiencing similar feelings of guilt and self-deprecation at not fulfilling their familial role as caretaker and mother.[9]

AIDS exposes and exacerbates all of the above conditions for women. It illuminates the extent to which women use drugs, the oppressive social and economic forces which compel their drug-related behavior and the personal contradictions and indignities women suffer as a result.

Sex as a Risk Factor

The overwhelming majority of women who contracted AIDS through heterosexual contact did so by having sex with a man who was an intra-venous drug user. Thus, even when a woman herself does not use drugs, she is still vulnerable to the repercussions of her partner's drug use. She therefore depends on her male sexual partner to practice safe drug behavior and to be honest about those behaviors.

Men are not always forthcoming about their drug practices,

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[9]Interview with Sister Margaret Leonard, Director of Project Hope, Dorchester, MA. March, 1989.

however. A young woman I interviewed in Western Massachusetts[10] contracted AIDS from her boyfriend, who, unbeknownst to her, used intra-venous drugs. She only found out about his condition after reading AIDS as the cause of death on his death certificate. She was subsequently confirmed as carrying the AIDS virus. Before this all happened, she did not know much about AIDS let alone about what was meant by AIDS prevention. The little AIDS television blips she witnessed were not enough to inform her about the real risks of transmission, and she mistakenly perceived the epidemic to be far removed from her immediate life.

As a consequence of her AIDS diagnosis, her family shunned her, her employer fired her and she was forced to give up her apartment because she could no longer afford the rent. She felt she would now be living in a homeless shelter if she were not able to secure residence in a congregate home for people with AIDS. The pillars of this woman's social and economic existence were fractured as a result of not having the information she needed to protect herself. Public health education failed to reach her because it has been sporadic and largely inaccessible to people in small towns like the one in which she lived. The media portrayal of AIDS as a male disease also contributed to her perception that the disease was of no personal threat. Perhaps the most important reason why her life has been fractured in this way, however, has to do with her boyfriend's deception about his drug use.

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[10]Interviewee to remain anonymous, February 1989.

One could understand and explain his deception using a variety of analytical lenses. A psycho-social analysis might explore the history of the boyfriend's alienation from his family (who did not even attend his funeral) in order to identify his formative role models of failed communication. Or one could invoke theories of patriarchy to assert that men seek to control women and one way men exercise control is through with-holding personal information. One could also broaden the explanation by citing institutional political and economic forces which created conditions of exclusion and despair, thereby leading individuals to use drugs. Once individuals are addicted, those same institutions label them criminals. This stigmatization in turn serves to further alienate that individual and cause him to deceive others about his ostensibly criminal behavior. It seems to me that none of these analyses by themselves fully explain the roots of the problem. Taken together they demonstrate an interplay of oppressive forces which contributes to a more dynamic understanding of the some of the underlying social causes of a woman's risk for AIDS.

Women who are aware of AIDS prevention imperatives contend with additional obstacles to practicing safe sex, namely, men refusing to wear condoms. As opposed to other birth control methods which are nowadays mostly female-centered, preventing AIDS requires condom usage, a male-centered contraception. This has been problematic because although a woman can suggest that her male partner wear a condom, and even buy the condom for him,

she cannot control whether or not he uses it. Men sometimes justify their negative attitudes towards condoms by complaining that "they're uncomfortable" or, "they don't fit right."[11] Although both may be true, refusal to wear them suggests that uninhibited sexual pleasure is more important to some men than their female partner's preference to practice safer sex. With regard to women's right to refusal, but also applicable to safe sex more generally, Julien Murphy outlines this ethical principle:

> Any act of sex that undermines the respect and autonomy of oneself or ones partner by endangering the health and livelihood of either or both persons treats persons as mere instruments of but not the proper ends of sexual pleasure.[12]

Some evidence shows that women have experienced violence when they raised the issue of safe sex and the use of condoms.[13] Men are often offended by a woman's suggestion to wear condoms because they think she is implying that they are somehow "dirty" or "queer," (i.e. gay.)[14] As Schneider explains,

> Homophobia is one expression of being male. Homophobia, coupled with the belief in immortality and invincibility among young heterosexual men, seemingly accounts for their own resistance to efforts at education and to their denial that AIDS has anything to do with them.

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[11]Interview with Dr. Miguel Cortez, Philadelphia, April 1988.

[12]Murphy, Julien S., "Women with AIDS"in AIDS: Principles, Practices and Politics, I Corless and M. Pittman-Lindeman, Eds. Hemisphere, WDC, 1988.

[13]Schneider, Beth, op. cit. and Beny Primm, Conference presentation March 1988.

[14]B. Primm, ibid.

This fierce denial of homosexuality is encouraged both by prevailing socio-cultural attitudes and by institutional religious forces in Black, and particularly in Latino communities. In the Latino community, the Catholic Church wields a lot of power and authority and the Church's dogmatic condemnation of homosexuality strongly influences negative cultural associations with being gay. In fact, according to one gay Latino man I interviewed,[15] a homosexual/bisexual Latino man with AIDS would preferably claim to be an ivdu before he would admit to being gay, even if he never used drugs! Cultural machismo is thus reinforced by homophobia in the Church.

But as we have seen time and again, prejudice against gays does not eradicate homosexual activity, it just drives it underground and into the closet. One of the manifestations is gay/bisexual men living in heterosexual marriages and, unbeknownst to their wives, having homosexual relationships on the side. Because they are often unaware of their husbands' homosexual involvements, and believe their marriages to be monogamous, these women are also unaware that they are at risk for AIDS.

Creating further barriers to prevention for women at risk are the institutional pressures generated by public health injunctions, and the literature disseminated by AIDS service organizations. For example, the gist of the AIDS prevention messages to women, from both the public and private non-profit

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[15]Interviewee to remain anonymous, Philadelphia, April 1988.

sectors, has been for women to be responsible for their own protection in sexual activity. In contrast, no major AIDS campaign has insisted that heterosexual men equally share that responsibility. As a result, almost half of the condom purchasers in this country are now women.[16] Because men tend to control what goes on in the bedroom, particularly when considering Black and Latino adolescents, it is imperative that AIDS prevention messages be targeted to men as well as women.

As Dr. Janet Mitchell, Director of Perinatology at Harlem Hospital Center in New York has pointed out, by excluding men from the normal counseling process in family planning clinics, a similar message of unequal responsibility is communicated. Because the women at highest risk for AIDS are those of lower socio-economic status with traditionally less access to health care, it is often when they become pregnant and seek out pre-natal care that these women first encounter counseling regarding their health and sexuality. Pre-natal counseling can be an ideal time to educate women about AIDS/HIV. Some family planning clinics are beginning to include HIV information in pre-natal counseling sessions, but most do not request that the male partner be present. Dr. Mitchell argues it is essential to involve the man in the counseling process because, particularly in the Black community, a pregnant woman tends to be faithful to the father of her baby and that father tends to make decisions regarding sex. Thus, Mitchell argues, if one wants to empower

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[16]Consumer Reports, February 1989.

women in terms of AIDS prevention, one also needs to enlighten men about the potential dangers of unsafe behavior.

Male education is especially important because it can help to facilitate more open dialogue between men and women regarding their sexual relationships. Much of the literature on AIDS prevention stresses the necessity to talk openly with ones partner about sexuality, past involvements and explicitly about the sexual activity that goes on between them as lovers. This has been problematic for women as talk about sex is not only taboo for women in general, but language regarding sexuality is highly gendered and often inaccessible to women. It is either "objectively" scientific where the terms hold no personal meaning for women, or it is slang which women often consider to be vulgar, as slang has largely been created for and used by men.[17]

Many of the sexual issues which AIDS uncovers can be generalized under the broad inquiry regarding who controls women's bodies and their sexuality. Despite the ideal claim that women should have the right to control their own bodies, through the lens of AIDS, we can clearly see that this is in reality, not the case. The pressures on women to relinquish control over their reproductive capacities have also controversially come to the fore in light of potential perinatal transmission of HIV.

P. Clay Stephens, a planner for the AIDS program at the Massachusetts Dept of Public Health, tells of an occurrence at a public policy conference she attended:

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[17]Schneider, Beth, op. cit.

> In early 1985, a Black physician, speaking during the question-and-answer portion of a public health issues conference, stated that "no Black children should be born until there exists a cure for AIDS." Yes, he was responding to the devastating effect of AIDS-related illnesses on the community he represented, but as the Black women in the audience responded, "No Black babies means genocide, whether we do it to ourselves or whether they do it to us."[18]

Indeed, the ever more audible whispers advocating mandatory HIV testing for all pregnant women and forced abortions for those who test positive, are frightening indications of the power which regulatory authorities can exercise over women's reproductive capacities. Many pregnant Black and Latina women who know they are infected with HIV and receive counseling on the possibility that the virus may be transmitted to the unborn fetus, nevertheless decide to go ahead with the birth much to the amazement of the typically white, middle class woman counselor. The mothers-to-be tend to make this decision because of the importance of child-bearing in their cultural, religious and personal lives. The option of abortion is also often antithetical to their religious convictions. Furthermore, the chances of an HIV infected pregnant women bearing a healthy child who will NOT develop AIDS are estimated somewhere between 35%-80% which represent better odds for success than these women often contend with in their daily lives.

The question of who or what maintains power over women's bodies, sexuality and reproductive capacities in terms of AIDS

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[18]Stephens, P. Clay, "U.S. Women and HIV Infection" in New England Journal of Public Policy, 1988.

prevention, requires a complex answer. It involves a diversity of power interests at play, including those at the personal, family or community levels and at those at the institutional level. Over time, these different forces have developed into symbiotic kinds of relationships such that together, they all increase women's risks of AIDS and women's abilities to make viable choices about AIDS prevention.

USING PRACTICAL AND STRATEGIC INTERVENTIONS IN PREVENTING WOMEN'S RISK FOR AIDS

As the numbers of women being diagnosed with AIDS in this country continue to grow, it is clear that effective interventions are needed to stem the tide of infection. As enumerated in chapter two in relation to ivdus, I propose that these interventions be formulated on both the practical and the strategic levels.

Practical interventions would include broadly and systematically disseminating information in a culturally and linguistically sensitive fashion so that it is accessible to women who are not proficient at reading or whose first language is not English. It would also include providing condoms and a range of options for drug treatment, including easy access to methadone, outpatient clinic programs and adequate numbers of residential treatment facilities capable of serving women with dependent children. For those who are not ready or able to make the decision to enter treatment, bleach should be available for

people to clean their works, and clean needles distributed so that in the heat of drug hunger, addicts will be less likely to share their drug works. These practical interventions mostly fall under the rubric of public health, although traditional public health methods of regulation and education need to be better adapted to accommodate populations with which they are unaccustomed to dealing, i.e. prostitutes, homeless families, drug addicts, and in general, women who have ample reason to distrust the motives of public institutions.

Strategic interventions are intended to respond to women's over-arching needs, those which derive from an analysis of the dynamic forces which contribute to putting women at increased risk for AIDS/HIV infection. Because the status of women who are at highest risk for AIDS is so intricately woven with issues of race and class, strategic interventions must effectively address multiple oppressive forces. Strategic interventions need to focus on removing the institutional forms of discrimination which have led to the feminization of poverty as well as rampant homelessness; they need to remove gender, class and racial barriers to equal political and economic participation; they need to change consciousness and regulations regarding women's control over their own bodies; but most of all, strategic interventions must empower women to make positive changes in their own personal, political and economic lives. These interventions lay outside of public health jurisdiction and require extensive and

dynamic planning and coordination in order to develop effective programs and equitable public policies.

IV. CONCLUSION: WAVE OF THE FUTURE

AIDS strikes beyond the immune system deep into people's personal, cultural, social and economic lives. The epidemic is moving along the fault lines of our society and highlighting those on the margins. It is exposing inequities too big for public health and at the same time presenting opportunities for a broad, multi-disciplinary response to the problems associated with AIDS. Practical public health interventions are indeed essential in slowing down the rate of HIV infection, but if the objective is to STOP this epidemic, so is poverty alleviation, anti-discrimination legislation, affordable housing development, social service supports, community development initiatives, and other planning initiatives.

In the gay community we have seen how the convergence of practical and strategic interventions, spurred by love and fear and compassion, has led to a dramatic decrease in the spread of HIV infection among gay men. Although the conditions of gay men's lives were typically very different from those in the second and third waves, the lesson learned is that transformation on many different levels is possible with the right combination of interventions. Although the specifics of the gay community's intervention techniques are not easily transferable to poor communities of color, the lesson of transformation can and should be applied in new ways to these poor communities now struggling with the specter of AIDS.

The key is to confront specific obstacles to behavior change and to tackle head-on, the complex web of political, economic and social realities which have shaped the conditions of poor people's lives. Practical interventions, those designed to disseminate information, condoms, bleach and needles -- must be intensified. Drug treatment programs, presently inadequate in both quantity and quality, clearly need to be regarded as a priority so that a range of treatment alternatives become available on demand. But, as has been demonstrated throughout this thesis, each practical intervention encounters numerous strategic obstacles in its path. Sometimes those obstacles are in relation to public policy, such as the illegality of possessing needles. Some obstacles relate to interpersonal power dynamics such as a man's refusal to wear condoms at a woman's request. And other obstacles derive from bleak economic realities, as manifest, for example, in a homeless person's lack of incentive to change behavior, despite his/her awareness of the potentially fatal consequences of unsafe behavior. Thus, strategic prevention efforts must specifically address these obstacles to sustainable transformation; they must bring new meaning to the lives of poor people at risk for AIDS by promoting some real opportunities which can serve as incentives for changing ingrained patterns of behavior.

In the gay community, successful transformations were initiated and primarily carried out within the community itself. The gay community's task was eased somewhat because gay men often

had their own political and economic resources on which to draw, and their identities were already largely constructed around issues of sexuality. In contrast, poor communities of color typically do not have an equivalent warehouse of resources, and their community identity has not historically been constructed around sexuality or around drug use. Further, the institutions which have traditionally played a leading role in shaping consciousness and meaning in both the Black and Latino communities, most notably the churches, have been reluctant to explicitly tackle the "messy" issues which AIDS illuminates, exacerbates or creates. This reluctance raises pressing questions about who is able and/or is willing to take on the task of leadership in responding to the AIDS epidemic in poor communities of color.

Neither the Black Church nor the Catholic Church are very comfortable openly confronting issues of safe sex -- heterosexual or homosexual, or safe drug behavior. Even those that are concerned with the effects of the epidemic on their congregations, have not effectively mobilized against AIDS. They have willingly left the organizing details up to others and in the few instances of church involvement, action has largely focused on children with AIDS. Apparently, religious institutions can in good conscience care for sick babies, but intervening in adult issues which carry long-standing taboos, is more difficult for the churches to handle. This rigidity seems to be a particularly serious problem in the Latino community where

Catholic Church hierarchy dogmatically dictates that sex and drugs represent blanket transgressions, leaving little room for responding to the reality of Latino life in urban America. The Black churches operate more independently -- less driven by dogma and, as evidenced by their strong involvement in the civil rights movement, are somewhat more in touch with the needs and activities of their communities.

Because the churches are admittedly very powerful forces in the communities now at highest risk for HIV infection, it is important to involve them in the mobilization efforts for collective community transformation. But, because most church leaders are reticent to explicitly confront the issues which are essential to affecting behavior change, leadership on these issues may have to emerge from elsewhere within the communities.

Indeed, there are now some leaders and institutions which are willing and able to take on AIDS concerns within communities of color - for example, Shirley Gross, the Executive Director of the Bayview Hunters Point Foundation in San Francisco which has successfully organized around a host of health and community development issues for Blacks in that city; Katie Portis, the director of Women, Inc., the only residential treatment center for women and their children in Boston which is involved in intensive street outreach to reach poor women with AIDS prevention materials; Carmen Paris, who runs the AIDS services department for Congreso de Latinos Unidos in Philadelphia, a multi-service center for the large Latino population in that

city; Nate Askia, an advocate for iv drug users, who manages successful drug treatment programs in Massachusetts and has become increasingly active in addressing the practical imperatives associated with the epidemic's impact on ivdus. All of these people and the institutions they represent, reflect the potential for new leadership to emerge in response to the AIDS crisis -- community-based leaders who are willing to challenge existing conditions of people's lives, and to pose a new kind of politics, one that fuses the personal dynamics of people's lives and needs, with the institutional powers and resources to meet those needs.

The street-level organizations with which these leaders are associated and/or which they themselves have built, understand the human dimensions of the epidemic all too well. They have experienced the deaths of friends and clients and they have seen the daily suffering of people with AIDS in their communities. They are in positions to address and to communicate the imperatives of transformation, both to those within and outside their communities. They speak the same language as the people whom they serve and they also exercise the political courage and tenacity to demand attention and resources from the state.

Through very practical intervention efforts, these leaders appear to have gained some momentum in making inroads towards more strategic changes. Katie Portis' Women Inc., cannot permanently alter the conditions of poverty which addicted women with children face, however, Women Inc. does help to empower

women by helping them get off drugs and to recognize that behavior change is possible. By showing these women compassion on a very practical caring level, and providing the space for women to make positive changes in their lives, Women Inc. is making a dent in the "crisis of meaning."

But, many more dents are needed. Because AIDS touches on so many facets of people's lives, and the resources needed to address prevention comprehensively, are indeed staggering, the Katie Portis's of the world cannot shoulder the burden alone. Newly emerging leaders and institutions must be supported by, as well as encouraged to work with the churches in some kind of fruitful and collaborative effort to affect community-wide transformation. This may mean that the churches offer advisory or political support to lend legitimacy to the community-based efforts in the eyes of the community. It may also mean a division of labor such that the religious sector cares for the sick without uncomfortably venturing into the "moral issues" of sex and drugs. The community institutions would then intensify their interventions on the ground level and maintain their relationships both with the people and the politics of AIDS. In addition, groups internal to the community necessarily need to work with agencies and institutions external to the community because resources are located externally.

Thus, if strategic transformation is to come about, there needs to be not only internal community recognition of the multi-dimensional nature of HIV risk, but also a willingness among

professions to respond in an interdisciplinary fashion. Cross-cutting professional alliances between health care professionals, economic development planners, social service workers, and public policy-makers, however, have not been easy to develop. Such a cooperative approach remains one of the major challenges and opportunities presented by the second and third waves in responding to both the symptoms and the sources of HIV risk. Some coordinated planning efforts have recently been initiated but most are in their foundling stages, treading shakily on experimental ground. We need to support and expand upon these experimental efforts, with an eye towards overcoming the historical insularity of many service-oriented agencies.

In Boston, the Boston AIDS Consortium has been working to identify AIDS-related needs and develop strategies for meeting those needs. The Consortium is comprised of over one hundred representatives of public and private sectors organizations, from hospitals and from diverse community-based social service agencies. But life for the Consortium has not been easy. When the Consortium's task forces first began to meet, there were people who would not talk to one another and saw little common ground from which to work together.[1] Over time, animosity has in some cases decreased, but adversarial relations still exist regarding AIDS priorities in Boston and in Massachusetts more generally.

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[1]Interview with Consortium coordinator, Holly Ladd, December 1988.

Recently, controversies have erupted about AIDS funding priorities in Massachusetts and have sparked publicized struggles over resources between gay and Black community advocates. Some Black community leaders like Norma Baker of Springfield, are demanding that scarce state resources be redirected from the gay-identified AIDS Action Committee to drug treatment programs for ivdus. Baker feels that AIDS prevention for ivdus should be a higher funding priority while Larry Kessler of the AIDS Action Committee is trying to preserve public support for the gay community's continuing battle to cope with the AIDS epidemic.[2] Although such self-protective stances are understandable given the enormity of the threat which AIDS poses to both communities, they foster the kinds of divisions we should be striving to avoid. If limited resources are the problem, then ideally, the gay community and communities of color should collectively demand more resources from the state and the federal government and cooperate to share those which are available. Communities need to forge new alliances, not draw enemy lines. AIDS is the enemy, not each other.

It seems to me that the struggle over resource allocation and prioritization like the one currently brewing in MA, is a product of deeper struggles about power and prejudice. It is in part a struggle between the state and the effected communities; in part it is a result of federal negligence and insufficient federal support, not only concerning AIDS, but also with regard

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[2]Boston Globe, April 27, 1989.

to conditions of political and economic exclusion which have contributed to increased risk of AIDS/HIV; and it is in part a result of racism, homophobia and sexism, both institutionally and within the effected communities themselves. The epidemic is thriving on all of these strategic obstacles and as long as they remain intact, relations of unequal power continue to reinforce one another and exacerbate HIV risk.

An alliance recently formed in New York is designed to overcome just such obstacles. A new coalition of fifteen diverse AIDS and social service agencies, representing the interests of the gay community and communities of color, has put together a list of funding priorities which responds to the distinct needs of different communities for tackling the AIDS crisis in New York City.[3] The city's Public Health Department supports the coalition's efforts, but because it is still young, the success and longevity of the coalition is still unclear. Nevertheless, such a broad-based coalition which fosters cooperation and understanding of the complexities of AIDS in various social contexts, is a step in the right direction.

The various coordination efforts with which different cities are experimenting, are mostly focused on practical rather than on strategic interventions. There is increasing attention being given to the need to reach ivdus with AIDS information, for instance, but little voice given to fundamentally changing the

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[3]Interview with New York City, Department of Public Health AIDS planner, Steve Schall, April 1989.

conditions of people's lives so that drug use is less desirable and less viable. Similarly, more people are advocating outreach to women at risk for AIDS but the practical interventions proposed do not account for the strategic obstacles to women's ability to practice safer behavior. Given the analysis presented on all of the "waves," it is clear that strategic interventions must compliment practical intervention if real and sustainable transformation is to be possible.

Recently, a group of Black community leaders in New York convened specifically to discuss the nexus of all of the problems illuminated by AIDS and to generate interest and ideas for addressing the still exponential rate of infection in their community. If it is a sign of things to come, the meeting represents an important dent in the snowballing crisis, for it implies community recognition that planning for AIDS prevention cannot be conducted in a business-as-usual manner, not when so many are dying.

There are some who argue that no matter what we do, AIDS is with us for "the long haul."[4] They argue that we must learn to live with that reality and cope in the best way we can. Kenneth Keniston, for example, argues that given the reality of people's lives, particularly the conditions of poor people in poverty who are now being disproportionately and increasingly infected with HIV, there is little hope for transformation. Keniston is in fact

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[4]Kenneth Keniston, "Living With AIDS: Social Construction and the Long Haul" STS Working Paper 1, to be published in Daedalus, Summer 1989.

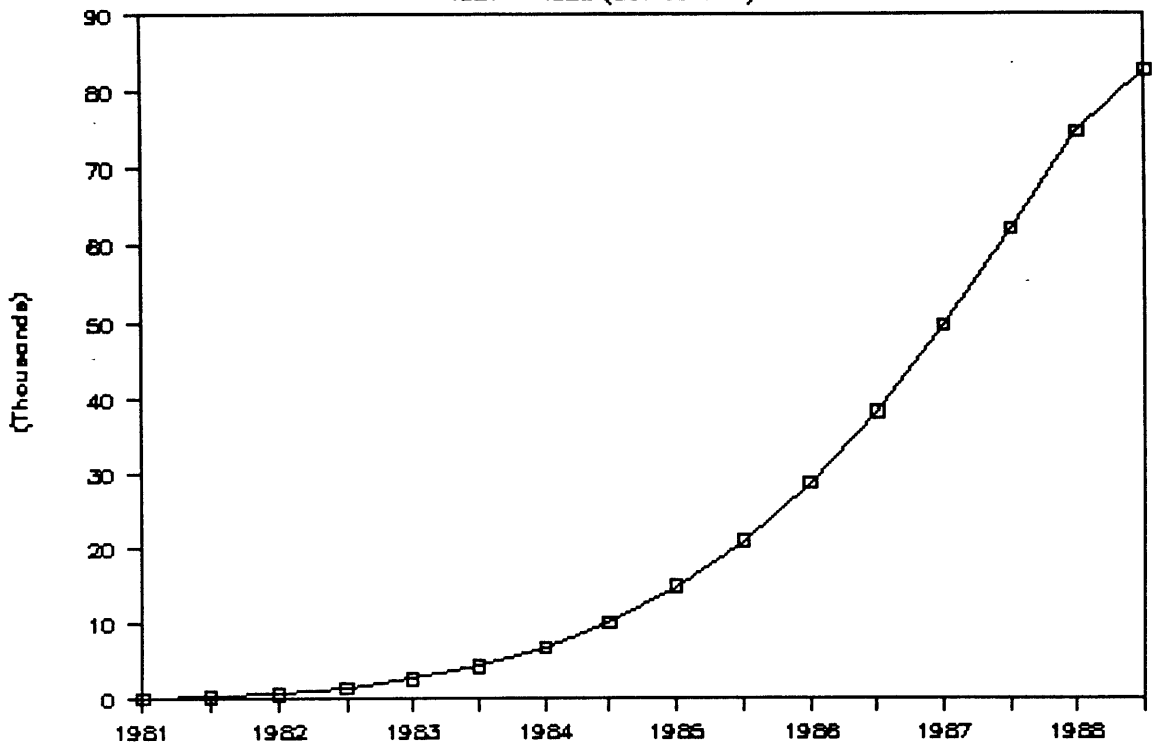
right, if we continue to only follow the practical path of intervention. If, however, we simultaneously follow the path of strategic interventions, and work to change those conditions which inhibit transformation, then we might not have to accept AIDS as being with us for the long haul.

A new and effective leadership within communities of color must put their strategic interests on the AIDS planning agenda along with all of the practical public health measures being discussed. They must make clear the connections between AIDS and poverty and drug use and discrimination and oppression of all kinds. The connections must be clear not only to themselves, but to everyone who has an interest in stopping the ravages of this epidemic.

Thus far the epidemic has thrived on the marginality of select groups -- on the basis of sexual preference, race, class, and gender. Our call is to erase those margins, not by condemning people to death, but by helping to improve their places in life.

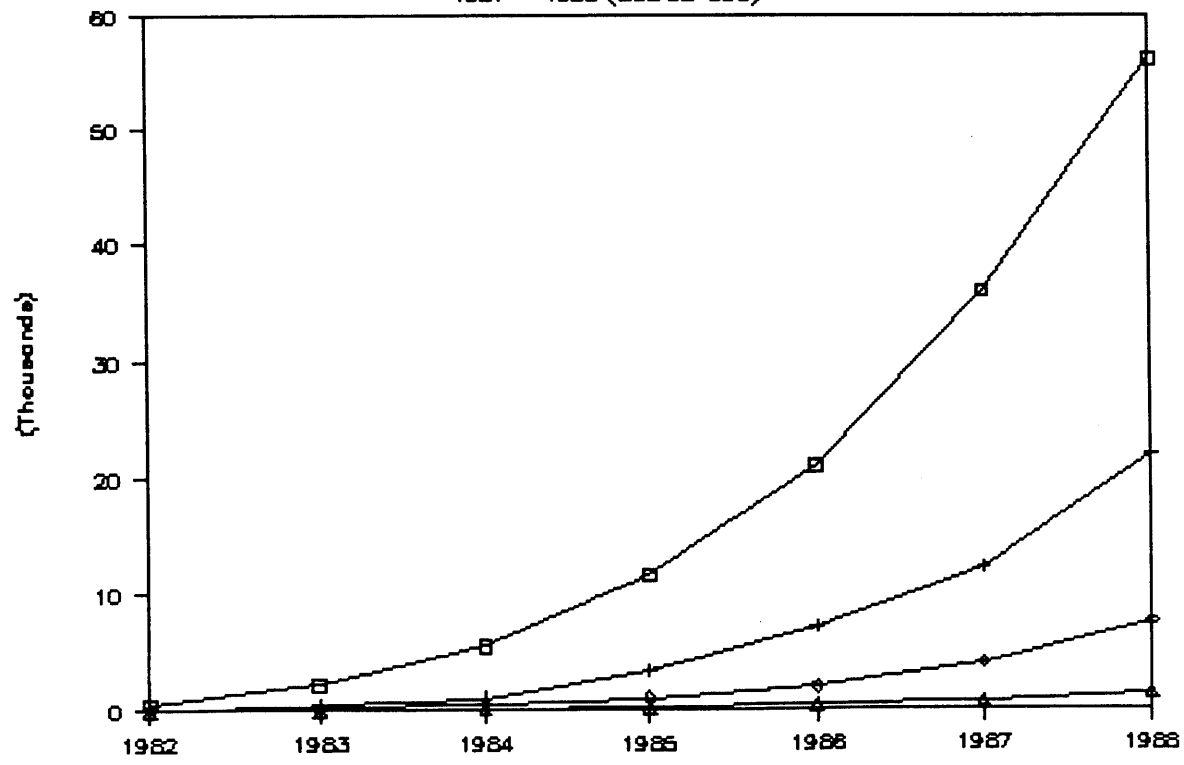
CUMULATIVE NUMBER OF U.S. AIDS CASES

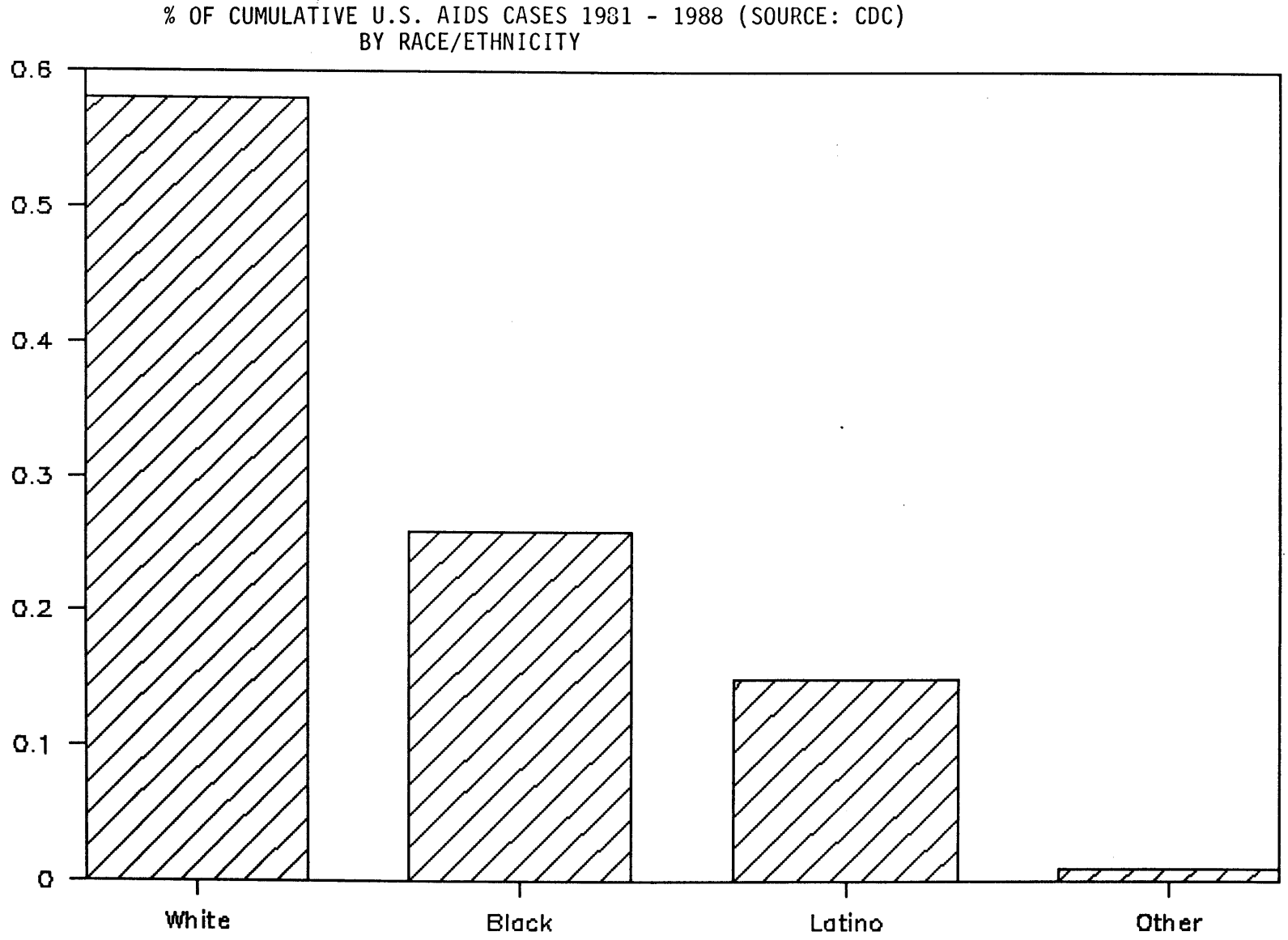
1981 - 1988 (Source: CDC)



"WAVES" OF U.S. AIDS CASES

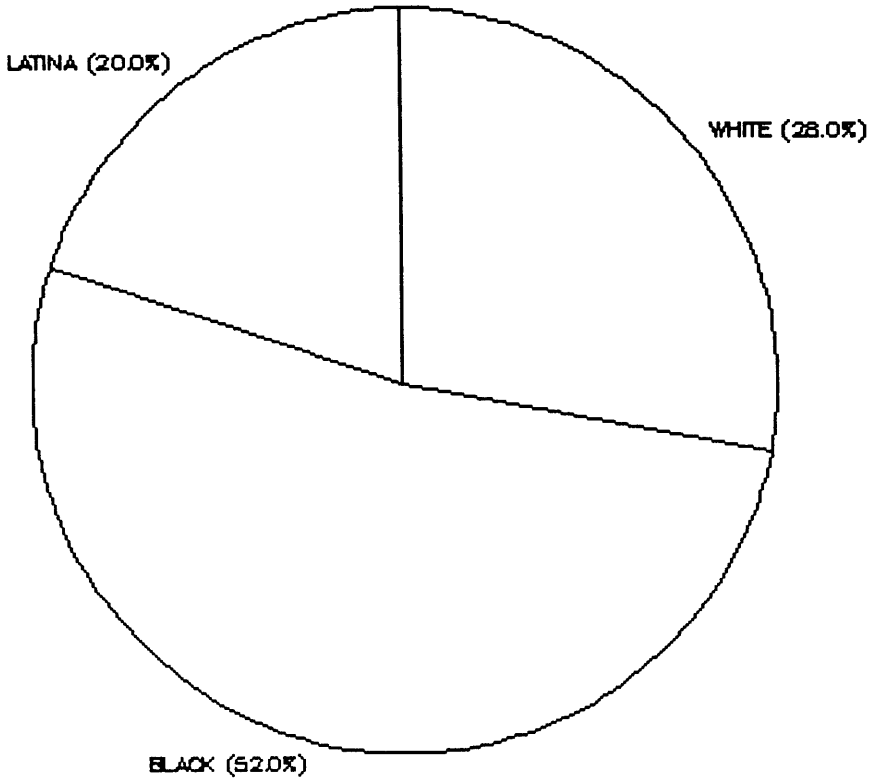
1981 - 1988 (Source: CDC)




% OF CUMULATIVE U.S. AIDS CASES 1981 - 1988 (SOURCE: CDC)
BY RACE/ETHNICITY
0.6
0.5
0.4
0.3
0.2
0.1
0
White
Black
Latino
Other

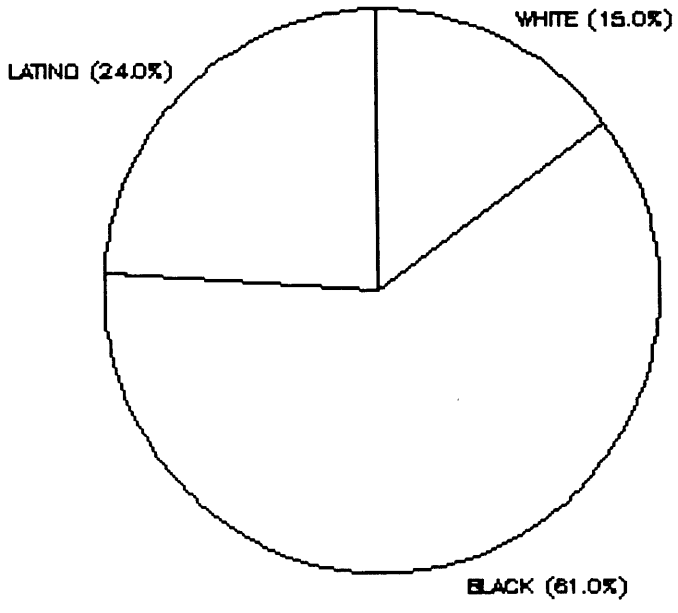
PROPORTION OF FEMALE AIDS CASES

BY RACE/ETHNICITY (Source: CDC 1989)



CHILDREN WITH AIDS BY RACE

THRU PERINATAL TRANSMISSION (CDC-1989)



APPENDIX A

What is AIDS?

Acquired Immuno-deficiency Syndrome (AIDS) is the final and most debilitating stage of Human Immuno-deficiency Virus (HIV) infection. It is a stage which entails a great deal of suffering and results in almost certain death.

The median amount of time from the point of initial infection until the onset of clinical or "full blown" AIDS, is estimated to be ten years. This estimate, however, is based on studies of gay men in San Francisco and there is conjecture that median HIV incubation time for other populations may vary. Intravenous drug users, for instance, may have a shorter incubation period because their pre-infection immune system may have been compromised by extensive drug use. Infants too, appear to have a shorter incubation because their immune system is less developed.

Once a person develops full blown AIDS, he/she has a life expectancy of 1 - 2, possibly three years depending on the individual's response to various experimental treatments. During this time, bouts of illness are interspersed with periods of apparent wellness.

AIDS is clinically diagnosed when an HIV infected person develops one of 25 opportunistic infections designated by the CDC as representing the final stage human immuno-deficiency. Many doctors, however, are now recognizing that HIV entails a continuum of disability and that the distinctions between asymptomatic stages, AIDS Related Complex (ARC), and full blown AIDS, are in fact quite arbitrary. AIDS is becoming increasingly

viewed as a chronic disease in the medical world, to the point where many now advocate eradicating the term AIDS altogether in favor of "HIV Disease," a name which better reflects the chronic nature of the virus.

How one defines AIDS/HIV is not just a question of medical semantics as it has very important practical implications. At the present time, treatment and care is usually reimbursable only when one is diagnosed with clinical AIDS. If one suffers from another condition as a result of HIV infection, a condition not included in the legal definition of AIDS, that person is ineligible for SSI, SSDI and disability benefits and is thus denied access to services funded by Medicaid.

What is HIV?

HIV is a retrovirus which means it employs RNA to reproduce itself as opposed to most viruses which use DNA to do so. Retroviruses are probably the least understood type of virus around and HIV has a particularly complex molecular structure. AIDS researchers have explained that looking at HIV with the best available technology is like looking at the planets with the naked eye. It is very difficult to understand and virus isolates tend to vary from one to another. Because of the complex nature of the virus, no cure or vaccine is likely to de developed within the next 20 - 25 years.

When HIV enters the body, it attaches itself to a cell surface whose molecular structure fits its receptor. The host cell it seeks has a CD4 structure which many different types of

cells have, including the T-helper cell, the backbone of the human immune system. Once HIV has locked onto a cell, the host cell internalizes the virus and that cell is converted into a microfactory which produces and sends forth more virus particles. These newly formed particles then attach themselves to other cell surfaces and the process continues.

Normally when cells carrying foreign antigens such as the flu virus, enter the body, the immune system mobilizes its T-helper cells to attack the foreign virus. By attaching itself directly to the body's T-helper cells, HIV gradually debilitates the immune system so that eventually it no longer has the capacity to fight infection. Clinically diagnosed AIDS is that stage of HIV infection when the human T cell count is so low that the body is susceptible to a whole host of opportunistic infections it would normally fight off. In fact, one of the first indications that AIDS was indeed a disease of the immune system, was when patients started presenting infectious diseases which previously were known only to affect pigeons or sheep.

Because HIV attaches itself to any CD4 cell structure, it affects not only T-helper cells. The virus often bridges the "blood-brain barrier" by insinuating itself onto other CD4 cells in the brain and produces AIDS dementias.

HIV Testing

Clinical AIDS, as mentioned above, can be presumptively diagnosed if a person suffers from one of a number of opportunistic infections. To find out if a person has HIV,

however, requires testing an individuals' blood serum for the presence of HIV antibodies. Within 4 - 6 weeks of initial infection, the body will develop antibodies which can be detected by confronting a blood sample with a trace of the virus and looking for recognition. A negative response indicates that antibodies to the virus have not been detected, hence that person is HIV-negative. A positive response indicates that antibodies to HIV have been detected and that person is considered HIV-positive.

Like any tests of this nature, HIV antibody tests (There are two: ELISA - enzyme linked immunoassay and the Western Blot) are not foolproof. It is possible to get either false positives or false negatives. If mandatory testing were ever instituted, such false results would result in potentially horrific repercussions. Furthermore, because the tests can only detect antibodies and not the virus itself, there is a 4 - 6 week "window period" from the time of infection until antibody detection, when blood testing will show a person to be HIV-negative when he/she is actually infected with the virus.

HIV Transmission

HIV is transmitted through blood, semen and vaginal fluids.[1]

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[1]In the U.S., female to male sexual transmission is thought to be less "efficient" because a man typically has few open cuts around the genital area. Male to female sexual transmission is more "efficient" because it is much more common for the vaginal walls to be torn during sexual intercourse, thus providing an entryway for the virus to enter the women's bloodstream. In Africa, where untreated sexually transmitted diseases have frequently resulted in open sores and cuts around the genital areas, transmission is equally "efficient" from and to persons of

Although the virus has been isolated in other bodily fluids such as tears or saliva, it is extremely difficult to detect and there have been no known cases of HIV transmission through fluids other than blood, semen or vaginal fluids anywhere in the world.

Most transmission both nationally and internationally, has been related to homosexual or heterosexual intimacy where infected semen enters a partner's bloodstream usually through tears in the walls of the anus or vagina though the virus can enter through cuts on the hands, in the mouth and so on. Because anal sex is so common in male homosexual sex, and the tissue in the anus is easily torn, transmission by this route is in scientific terms, very efficient. Hence, the virus spread very quickly amongst gay men, particularly those who had multiple partners.

In the U.S., transmission through sharing needles has become increasingly prevalent. As discussed in chapter two, this is because when ivdus are shooting up, they frequently do not have more than one set of drug paraphernalia and share that set between them. Not only is the blood on the needle from another person's usage, but in order to get the last bit of drugs into the body, ivdus often do a "rinse" of the syringe. This involves drawing one's blood back into the just emptied syringe to wash all the heroin off the sides, and then shooting the blood and drug mixture back into one's own veins or giving the mixture to somebody else to shoot. These practices of sharing and rinsing

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either sex. Thus in Africa the ratio of female AIDS cases to male AIDS cases is 1.2:1 (Presentation by Dr. June Osbourne, November, 1988.)

have been enculturated as standard practices and some claim it contributes to ritualizing and eroticizing the act of shooting up.

The third and increasingly common mode of transmission is from mother to unborn child, what is referred to as perinatal transmission. Not every pregnant woman who is HIV+ will pass the virus on to her unborn child, but enough studies have not yet been done to know exactly why this is so, or what the exact chances are that the child will develop AIDS. The most commonly cited probabilities are that an HIV+ woman has a 50% chance of giving birth to a baby who will test positive for HIV antibodies at birth. If at birth the baby is symptomatic, then that child will develop full blown AIDS fairly soon and will probably live only a few years. If at birth the baby is asymptomatic but does test positive, there is an estimated 50% chance that the antibodies are the mother's and that the infant's system has not internalized the virus as its own. When this is the case, the baby will usually test negative within 8 - 12 months of birth. The other 50% who test positive will go on to develop AIDS, but are believed to have a significantly longer life expectancy than babies born already symptomatic.

The nature of perinatal transmission is such that the mother of the infected infant is herself HIV+, and therefore not always in a position to care for the child. Because these women are often single mothers who cannot afford the costs of child-care, many HIV+ babies are abandoned in the hospital at birth - homeless already, having barely opened their eyes.