

## WOMEN AND HIV/AIDS The Silent Epidemic?

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### What Do We Know About Women and AIDS?

I always find it amazing that an argument needs to be made for women to pay attention to the human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS). From the very beginning of the epidemic, it was evident that women would be directly and intimately involved in it: as sexual partners of infected men; as recipients (in the early years) of infected blood; and as members of society caught up in intravenous (IV) drug use. In fact, it was still quite early in the epidemic when data began to emerge that male-to-female spread was much more efficient than the reverse. Therefore, as the identity of HIV as a sexually-transmitted pathogen became increasingly evident, it seemed to me that women were at special risk — and all the more so, because bisexual behavior among men was the quietest of many silent factors facilitating the spread of the new virus.

Let us put some numbers to that. We, in the United States, now have recorded more than 150,000 cases of AIDS in less than a decade, and there are almost sure to be more than 1,000,000 HIV-infected Americans who do not yet have clinical signs or symptoms to alert them to their infectious status. As is quickly pointed out in such recitals of numbers, the substantial majority of AIDS cases are in gay and bisexual men...and just as quickly, the inference is made that women have nothing to do with that. But wait: how does one define "bisexual man"? I believe the definition could be someone who has had three or more same-gender experiences in a lifetime. A bisexual man certainly is not defined by social appearances, and to the extent that he is, most such men self-identify as heterosexual and do not tell their women about the heterogeneity of their sexual lives. It is a common story that a man who is closeted in his same-gender orientation will "take cover" in marriage and a family. There have already been many tragic

stories of men whose wives and children learned of AIDS and bisexuality all at the same time, and in the context of dying.

What about women with AIDS? Well, just four years ago, the percentage of the total number of cases that were female was 7%; yet, now the total is 10% — and this is a percentage of a much larger number. Women are the fastest growing category of the epidemic, and since they are of childbearing age, children follow quickly behind. Some of the women are intravenous drug users (IVDUs) and some are workers in the sex industry. I guess such details have prompted some policymakers to dismiss their significance. (Although there have been a fascinating series of legal skirmishes, in which issues of prostitution have been broached by arresting the women, rather than by dealing with the "johns" who may well be putting them at risk). I am reminded of a time in the epidemic when AIDS and HIV were virtually unrepresented in the Philippines, except for two gay men out of several hundred tested, and 49 women, all of whom were in the immediate environs of U.S. military bases. I was still trying to absorb the import of those numbers, and was wondering what kind of outraged response the Philippine government would have to such importation, when I learned that the U.S. military had substituted a good offense as the best defense — accusing the bar-girls of putting Americans at risk, and demanding that they be incarcerated or, at least, moved away from the bases. (The analogy to our general approach to immigration policy is too apt to ignore.)

### Will AIDS Become Rampant in the Heterosexual Population?

But let us get right to the question that most people talk about: is AIDS going to be *rampant* in the heterosexual population? That word, *rampant*, seems to be the operative one, without which no one wants to pay attention, and of course it does not submit readily to scientific definition. Given the figures I just presented, my own feeling is that it is far too rampant already, and I certainly do not want anyone telling my daughters "not-to-worry."

But, as you know, there have been numerous successful efforts to say just that — the most notorious was an article in *Cosmopolitan*, in which the author concluded that if you were a straight, white, nondrug-using woman, who practiced vaginal intercourse, you could “swing” with impunity — and a book, the very title of which did a profound disservice, *The Myth of Heterosexual AIDS*. In the fine print, you could find that the author actually knew that the heterosexual spread of AIDS did occur and was no myth; but his outrage was directed at those of us who constitute the “AIDS establishment,” because it was not *rampant*.

So what does rampant mean? We have a 9-year-old epidemic of a virus that has a 10-year median incubation period before the disease becomes overt. We have more than 5,000 instances of AIDS itself in which heterosexual spread has clearly been the mode of HIV transmission — that is more cases of AIDS than most countries in the world have *total* cases of AIDS from any cause. We know that heterosexual intercourse *works* — so presumably it is the *inefficiency* in spreading the virus that prompts such a “not-to-worry” message; yet, inefficiency is a pretty scary crutch to lean on when sexuality is at issue, since people engage in so much of it. We know that most things do not spread the virus of AIDS, so we are in a position to focus on those that do. The cost of gambling wrongly is like losing a game of Russian roulette, when the bullet may take 10 years to strike its mark.

I really do not understand the reasoning behind waiting until overt AIDS is *rampant* in order to start caring and warning. The advent of the virus of AIDS has the same import as the events of Hiroshima — it is a new fact of life in our world, and all the time we are soothed by such deceptive propaganda, 10-year ticking time bombs are being planted among our sexually-active children.

But if one needs more convincing, let us look at HIV infection, rather than AIDS. After all, using AIDS itself as a way to chart the terrain of this epidemic is kind of crazy. It is a 10-year-out-of-date map of a very complicated landscape, and no one would ever plan military maneuvers using such archaic guidelines. If we were seriously trying to intervene, we could be looking for signs of change. And, in fact, the signs are everywhere one turns. As long ago as 1985, when the U.S. military began to screen volunteers, it was evident that the 11:1 male-to-female ratio that then described AIDS case distribution was already out-of-date. They found nationally that 1.6 men per thousand and 0.6 women per thousand, were infected, a 3:1 ratio; even more ominously, in the New York City area, where I believe the virus has had the longest time to “equilibrate” after its fortuitous initial introduction into an insular gay community, the rates were 1.6 per 100 men and 1.3 per 100 women, nearly a 1:1 ratio.

I confess those figures did not seem surprising to me — even then — for it is important to note that in most parts of the world where no structured gay communities existed to provide tragic, initial epidemic warnings, trends toward equality of the sexes were already much in evidence. And, of course, HIV/AIDS clearly was

spreading heterosexually in central and east Africa from the outset, as it now is in Thailand. Contrary to occasional suggestions, we Americans are not a different species, and the lesson seemed clear to me and to many others, a long time ago, that we need to be sending warnings of *universal* risk.

By now, those military data have been confirmed and extended everywhere one turns. Screening of cord blood — which is an effective surrogate for identifying infected women — has shown rates in excess of 1 in 100 in a number of studies of east coast populations. The recent screenings, in U.S. hospitals located away from the epicenters of the epidemic, yielded a 3:1 male-to-female ratio; subsequent data from the military, both volunteers and standing, show the same distribution. This is entirely consistent with the rapid rate of increase of AIDS in women that I mentioned before.

A final point about what we know: HIV/AIDS in adolescents is increasing, but in view of the increasing number of people in their twenties who are becoming ill with AIDS, it is probable that HIV risk in that group has been high for a long time, given the very long, silent interval

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before disease. That risk comes from many directions — same-gender encounters, drug injection, and multiple sexual partners. Adolescence, by definition, is an age of experimentation. Many teenagers experiment rather drastically during those years, and yet will end up with a lifestyle that we would label as “straight,” so categorical thinking and exclusionary statements about HIV risk are particularly deadly for their age group. It is a hard enough message to spread under any circumstances, and our adult lassitude clearly signals to adolescents a lack of concern that is highly contagious.

### How Else Are Women Involved?

I have said most of what I want to say about how women are directly involved — that is, how they become personally “at-risk” for HIV and AIDS. Two points should be underscored however: first, male-to-female spread is much more efficient than the reverse. Second, bisexuality is a much more prevalent phenomenon than is generally acknowledged, which is significant, both because of its invisibility and because a critical component of risk in these early years of the epidemic is the concentration of virus. If one inquires of male prostitutes who most of their clients are, the answer is, “Married men.” And, in many cultures around the world, there really is almost no such thing as overt homosexuality per se — instead, bisexual behavior is quietly prevalent. A final comment about direct risk. Much is being made of the role of other sexually-transmitted pathogens in increasing HIV transmission among heterosexuals. Statistically, that may be true, but it is clear that there need not be coexistent sexually transmitted diseases (STDs) in order to transmit HIV, and the distraction of that message is again worrisome.

Let us turn, for a moment, to other factors that put women in the path of this virus. Obviously, the most important one is IV drug use — now joined by crack. Women are in the minority as IVDUs, but adolescents are being pulled quickly into the loop through the use of crack with its currency of sex-for-drugs. Women who are sexual partners of men who use illicit drugs are at very special risk. Often, they are in the least likely place to recognize the relevance of warnings. Their culture is such that efforts to protect themselves with condoms, and other assertions of control in the sexual relationship, are met with violence. Also, there is remarkable cruelty implicit in our present policies, which simultaneously urge women to prenatal care while threatening dire punishment if they are drug-addicted, and yet provide essentially no access to drug treatment for poor people caught in the snare of drug addiction. Talk about “Catch 22s.”

Another terrible role for women in this epidemic is as mothers. This dynamic is again complex. There is the direct risk of HIV infection to 30% (not 100%) of infants born to HIV-infected mothers. But there is also the problem of stigma for *all* of their children, of impending orphan status for older children, and of the excruciating complexity of being, more often than not, single parents whose failing health makes them less and less capable of being caretakers. I sometimes try to insist that we could always talk about AIDS as a *family* disease, for it

has had an extraordinary impact on families, and sometimes it really is the disease of a *dying* family. In Africa this dynamic is very obvious now, but also in the U.S. there have been stories — growing more frequent all the time — of older children who have been left standing, like sole surviving trees in a burned-out forest, after their mother, father, and younger siblings have died around them. In one such poignant anecdote, a 13 year old was quoted as saying how happy she was to be pregnant, because at last she would have someone she could *keep!*

And then, there is the role of women as “mothers of former children,” a phrase I like very much, for that includes most of us! I have been startled by the apparent statute of limitations on childhood that has been operative in this epidemic. Politicians may hug babies with AIDS (nervously, to be sure, but never mind); they may pat toddlers on the head gingerly; and if a teenager is a bit aggressive about it, as Ryan White was, sympathy may be extended a bit further. But, for the most part, there is a brutal statute of limitations, after which even the term “innocent victim” does not serve to shield young people from societal anger. After all, *everyone is somebody's child*. The extent to which families have had to suffer the loss of beloved children, and have had to do even their grieving in secret, for fear of discrimination of perceived disgrace, is a real blemish on our society. This is often excused by saying, “Well, they brought it on themselves!” When was the last time we imposed such a heavy penalty for a behaviorally-related disease? The clear imputation is that, other than a few “innocent victims,” the rest are guilty. The smokers of this world ought to be leading the fight against such exclusionary thinking. In point of fact, most of the people now dying of AIDS could not have been warned, since the virus was not isolated until 1983.

There is a chilling anecdote, which I often think of when talking about the role of women as “mothers of former children” that was told to me by a social worker in New York City. She was trying to help a young woman with AIDS whose two children were also infected. The woman was able to continue working and paying an outrageous rent in a crummy fourth-floor walk-up because her mother was paying for the AZT. Relations between the mother and daughter had been strained at one time, since the initial infection came from the IV drug use of the daughter's deceased spouse. The fact that IV drug use was the mode by which her daughter had become infected caused the mother to have an especially virulent hatred for illicit drugs. So they were struggling and coping, until one day, the daughter called the social worker hysterically. She said that the plaster ceiling had just fallen into the meal she was cooking on the stove; that she was too sick and too tired after a day's work to go downstairs for more food; and, besides, she did not have the money. This is the chilling part of the story: the social worker said, “Come, come now! You have survived much worse than that. What is *really* the matter?” The social worker was correct, though; after a pause, the woman said: “You are right. There is something else. You know that crack raid last night that was in the papers? My mother was caught in the sweep. She had been selling crack to pay for my AZT!”

So that is what an awful tangle we are in right now, and women are in the middle of the mess in a dozen poignant and dreadful ways: as people at risk; as parents of small children and adolescents who are not yet adequately warned; and as mothers of "former children," who need love, solicitude, and help, as they always did, but now more than ever.

### What To Do?

What is there to do? Well, there are many items on the agenda. Women need to be brought into treatment protocols, and in sensitive ways. One powerfully moving witness to the National Commission on AIDS pointed out, not so long ago, that she could not gain access to treatment because she might be pregnant, whereas now it is difficult to be included unless she is pregnant. What a crazy way to function when women themselves are the glue that is keeping the society working. We must learn to adapt strategies of clinical care for women that take into account their multiplicity of roles as patient, provider, and caregiver. And we must reassure the women who *are* caregivers — professionally — so that they can understand their relatively low level of risk and can continue to function without a sense of conflict of interest in regard to their own families.

*"After all, education is going to be the vaccine for AIDS, for at least a decade to come, but, just as a vaccine is of no use in its bottle, so education will not help unless it is delivered, reiteratively and convincingly, in the language of our intended listeners."*

Others will say more about this, but whatever else we do, we must WARN. The misleading message, which that suggests that women (or at least majority, nondrug-using women) need not worry, is a horrid postponement of our obligation to our children's children. After all, *education is going to be the vaccine for AIDS, for at least a decade to come*, but, just as a vaccine is of no use in its bottle, so education will not help unless it is delivered, reiteratively and convincingly, in the language of our intended listeners.

In closing then, let me turn back to the fundamental goal of prevention, for we can do far better than we have been doing. Doris Lessing recently wrote a book called *The Wind Blows Away Our Words*. Most of the book is about Afghanistan during its gruelling war, but the fitst chapter is a re-visitation of the myth of Cassandra, with whom I feel an increasing kinship as I function as chairwoman of the National Commission on AIDS. Lessing recounts the usual version of the myth, albeit colorfully. When Apollo gave Cassandra the gift of foresight, it was in anticipation of certain favors. When Cassandra did not ante up as expected, Apollo punished her by leaving her with the ability to predict upcoming events, but arranged it so that others would not be able to hear her. Her punishment was that she would go through life shouting warnings that, thanks to

Apollo, could not be heard. That is the way we have all been taught the myth.

But, Lessing suggests that, as in many other instances, such invocation of the gods is too easy; that many others besides Cassandra could hear the voices within the Trojan Horse and could see the trouble coming. They also probably tried to warn that there were ominous indicators of future disaster. She proposes that perhaps the problem was not with the voice of Cassandra at all, but rather with her listeners, Apollo notwithstanding.

Lessing proposes, that if enough voices are raised in harmony, the failure to heed might be overcome. Alternatively, she suggests, it might be the listeners who are at fault. She indulges in a fantasy to make that point, positing that there might be, in these modern times, a secret conference at which all participants would agree:

...to set aside all the slogans and battle cries and the circling for better positions just for the duration of the conference, which will discuss: 'What is the matter with us, what is wrong with mankind, that we can't listen to Cassandra? It is as if the world, as if we, were being dragged along by some undertow of stupidity too powerful to resist, and all the sharp, frantic, desperate cries of warning are like gulls glinting as they wheel over the scene, and then dip and vanish, screaming *If you do this, then that must follow* — Surely there must be something we can do, together; perhaps we can learn to listen...'

## Public Policy, Women, and HIV Disease

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### Women Are the Fastest Growing Population of People with AIDS

Women now make up the fastest-growing population of people with AIDS. According to the figures compiled by the Centers for Disease Control (CDC), in 1984, 6.4% percent of all people diagnosed with AIDS in the United States were female.<sup>1</sup> By July 1990, this figure had risen to nearly 10% and represented more than 13,000 women. Almost all of these women were exposed to HIV through the use of IV drugs, their partner's use of IV drugs, or through heterosexual sexual activity with an infected partner.<sup>2</sup>

### Women Get Sick Faster and Die Sooner than Men with AIDS

Once diagnosed, women become sick faster and die sooner than men with AIDS. Preliminary studies, conducted in California, Florida, and New York, indicate a significant difference in the length of survival for men

and women infected with HIV.<sup>3,4</sup> The reasons for this are unknown. Does infection with HIV result in a different disease profile for women than for men? Is the difference due to socioeconomic rather than medical factors? We do not know, because public policy, research, prevention, and treatment have basically ignored the special needs of women infected with HIV.

### **Women Infected With HIV Are Largely Economically Disadvantaged Women of Color**

Members of the male AIDS population are predominantly white and middle class. However, when speaking of women infected with HIV, we are speaking of economically-disadvantaged women of color. Among women with AIDS, 53% are black and 21% are Latinas.<sup>2</sup> The fact that women of color have been consistently underrepresented in the development of AIDS programs appears to be clearly discriminatory.

### **Women's Needs Must Be Identified, Prioritized, and Met**

If we are to gain control of the AIDS epidemic, women's needs must be identified, prioritized, and met.

**There must be access to drug programs targeted to women.** Although the use of drugs has clearly been identified as a risk factor for exposure to HIV, the availability of drug treatment centers remains woefully inadequate. Programs targeted to women are particularly limited. There are only three methadone treatment programs in the United States designed for women who are pregnant. The link between the use of drugs and transmission of HIV must be addressed at all levels of government. Immediate treatment, on demand, must become a top priority, both in planning and funding. Alternative, innovative approaches, such as needle-exchange programs, are essential. They must be initiated for drug users who cannot, or will not, give up drugs.

**There must be access to the health care system.** Discrimination against women with HIV disease is common and frequently occurs even within medical and social services designed to meet the needs of HIV-infected patients.<sup>5,6</sup> To qualify for many of the benefits funded by public agencies, people with HIV disease must be diagnosed with advanced ARC or AIDS. This diagnosis is defined by guidelines set by the CDC — guidelines based upon clinical conditions common to a predominantly male patient population. Gynecological manifestations of HIV disease and other conditions, common to women infected with the virus, are not represented in the case definition. Thus, it is often more difficult for women, than for men, to qualify for federal, state, and local HIV assistance. Proving eligibility for disability benefits, both public and private, may also be more difficult for women.

**There must be access to treatment.** Women with HIV disease have also been discriminated against in their ability to access treatment. Researchers, investigating potential new drugs, have made little or no effort to recruit women for their studies. Although many of these studies receive federal funding, there are no federal guidelines to assure that subjects are representative of the entire HIV-infected population. In addition, Federal

Drug Administration regulations permit the exclusion of all women of childbearing age as subjects in early trials of experimental therapies. The World Health Organization estimates that there are 100,000 women in the U.S., between the ages of 15 and 49, who are infected with HIV.<sup>7</sup> Few of these women, if any, have been given the opportunity to participate in clinical trials, although most will eventually receive treatment based upon the results of the studies.

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**There must be more research.** Early intervention is increasingly becoming the standard of care for HIV disease. Asymptomatic women infected with HIV now qualify for antiviral treatment. Unfortunately, however, nearly all information about the safety and efficacy of the drugs used has resulted from studies done primarily on males, predominantly white males; the effects of the same drugs on women have yet to be determined. Research protocols have also failed to investigate the effects of the therapies, which have been approved for treatment of HIV disease and opportunistic infections on people who abuse drugs. Heretofore, issues of women and HIV have centered mainly on their role as childbearers and mothers. We need to look beyond that, to the full scope of the disease as it affects women overall.

### **Conclusion**

From the beginning of the AIDS epidemic, women have been deeply involved in the disease. As health care workers, counselors, nurses, social workers, educators, primary caregivers, lovers, mothers, and spouses, they have provided care and support to people in all stages of HIV disease. Now women, themselves, are becoming infected at an alarming rate. We must commit ourselves — through comprehensive planning, based on needs assessment, funding, and program development — to redressing past exclusions, to reversing the trends, to drastically improving the quality of care, and to ending the discrimination and stigma of women who are infected with HIV.

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# Why Women Wait To Be Tested For HIV Infection

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If people infected with HIV are to benefit from early intervention, they must be identified as having the virus in the early stages of infection, and they must receive routine and continuous monitoring. Unfortunately, for the majority of women infected with HIV disease, early intervention is either an unattractive option, or an unavailable one.

## **Women with HIV Are Not Identified Early Enough**

In New York City, AIDS has become the primary cause of death for women between the ages of 25 to 34.<sup>1</sup> With few exceptions, women with HIV disease are receiving too little attention, too late. Many health professionals perceive signs and symptoms of HIV differently in women than in men. Weight loss, headaches, and fatigue in women infected with HIV are more likely to be regarded as signs of overwork, or of domestic stress, than as manifestations of clinical illness. When women finally seek medical care, their sources are limited by finances and accessibility. They will usually go to a gynecological or prenatal clinic or to an emergency room — facilities that do not necessarily screen for HIV. Unless access to care for women is addressed in the broadest possible way, transmission of HIV infection will continue at epidemic proportions.

## **Women Have Limited Access to Medical, Financial, and Social Support**

The women infected with HIV are predominantly blacks and Latinas. They have limited access to medical, financial, and social support systems and, as a result, have very little incentive to learn about HIV disease. In fact, given the scope of the problems they face, they may even feel they have good reason to deny the threat of HIV. Many have no health insurance and seek health care only in emergencies. They also tend to delay medical care because their families come first. The woman is often the core of a family system, which requires her to care for her spouse, her children, and older or ill family members. Moreover, she must continue to fulfill this role, even if she herself is ill.

Although government-subsidized health insurance is available, many practitioners and health care facilities do not accept it. Those facilities that do are often understaffed and located in areas that are difficult to reach by public transportation. Patients are frequently subjected to long waits, inconvenient appointment hours, and insensitive treatment.

## **Women Fear Discrimination and Loss**

Personal issues also stand between women and effective HIV treatment. For most women, fears concerning exposure to HIV, or even early warning signs of HIV disease, are less immediate, and are therefore easier to ignore than the daily survival needs of their families.

In addition, most women of color generally do not identify themselves as members of "high risk" populations. However, they do identify with the stigma these groups have often suffered, and fear that an HIV-antibody-positive test result will make them subject to the same kind of discrimination.

Women who test positive for HIV infection fear loss of control over their lives, possible loss of their children and housing, and the ultimate loss of social supports. For this reason, many women who are tested, and who test HIV-antibody positive, keep the information secret. Unlike gay men, who have established a strong sense of community around HIV disease, women who are infected tend to isolate themselves and often hide their diagnosis even from members of their immediate families.

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## **The Dilemma of Pregnancy and Fears of Involuntary Sterilization and Abortion**

The issue of pregnancy is a difficult one. The number of children diagnosed with AIDS in the U.S. has already surpassed 2,500, and is increasing at an alarming rate.<sup>2</sup> The U.S. Public Health Service estimates that this number will reach 3,000 by 1991.<sup>3</sup> Women, who are infected with HIV, can infect their infants while in utero, during delivery (whether vaginal or Cesarean), and through breastfeeding. The dilemma of pregnancy must be faced squarely by all health educators and providers. Although efforts are made to encourage seropositive women to postpone pregnancy, many nonetheless become pregnant. And, although seropositive women in the early stages of pregnancy are counseled about the risk of infecting their unborn child, about half continue their pregnancy.<sup>4,5,6</sup> It is estimated that approximately 30% of babies born to seropositive mothers will be infected with HIV.<sup>4,7,8</sup>

However, no woman should fear, or be subject to, involuntary sterilization or abortion. Women who are infected with HIV and become pregnant, or who discover they are infected while pregnant, must be assured of continuing, nonjudgmental, quality health care; must be presented with information in a neutral manner; and must be allowed to make their own informed decisions. The dictates of religion, family members, and sexual partners, however, often determine their behavior. Moreover, for many women, a 30% chance of having a normal baby

may be an acceptable risk. Fertility, especially for women of color, is one aspect of life that provides them with pleasure, control, and respect: having children grants them greater status in their families and in their communities.

### **Providing a Comprehensive Community Approach**

The above issues must be considered, not only when asking why women fail to be tested for HIV, but also when programs are designed that encourage HIV testing. HIV in women cannot be dealt with in isolation. An effective campaign to encourage testing will offer testing in a context that also addresses cultural and financial constraints, healthy sexuality, and general health.

*"We must begin prescribing for communities, not just for diseases."*

We must begin prescribing for communities, not just for diseases. For example, programs already in existence in a community, such as STD clinics, prenatal care programs, and family planning programs, could be expanded beyond their original charge to include HIV screening and treatment. With additional funding, training, and staff, these programs could provide HIV risk assessment to every client, as well as appropriate pretest and posttest counseling. Expanding a drug rehabilitation program, for example, to include HIV screening and a health care component for the family, would be taking a significant step toward meeting serious health problems within the community. Each program could confront several interrelated problems — not just one single aspect of a community's health crisis. Ideally, the expansion of programs such as these could lead to the evolution of community-based primary care facilities that offer HIV care as part of their overall health programs.

*"Providing adequate health care to all people, including people of color, has long been a public health goal. If HIV disease can lead us toward a comprehensive approach toward community health, then perhaps that will be compensation, in some measure, for the enormous loss that the epidemic represents."*

Also, ambulatory clinics, staffed by case managers, drug treatment professionals, nutrition counselors, and primary care providers could be available at convenient locations and times to serve the entire family. This kind of clinic could be an ideal way to provide comprehensive care for women — particularly poor women and women of color — as it could offer counseling about prevention, diet, general health, psychology, and sexuality, and advice on financial assistance and access to care issues. Within the context of a general health program, the HIV test also might be less threatening. The clinic would need to offer hours convenient for women,

and would need be equipped with a daycare facility for children.

But what about women who will not seek out any kind of routine health care? Mobile units, staffed by one or two people trained to provide HIV education and pretest counseling, could act as a distribution source for educational materials, a site for confidential testing, and a referral center for women who are infected and for their families, loved ones, and friends. It would be able to offer services wherever women congregate — laundromats, daycare centers, schools, community centers, churches, the corner grocery, soup kitchens, parks, and homeless shelters.

### **Compassionate Consistent Care**

The success of these approaches depends on the availability of compassionate, consistent care for those who test HIV-antibody positive. In the early stages of HIV disease, intervention will consist primarily of education and counseling, rather than clinical care. But, at all stages of infection, the family, and often the extended family, should play a primary role. The development of programs to compensate family members for at-home care, for example, could especially benefit many late-stage HIV patients and ease the burden on public hospitals.

Finally, special programs are needed that study the manifestations of HIV disease in women. They need to address, not only the disease itself, but also the effects of women's fears, for instance, the fear that they will lose their children, or the fear that their children will lose them, due to HIV infection.

Providing adequate health care to all people, including people of color, has long been a public health goal. If HIV disease can lead us toward a comprehensive approach toward community health, then perhaps that will be compensation, in some measure, for the enormous loss this epidemic represents.

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# BLACK WOMEN AND HIV/AIDS

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## AIDS is the Leading Killer of Black Women

Epidemiologists, public health workers, medical professionals, and the entire population of concerned citizens could not help but be alarmed by an article in *The New York Times*, July 11, 1990, entitled "AIDS in Black Women Seen As Leading Killer."<sup>1</sup> However, those of us who have followed this epidemic were not surprised at all. Nonetheless — although the devastating nature of the AIDS epidemic has been generally recognized — it has taken two years for the public to become aware of this dangerous trend.

## Epidemiological Data

The epidemic of HIV infection has predominantly affected young men, but HIV infection is rapidly becoming a major health problem also of young women — especially young women of color. It is now among the 10 leading causes of death nationally in women of reproductive age, and the female death rate from AIDS continues to rise.<sup>2</sup>

The higher overall death rate for black women in the U.S. has been consistent across all states. In New Jersey and New York in 1987, AIDS adjusted death rates among black women, 15 to 44 years of age, were 40.7 and 29.5 per 100,000 population respectively; among

white women, the adjusted rates were 3.9 and 7.8 per 100,000 population respectively. In the same two states, among black women, 15 to 44 years of age, AIDS moved ahead of malignant neoplasms and heart disease to become the leading cause of death in 1987 (see Table I below).

These numbers are just the tip of the iceberg. Our current understanding of the public health problem posed by HIV infection in women is seriously distorted by the under-representation of women in official data, and by the misrepresentation of their disease. The information we have is small in number and poorly collected. The Centers for Disease Control (CDC) definition for AIDS is limited: a person must have severe systemic changes manifested by recurrent pneumonia and opportunistic infections and/or skin changes, such as Kaposi's Sarcoma, to be classified as having AIDS.

Moreover, it is unlikely that the CDC numbers accurately reflect the number of women who, in fact, have serious manifestations of HIV infection. The very case definition of AIDS is centered on how the disease manifests mainly in white men. Thus, HIV-infected women with severe chronic pelvic inflammatory disease (PID) for example — a tubal infection — are not categorized as having AIDS in spite of the fact that many institutions

Table 1

### DEATHS AND DEATH RATES FOR THE FOUR LEADING CAUSES OF DEATH AMONG BLACK WOMEN 15 to 44 Years of Ages, New Jersey and New York\*

New Jersey			
<u>Rank</u>	<u>Cause of Death</u>	<u>No. of Deaths</u>	<u>Adjusted Death Rate**</u>
1	HIV/AIDS	121	40.6
2	Malignant Neoplasms	96	30.1
3	Diseases of the heart	71	23.1
4	Unintentional injuries	57	20.3
New York			
<u>Rank</u>	<u>Cause of Death</u>	<u>No. of Deaths</u>	<u>Adjusted Death Rate**</u>
1	HIV/AIDS	235	29.5
2	Malignant Neoplasms	202	23.8
3	Homicide and legal intervention	130	17.5
4	Diseases of the heart	126	16.3

\*Excerpted from Chu, SY et al. Impact of the human immunodeficiency virus epidemic on mortality in women of reproductive age, United States. *JAMA*, 264(2), 225-229.

\*\*Deaths per 100,000 women aged 15-44 years (1980 Census)



and providers have found that PID in HIV-infected women behaves differently than in noninfected women. Moreover, treatment for women who are infected with HIV is more difficult and less likely to be successful, i.e., the PID is a manifestation of immune suppression.<sup>3</sup>

To this day, it is unclear how many of the estimated 1 to 1.4 million HIV-infected individuals in the U.S. are women.<sup>4</sup> Moreover, among the women who are HIV infected, many are unaware that they are at risk. In one study of HIV-infected blood donors, 44% of the seropositive women could not identify a risk factor.<sup>5</sup>

Epidemiologic data, collected by the CDC, documents that seroprevalence rates in inner city hospitals are astronomically high, even when people with known risk factors are not counted. Available information about women giving birth suggests that in some inner city areas as many as 5% to 9% of deliveries are to women who are HIV infected. Breakdown of New York City prevalence data reveals that the most devastated inner city areas are those with high seroprevalence. This means that poor black women and Latinas are at unduly high risk for infection, whatever their lifestyles, because poverty, lack of resources, and the lack of opportunities prohibit them from leaving areas of high HIV seroprevalence. Contiguous affluent areas have HIV seropositive rates in line with national average figures.<sup>6</sup>

Deeply ingrained societal racism, sexism, and classism has skewed the public's perception of AIDS and HIV infection in women in the U.S. Since the first U.S. case of a woman with AIDS was reported in the Bronx in 1981, women have remained a forgotten group. They are regarded by the public, and studied by the medical profession, primarily as vectors of transmission to their children and as a male's sexual partner, rather than as people with HIV/AIDS — and are, themselves, frequently infected by their sexual partners. Until recently, one could learn epidemiologic information concerning women and AIDS only from perinatal studies, which define women exclusively in terms of childbearing activity, and ignore the fact that pregnancy lasts only a relatively short period of time and that the bulk of serious illness in women occurs outside of pregnancy.

### **Heterosexual Transmission and Testing for the Virus**

It is relatively common knowledge that the HIV epidemic parallels and collates with drug usage — both intravenous and crack — in inner-city populations. This well-documented fact obscures the reality of heterosexual transmission, regardless of the history of drug usage. Inner-city populations are rapidly approaching a new risk definition for transmission of HIV. That risk is penile, vaginal, and rectal — and even oral intercourse is now in question. The epidemic has reached such proportions that engaging in any of these sexual activities without practicing safer sex may be putting one at risk for HIV.

The main prevention strategy at this time is to

## **WOMEN OF NEW YORK STATE AND CITY AND AIDS, 1990**

### **Seroprevalence**

One-third of women in the country diagnosed with AIDS live in the state of New York.

Nearly 50% of adolescents with AIDS in the state of New York are young women, a gender breakdown indicator of heterosexual transmission, not of IV drug use.

### **Morbidity and Mortality**

AIDS is the leading cause of death for females ages 1-9 and 25-34 in the city of New York.

By 1993, AIDS will be the leading cause of death for all women of reproductive age in New York City.

### **Demographics**

82% of women with AIDS in the state of New York are black or Latina, although blacks and Latinos constitute only 23% of New York's population.

In New York City, 86% of the women are black or Latina; outside New York City, 53% of the women with AIDS are black or Latina.

### **Transmission**

Approximately 57% of diagnosed women are presumed to be infected through IV drug use.

23% have been infected through heterosexual intercourse.

Nearly 20% have an unknown risk factor for mode of transmission.

### **Future Trends**

By 1994, the number of IV drug use cases is expected to increase by 200%.

The number of AIDS cases among women is expected to increase 170% by 1994.

*Reference: McArthur, I, ed. Women and AIDS Project Newsletter, New York State Department of Health AIDS Institute, 1990, 5.*

encourage the use of condoms. However, requiring women to force their sexual partners to use a condom may be traumatic for some and is, perhaps, a narrow way of dealing with the epidemic. Certainly, condom usage is critical, and should be the responsibility of the male partner as well, but well-informed, confidential testing with informed consent is absolutely critical in order to educate and inform patients of their present and future health status.

### **Education and Community Health Services**

A heroic education job is needed in order to achieve voluntary, well-informed HIV testing. Mandatory testing,

such as has been instituted in New Jersey for pregnant women, is hopefully the method of last resort; unless such mandatory testing is done across the board, it is discriminatory against pregnant women and women of color who have higher fertility rates. Mandatory testing is *not* the answer.

There are a number of tremendous discrimination issues that arise when looking at this epidemic. Approximately 80% to 85% of the women infected with HIV are black women and Latinas.<sup>5</sup> This is not a reflection of genetic inferiority, rather it is the result of conditions of poverty. Wherever the extreme conditions of homelessness, joblessness, poor health, etc. exist, the general health of the population, including its immune status, will be depressed. Therefore, the assault by a virus, such as HIV, is more devastating than it would be in people who are not immune-compromised.

Also, because the epidemic of HIV has hit the inner cities hardest, and has affected people of color disproportionately, it is important for educational efforts to be conducted with a particular emphasis on inner city education. This education must be culturally relevant and in an appropriate language. Also, needless to say, broad public education policies at the federal, state, and local levels are absolutely critical, regardless of their policies on testing:

The historical role that the mass media has played, in hyping the HIV epidemic and in targeting gay men and IVDUs as the main source of infection, must be reversed, and an understanding of current medical, nutritional, and social therapies to slow the disease must be broadly disseminated. HIV disease should also be classified as a chronic disease in order to significantly change how it impacts on the public.

How do we, as health professionals and those concerned about the general well-being of black women, approach the HIV problem? The role of education should not be underestimated, however we must also look at how services are provided for women infected with HIV. There is a tremendous need for the medical profession, not only to understand this disease medically, but also to understand the social and ethical consequences of being labeled as infected with HIV. For this to happen, there must be training of medical staff at all levels. Access to services, medical and social, is also a burning issue. There is a need for services at the community level. Primary care clinics and services, not necessarily attached to hospital settings, must be developed and expanded. The use of neighborhood health centers for the diagnosis and treatment of asymptomatic and symptomatic women is one of the ways this epidemic could be controlled. These facilities have shown their receptivity in the community as centers of medical care, and offer social interventions that are trusted by the community in inner city and poor neighborhoods. It is therefore logical and necessary that they be utilized for HIV patients.

To ensure that community clinics are able to deliver HIV services in a caring and culturally sensitive way, it is necessary first to train the staff — from receptionists to janitors to directors — in the nature of HIV infection. This training must be continuously done, and

continuously updated, given the rapid expansion of knowledge surrounding treatment of this disease.

Above all the medical profession, and society in general, must not seek to place blame for this disease on any sector of the population. As in previous assaults on women's reproductive freedom, it is women of color and the poor who are most affected by such scapegoating.

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# LATINAS AND HIV/AIDS

## Implications for the 90s

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### The Demographics

As we enter the second decade of the AIDS epidemic in the United States, greater attention is being focused on the so-called "changing face of AIDS," the new faces of the epidemic. These references are made in relation to communities of color, intravenous drug users (IVDUs), women, and children, in AIDS literature, in public health circles, and among activists. The reality is that the face of the epidemic has *not* changed. In the case of Latinos, for example, *AIDS is not a new phenomenon*. In the Latino community, what is new is the attention from the government, media, research community, and AIDS service establishments.

The Latino community, which represents 8% of the U.S. population, has been disproportionately affected by HIV/AIDS since the early days of the epidemic. Cases of Latinos with AIDS were identified as early as 1982, when they accounted for 14% of the U.S. AIDS cumulative cases.<sup>1</sup> Today, on a national level, they account for 16% of cumulative AIDS cases.<sup>2</sup> In New York City, which alone accounts for 30% of nationally-diagnosed cases of AIDS among Latinos, they presently account for 27% of the cumulative AIDS cases,<sup>3</sup> and it has been projected that they will account for 34% by 1993.<sup>4</sup> Within the Latino community, men account for close to 90% of the cumulative AIDS cases nationwide; 83% in New York City.<sup>2,3</sup>

Although the majority of people with AIDS are males, within this past decade the proportion of cases among women, particularly women of color, has dramatically increased from 3% in 1981 to a projected 10% by 1991.<sup>5</sup> Moreover, the distribution of AIDS cases by race and ethnicity starkly highlights the disproportionate burden borne by women of color. Nationally, women diagnosed with AIDS are overwhelmingly black (52%) and Latina (20%),<sup>2</sup> which sharply contrasts with the fact that they respectively represent 12% and 6% of the U.S. population.<sup>6</sup>

It is important to note that there has been a clear and unrelenting trend of spiraling cases AIDS cases among Latinas: from August 1989 to August 1990, there was a 53% increase on a national level in cumulative cases among Latinas; from October 1989 to October 1990 in New York City, there was an increase of 42%. Cases among Latino men showed increases for the same periods of 40%, nationally, and 30%, in New York City.<sup>2,3</sup>

AIDS is differentially present among the Latino subgroups which represent the total Latino population in

the U.S. In a study conducted in 1989 by Selik, Castro, and Pappaioanou, the case incidence of AIDS in heterosexual IVDUs in Puerto Rican-born persons was documented as several times greater than that in other Latin American-born persons. Among persons born in Mexico, Cuba, and other Latin American countries, the proportion of cases in heterosexual IVDUs was 10% or less. Among Puerto Rican-born persons, the proportion of cases ranged from 32% in the south and west, to 52% in the midwest, to 61% in the northeast.<sup>7</sup>

In a study conducted by Barbara Menendez et al from 1981 to 1987, in regard to AIDS mortality among Puerto Ricans and other Latinos in New York City, Puerto Ricans represented the racial/ethnic group most severely affected by the HIV/AIDS epidemic. Cumulative age-adjusted AIDS mortality rates were found to be higher among Puerto Rican-born males (362 per 100,000) when compared with black (267), other Latino (217), and white (182), males. Among Puerto Rican-born females, the mortality rates per 100,000 were significantly higher (59) than other Latina (25) and white (14) females, but reflected a similar pattern to the rates among black females (56).<sup>8</sup>

The differential impact of HIV/AIDS on women of color is further crystallized by a recent study published by the Centers for Disease Control (CDC) on the mortality rates in women of reproductive age in the U.S. The findings of the national study, which examined the mortality of women ages 15 to 44, for the period from 1980 to 1988, indicate that between 1985 to 1988, HIV/AIDS became one of the 10 leading causes of death among women of reproductive age. Comparisons made on race-specific death rates indicate that the rate of death in 1988 as a result of HIV/AIDS in black women, ages 15 to 44, was nine times the rate of white women of the same age.<sup>9</sup>

Unfortunately, although it is a well-known fact that Latinas comprise a disproportionate percentage (20%) of the women diagnosed with AIDS nationally, the study failed to include Latinas in the analysis. Further, in New York City, Latinas represent more than one-third of the cases of women with AIDS, and nearly one-half (48%) of the total U.S. Latina AIDS cases. Finally, *AIDS is the leading cause of death in New York City among Latinas ages 25-34*.<sup>10</sup>

The failure to include a disproportionately affected group of women in a major study, which has broad implications for public policy, was clearly an egregious oversight. Nonetheless, the study's findings raise critical

issues and concerns regarding public policy response to women, particularly women of color, those most adversely affected by this monumental health crisis.

The accelerated growth of HIV/AIDS among Latinas is not just a question of numbers. Behind every statistic, there are thousands of women who are finding themselves devastated by the unrelenting course of this disease. Moreover, by virtue of their multiple roles in society — as lovers, wives, mothers, and caregivers — the impact of HIV/AIDS on them has a rippling effect on whole families, and ultimately on entire communities.

### **Socioeconomic, Cultural, and Political Factors Which Place Latinas At Risk**

Given this context, the issues related to HIV/AIDS among Latinas must necessarily be examined within a comprehensive framework. It must be one that accounts for the social, economic, cultural, and political factors that set the stage for, and contribute to, escalating rates of HIV infection and AIDS, and that further compromise survival rates once AIDS has been diagnosed. Strategies intending to stem the spread of HIV/AIDS among Latinas cannot be solely focused on promotion of safer sex and/or risk reduction related to IV drug injection. In addition, prevention approaches must address the economic, social, and environmental factors which impact on the very behaviors that are targeted for change.<sup>11</sup> The conditions and circumstances that place Latinas at greater risk for HIV infection, such as: poverty, substance abuse, lack of access to primary health care, late or no prenatal care, the increase in STDs, high rates of adolescent pregnancy, and culturally-prescribed gender roles and sexual attitudes, are clearly related to the socioeconomic and political disempowerment and disenfranchisement they experience.

Poverty, and the living conditions concomitant with it, set the stage for the poor health status of Latino communities. Their vulnerable position in the face of the HIV/AIDS epidemic is largely due to the fact that they are the poorest ethnic group in the U.S. In 1979, there were 2.9 million poor Latinos living in the United States; by 1987, this figure rose to 5.5 million. In less than 10 years, the ranks of the Latino poor expanded by nearly 90%.<sup>12</sup>

At highest risk for poverty, however, are Latina-headed households, which represent 23% of the total Latino households. Nationally, more than 50% of these households are living below the poverty level; 61%, in New York City.<sup>12</sup> Compounding the problem is the fact that the national fertility rate among Latinas, ages 15 to 44 years, is 42% higher than that of non-Latina women. In a study of the tri-state area of New York, New Jersey, and Connecticut, 38% of single women, with five or more children, were Latinas.<sup>13</sup>

Poverty in the Latino community leads to lack of access to quality health care and is conducive to the transmission of HIV: poor people, with already compromised immune systems, do not receive adequate care; they receive disease prevention information too late; they forego treatment of sexually transmitted diseases (STDs); and they do not receive adequate treatment for substance abuse.<sup>11</sup> The relationship between poverty

and the lack of access to quality health care is clearly presented in the following quote from the New York City AIDS Task Force Report:

...An increased proportion of the City's population is poor. The economic profile of New York City in 1989 is one in which 25% of all New Yorkers and 40% of New York's children live in poverty. The problem of providing appropriate health care services is exacerbated by poverty. In general, persons living in poverty are more frequently ill. Moreover, they have well-documented difficulty in gaining access to primary health care services due to financial or other obstacles. As a result, they are compelled to rely on the most expensive forms of care—emergency rooms and inpatient hospital services.<sup>14</sup>

Exacerbating the lack of access to quality health care is the fact that Latinos are the ethnic group least likely to have health insurance; approximately 33% lack private insurance or Medicare/Medicaid, as compared to 11% of the general U.S. population.<sup>15</sup> Because of the lack of adequate health insurance, Latinos historically have relied on public hospitals, and their emergency rooms and clinics, for addressing their health care needs. Unfortunately, however, the AIDS epidemic has already overburdened, and threatens to topple this inadequate public health care system. In New York City, for example, 43% of the city's Latinos receive both primary and acute inpatient care in the municipal hospital system,<sup>16</sup> but this system presently is on the verge of collapse due to diminishing resources and ever-increasing demands. Also, all too often, Latinos go to emergency rooms for care only after they have progressed to full-blown AIDS — when the benefits of early interventions are no longer of use to them.

### **Other Factors That Put Latinas at Risk**

Other health and social factors, inextricably tied to their socioeconomic class and gender status, place Latinas at further risk for HIV/AIDS. Among the complex problems associated with rising cases of HIV infection among Latinas are substance abuse; the absence of, or late, prenatal care; adolescent pregnancy; and culturally-prescribed gender roles.

**Intravenous Drug Use and Perinatal Transmission.** IV drug use presents a significant threat to the Latino community because of its critical role in the transmission of HIV infection. National statistics and New York City surveillance data indicate that IV drug use accounts for 40% and 54%, respectively, of AIDS cases among Latino adults. Among Latinas, IV drug use is the primary mode of transmission (51% nationally, 60% New York City). The threat is even greater when we consider that maternal transmission of HIV in Latino pediatric AIDS cases is overwhelmingly related to IV drug use. Nationally, 53% of maternal transmission cases among Latino children has been attributed to IV drug use by the mother; 31% to maternal sexual contact with an IVDU. In New York City, 78% of perinatally-transmitted cases among Latino children have been related to IV drug use, either directly (58%) or through maternal sexual contact with an IVDU.<sup>17, 18</sup> There is little information available that provides us with a good grasp of the incidence of IV drug use among women in the U.S., let alone among

Latinas. However, the National Institute on Drug Abuse estimates that there are 350,000 to 400,000 IV heroin users in the U.S., and approximately one-third are women.<sup>19</sup> In New York City, it is estimated that there are 200,000 IVDUs, 35,000 of which are in drug treatment; in New York State, Latinos represent 34% of the IVDUs in drug treatment.<sup>20</sup> Women are traditionally underrepresented in drug treatment facilities, and, more importantly, drug treatment programs have not begun to adequately address reproductive health, and the provision of treatment for pregnant addicts or women with children,<sup>21</sup> issues of great importance to women. The inadequacy of the drug treatment system, in respect to women, is now contributing to the rise in HIV infection and AIDS among Latinos, who are disproportionately represented among IVDUs in the nation and in New York City. Prevention strategies that focus solely on reducing the risks to HIV related to injection of drugs and needle-sharing behaviors, but which do not focus on the need for increased treatment slots for women, particularly pregnant women or women with children, will fall short of what is required to address this serious problem.

**Prenatal Care.** Poor Latinas, as a group, have a higher percentage of late or no prenatal care (40% in New York City). Inadequate prenatal care is a serious health problem. It is associated with low newborn birthweight, high infant mortality, and higher rates of newborns with birth defects. The statistics for subgroups of Latinas, such as Puerto Ricans for example, reflect a very serious health care issue. About 57% of Puerto Rican women begin receiving prenatal care during their first trimester, of pregnancy; 16% do not begin prenatal care until their third trimester as compared with 4% of white non-Latina women; approximately 9% of Puerto Rican newborns have low birth weights, as compared to 5.5% of white newborns; in New York City, Puerto Rican infants are twice as likely to be low birthweight babies as are white infants (10% and 5.5% respectively).<sup>22</sup>

The implications of late or no prenatal care are critical in terms of HIV infection. Given the high incidence of maternal transmission of HIV to children among Latinas, the lack of adequate prenatal care serves to further compromise the health of the mother and the unborn child. HIV infection also may be diagnosed late in the pregnancy, or not at all, and thus delay appropriate and early medical intervention and management for both the mother and the unborn child.

IV drug-injecting women have a high rate of pregnancy and a low utilization rate of prenatal care. The high pregnancy rates are due, in part, to the lack of use of birth control methods; irregular or missing menses due to drug use that leads to the false assumption that pregnancy cannot occur; a tendency to deny pregnancy until it is too late to have an abortion (if this option is chosen); and the inability to obtain an abortion if one is opted for and possible.<sup>23</sup> As previously stated, substance abuse treatment programs have been unresponsive to the needs of pregnant addicts. In April 1990, for example, the American Civil Liberties Union filed a class action suit on behalf of three pregnant women who sought treatment and were turned away from four drug

treatment programs in New York City.<sup>21</sup> The lawsuit further highlights the lack of services available to pregnant addicts, who generally lack both drug treatment and prenatal care.

**Adolescent Pregnancy.** The problem of HIV infection among adolescents has not received enough attention. Although adolescents represent less than 1% of all diagnosed AIDS cases in the U.S.,<sup>17</sup> because of the long incubation period prior to the diagnosis of AIDS, it has been projected that many adolescents who become HIV infected may not be reported until their early twenties.

Latino adolescents account for approximately 18% of the cases of AIDS reported among 13 to 19 year olds. A greater percentage of AIDS cases are found among the 20 to 24-year age group, and within this group, Latinos account for 18% of the cases. The proportion of female AIDS cases among adolescents (25%) is much higher than female cases among adults (10%). Of Latinos, ages 13 to 19, females account for 21% of diagnosed AIDS cases.<sup>17</sup> These statistics are alarming. However, when they are considered within the context of the high rates of adolescent pregnancy among Latinos, they are frightening.

According to the National Survey of Family Growth, births to adolescents account for 17% of the births to Latinas, with rates highest among Puerto Rican and Mexican American teens. A study of contraceptive and sexual practices, conducted by The Alan Guttmacher Institute, found that 50% of Latinas, between the ages of 15 to 19, had sexual intercourse before the age of 16. Although 68% of Latina adolescents used contraception, only 23% used contraception at first intercourse, a practice which could place them at high risk for HIV infection, particularly when one considers the low rate of condom utilization among Latino youth.<sup>24</sup>

**Sexually Transmitted Disease.** The increase in STDs is also associated with greater risk for HIV infection. In the past several years, there have been dramatic increases in the rates of primary and secondary syphilis reported in the United States. In 1987, for example, there was a 25% increase in cases of primary and secondary syphilis reported over the 1986 cases. Among Latinas, the rates increased from 17.8 to 22 per 100,000 persons in a single year.<sup>25</sup>

### **Culturally-Prescribed Gender Roles and Condom Use**

Another factor which is important to consider in understanding the high risk of HIV infection among Latina women, is the impact of culturally-prescribed gender roles. Authors such as Marin and Acuña-Lillo have pointed to the double standards for sexual behavior prevalent in traditional Latino cultures. Sexuality is viewed as private and personal, and discussions of sexual matters are considered taboo. Many Latina women are socialized without a clear understanding of their sexuality, and are not knowledgeable about their bodies and sexual responses. Their sexual roles are often viewed within the context of procreation and giving pleasure to their male partners. Moreover, in traditional Latino culture, a "good woman" is not expected to be knowledgeable about sexuality, nor is she expected to

raise topics such as condom use. Men, on the other hand, are expected to be knowledgeable about sexuality and to initiate sexual contact at an early age. While the ideal woman is expected to be chaste and sexually faithful to her mate, men are allowed to have sexual intercourse outside of the marriage.<sup>26,27</sup>

*"Single-sided strategies, which focus on the promotion of prevention and risk reduction, may be ineffective if women are not provided with the means and real options to introduce such behavioral changes into their lives. Empowerment of women must therefore become a key element of risk reduction."*

Condoms have been traditionally viewed by Latinos as a method of birth control or as a means of preventing infection with STDs with women outside of the marriage or a stable relationship. Many Latino men associate condoms with prostitutes and, as such, respond negatively to their introduction into their sexual relationship by a wife or a lover. Given the strong emphasis on procreation within Latino culture, and the prohibition of contraceptive use by the Catholic Church, one would assume that Latinos would be less likely to use contraception than other groups. But, according to Marin, Latinos are as likely as non-Latinos to be users of birth control, but they are less likely to use condoms. The 1986 National Center for Health Statistics report indicated that there was 14% utilization of condoms among married Latinas, as compared to 25% utilization among non-Latina married women.<sup>28</sup>

The implications of lower utilization of condoms among Latinos is a critical issue when viewed within the context of prevention and risk-reduction strategies for women that promote condoms as a barrier to HIV infection. Many prevention campaigns have focused their messages on women, appealing to them to use condoms and to negotiate condom use with their male sexual partners. In placing the onus on woman for risk reduction, such strategies have shown little recognition of the subordinate position of many women who are economically and emotionally dependent on their male sexual partners. They have failed to recognize that, for women who are in subordinate relationships with their sexual partners, negotiation of safer sex is not an option. If a woman is economically and/or emotionally dependent on her male sexual partner, she will be hard-pressed to insist on condom use when her partner is not in agreement. In fact, women have often been subjected to verbal and physical abuse in these situations, and they have had to comply with their partner's demands for unprotected, penetrative sexual intercourse in order to avoid further abuse or the loss of their partner's economic and/or emotional support. Traditionally-socialized women also may be reluctant to introduce condoms into their stable relationships with their male partners, for fear that they will be suspected of infidelity or viewed as promiscuous. The association of condoms with contraception also may raise a direct conflict for women who

have strong desires to fulfill their procreative roles or who are pressured to do so by their sexual partners and families.

In her discussion of the promotion of condom use among Latinos as an HIV/AIDS prevention strategy, Marin recommends that campaigns be targeted to heterosexual men rather than women. Considering that the Latino cultural dimension of machismo (particularly male dominance and double sexual standards) has been viewed primarily as a barrier to HIV/AIDS prevention, Marin suggests that an appeal could be made to the more positive dimensions of machismo which emphasize the male's responsibility for the protection of the family. Messages, which frame HIV/AIDS as a threat to the family and therefore promote condom use by the male — as a demonstration of his concern and an enactment of his role as "protector" — may prove to be a more effective preventive approach.<sup>29</sup>

Single-sided strategies, which focus on the promotion of prevention and risk reduction, may be ineffective if women are not provided with the means and real options to introduce such behavioral changes into their lives. Empowerment of women must therefore become a key element of risk reduction. In addition, strategies to promote condom use among Latinos must be developed within the context of an understanding of the variations of sexual-role traditionalism and assertiveness among Latinas. In a study of the effects of acculturation on sexual-role traditionalism and assertiveness among Puerto Rican women living in the U.S., Soto found that a person's generation (first versus second), and education, is significantly related to sexual-role traditionalism. Specifically, second-generation women, and better-educated women, are less gender-role traditional. Gender-role traditionalism is also associated with assertiveness. The more gender-role traditional the woman, the more difficult it is for her to initiate behavior, to express opinions, and to assert herself in public and in private with friends and intimates.<sup>30</sup> The findings of this study are useful when planning prevention or education strategies that take into account the differential levels of sexual-role traditionalism and assertiveness among Latinas, and their levels of acculturation and education. The findings also challenge the widely held notion that all Latinas are passive and nonassertive in their interactions with others — particularly men — and therefore are unable to assume an active role in practicing safer sex.

### **The Issue of Reproductive Rights**

One of the major concerns that arises, regarding HIV infection and AIDS among women, is the potential for abuses of reproductive rights. Amaro, in her article on these issues highlights the major areas of concern:

HIV infection and AIDS is fertile soil for encroachment on the reproductive rights of women in general. The entrenchment of the rights of women has been facilitated by the public's fear of AIDS, the stigma associated with the illness, and by the fact that AIDS is a public health problem that affects women who are disenfranchised, not only because of their sex but also because of their social class, ethnicity, and addiction.<sup>31</sup>

Chavkin, in her analysis of HIV/AIDS prevention and reproductive rights, points out that government-sponsored HIV/AIDS prevention programs, targeted to women in their reproductive years, focus on the vertical transmission of HIV infection from mother to fetus, and give little attention to the health care needs of the woman as a person. The focus on testing women in family planning and prenatal care clinics is based on a rationale that identifying seropositive women will provide public health providers with an opportunity to offer early interventions, and to avoid future pregnancies. And, if the woman is pregnant, it would also offer the opportunity to provide comprehensive medical care and to initiate early therapeutic interventions with future children.

An underlying danger in these approaches, however, is that health care providers may overtly, or covertly, promote reproductive decisions (contraception, sterilization, and abortion), that conflict with a woman's religious beliefs and deeply valued procreative needs, in the spirit of preventing vertical transmission of HIV infection to children.<sup>32</sup> It is important that prevention strategies and approaches be carefully evaluated to ensure that women's reproductive choices are safeguarded, and that they are not consciously or unconsciously coerced to make choices that are in direct conflict with their needs, values, and beliefs. This is a critical issue for Latinas, given the long documented history of the violation of their reproductive choices and rights where there have been major efforts to control population growth, as in Puerto Rico and other third world nations.<sup>33</sup>

### Conclusion

The challenges for prevention of HIV infection and AIDS in the second decade of the epidemic raise a variety of social, economic, political, cultural, and civil rights issues.

The AIDS epidemic among Latinas must be viewed and responded to within a comprehensive framework, that takes into account the social, economic, cultural, and political factors that contribute to increasing rates of HIV infection and AIDS. Preventive strategies must address the impact of socioeconomic class, gender, and political disempowerment and disenfranchisement, access to health care, and the high risk of infection. Strategies that do not take into account the socioeconomic and political realities that Latinas must confront on a daily basis will fall short in preventing HIV infection and in stemming the epidemic.

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## ***SIECUS Dedicates This Issue...***

We have been living with AIDS for 11 years. As we continue to educate, counsel, and advocate, as we work to foster prevention, compassion, and nondiscrimination, we must forever remember why we are so driven. And so, this issue of the *SIECUS Report* is published in celebration of the lives of our brothers and sisters who have died of AIDS-related illnesses. That they lived is truly cause for great celebration. That they died will always be cause for grief, anger, and frustration. May their lives fuel our commitment to end the ravages of this epidemic.

The SIECUS staff and board of directors would like to especially remember the following friends and family:

**Melvin Boozer  
Raul Campanioni  
Joseph Dilorio  
Reverend Raymond Harrison  
Stuart Jacobsen  
Eddie King  
Stewart McKinney  
Frank Ponce  
Bill Tatum  
Bill Travis**

... And all the women who have died of conditions not recognized as related to HIV illness.

## **Critical Cultural Barriers That Bar Meeting The Needs of Latinas**

**Aliza Lifshitz, MD**

Member, Los Angeles Commission on AIDS  
Member, Board of Directors, California Hispanic  
American Medical Association

**A**lthough more than 2,700 Latinas (20% of all women) have been diagnosed with AIDS, and many thousands more are infected with HIV, they remain largely invisible to health care professionals. Among infants born with HIV disease, Latino children are also disproportionately represented.<sup>1</sup>

It is therefore important for health care workers and health educators to recognize that efforts to identify and educate Latinas at risk of exposure to HIV are largely failing.<sup>2</sup> Although language barriers play a part, cultural barriers are the primary cause of this failure.

### **Sexual Privacy**

In all sectors of the Latino community, sexuality is intensely private. Often sexual issues are not discussed even between sexual partners. I recall the sad case of a Latina who found out she was infected with HIV after she delivered her baby. The baby developed symptoms that prompted physicians to test for the HIV antibody. This woman was aware that her husband went out with "the guys," but even though she knew deep down in her heart that he might have been with other women at these outings, she never confronted him. The woman was horrified when she realized that his outings had infected them all. What was even more difficult for her to cope with was the fact that her husband knew he was infected when they got married, and that he had done nothing to protect her or their child.

In the traditional Latino culture, the "good" woman is not supposed to know about sexuality. And she certainly is not supposed to make assertive decisions in her sexual relationship — her partner, her family, the Catholic Church, and the community are the primary forces dictating appropriate sexual behaviors.

### **The Catholic Religion**

The Latina's intense faith in the Catholic religion has been a source of strength for both herself and her family; however, because the Catholic Church prohibits the use of condoms, her devotion may now have fatal consequences. Counselors and health care providers, nonetheless, must be very careful to show respect for the Latina's religious faith — while at the same time, encouraging her to see that a condom can be used for intentions other than contraception. She must understand that it can be used to prevent STDs, and that using a condom in the case of HIV infection may be a matter of life and death.

### **The Family**

One of the Latina's primary motivations for staying



healthy is to be able to continue caring for her children. Anything that jeopardizes her life also jeopardizes the well-being of her offspring. That awareness may provide the leverage that could persuade her to reconsider her feelings against condom use.

It is also important to add that in developing HIV prevention counseling strategies, one needs to emphasize the need to choose a "safe partner," not just the need for "safe sex." People should not be given the impression that they are 100% protected if they use a condom, especially if they are with someone who engages in high-risk behaviors or who is infected with HIV.

*"HIV/AIDS strikes at the Latino community in the context of poverty and drug use — complex social phenomena that, along with the disease itself, affect the entire family."*

### The Community

Latinas must be provided, not only with information on how to protect themselves, but also with the negotiation skills that will enable them to act on it. The success of such communication may depend largely on how well the health care worker or educator is able to meet the social expectations of the Latino community. Critical social expectations of the community that must be understood are:

**Simpatia.** Simpatia mandates politeness and respect and discourages assertiveness, direct negative responses, and criticism. Any HIV prevention activities that involve confrontation will be interpreted as inappropriate.

**Personalismo.** Personalismo refers to a preference by Latinos for relationships with others in their own social group. In practice, *personalismo* means that Latinos are more likely to trust and cooperate with health care workers whom they know personally, and with whom they have had pleasant conversations. These talks are often referred to as *la platica* by Mexican-Americans.

**Respecto.** Respecto is the need to demonstrate respect, especially for authority figures. It also requires that personal integrity be maintained in interaction with others. Out of *respecto*, however, Latinos are extremely reluctant to question authority — even if they do not understand what the authority is telling them. HIV educators must not assume that silence equals understanding or accord.

HIV/AIDS strikes at the Latino community in the context of poverty and drug use — complex social phenomena that, along with the disease itself, affect the entire family. One of my patients, a 23-year-old woman, who was exposed to the virus through IV drug use, recently was diagnosed as infected with HIV. Her family, originally from Puerto Rico, was abandoned by her father when she was very young. Her two brothers, both slightly older, were drug users. Both are now dead: one died of AIDS; the other in a gang shooting. The woman's mother is in terrible emotional pain and in complete disbelief that all three of her children are either dead or dying. It is unlikely that any member of

this family received adequate routine medical care — a luxury few Latinas can obtain for their family or for themselves.

### Health Care Workers Must Seize Every Opportunity to Make Contact with HIV-Infected Women

Because of situations, such as the above, it is crucial that health care workers, including physicians, seize every possible opportunity to make contact with women at risk of HIV infection. Professionals working in STD clinics, prenatal clinics, and drug treatment programs that serve the Latino community, must expand their care to include risk assessment and appropriate counseling and referrals for every client or patient. Both the Centers for Disease Control and the American College of Obstetricians and Gynecologists now recommend counseling and testing of women at risk for HIV infection as a standard of prenatal care.<sup>3,4,5</sup> Hopefully, this will become the standard for all care.

Unfortunately, to date, however, denial on the part of patients, compounded by denial on the part of health professionals, has contributed significantly to the spread of HIV, particularly within communities of color. It is extremely pervasive among Latino health care providers. Most Latino physicians are Catholic and share moral values that make it difficult to discuss sexual issues or to support the use of condoms. Moreover, although homosexuality, bisexuality, and IV drug use are prevalent in the Latino community, they are strongly stigmatized and are adamantly disavowed by the community.

If efforts to prevent the transmission of HIV disease to Latinas and their unborn children are to be successful, health care providers must learn to overcome the cultural barriers that bar prevention messages from getting across. Time spent in the community — time spent listening — will be invaluable in this regard. Social workers, mental health and health professionals, also must seek out women of color who are at risk for HIV infection — women who have been, for too long, an invisible community to HIV treaters. Unless steps are taken to bring them into the treatment fold, prevention strategies, and early intervention treatment options will have little value in the very communities where they are most needed.

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# LESBIAN EXCLUSION FROM HIV/AIDS EDUCATION

## Ten Years of Low-Risk Identity and High-Risk Behavior

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**L**esbians need HIV education. They are in waiting rooms across America — waiting. More and more HIV infection among lesbians is showing up in clinics across America, yet lesbians remain an enigma to most health professionals and continue to be excluded from HIV/AIDS education.<sup>1,2</sup> Unfortunately, the history of HIV/AIDS has taught us that the longer a group is excluded from education, the more likely infection rates within that group will rise.

The term "lesbian" is used in different ways by public and mental health professionals, and its definition has long been a source of debate among women who self-identify as lesbians. Though most health professionals use the term "lesbian" to describe women who engage in sexual activities exclusively with women, for the purposes of this article the authors would like to broaden this definition to recognize, not only women who self-identify as lesbian, but those who engage in sexual activities with both women and men (bisexuals), those who assert a sexual desire for women but do not self-identify as lesbians, and those who may have, or have had, a sexual experience with another woman. The labels, "lesbian," "bisexual," "gay," and "homosexual," moreover, are used by some scientists to define sexual behaviors only, while lesbians, bisexuals, and gay men use the labels to define themselves, their sexuality, and their communities. AIDS education that ignores lesbians, or supports the notion that lesbians only have sexual contact with women, may be obscuring the various sources of risk in a lesbian's life and may unwittingly be supporting the reluctance of lesbians to confront their personal risks.

A lesbian can become HIV-infected the way any woman can: some lesbians engage in oral, vaginal, and anal intercourse with men by choice, force, or necessity; some use drugs and share needles, some have blood transfusions, some are artificially inseminated, and some exchange blood and vaginal secretions during sexual contact with women.

It will not be sufficient to simply include lesbians in HIV/AIDS educational materials by tacking on a few lines about dental dams. Lesbians need full institutional support and recognition. Only then, will those categorically dismissed as "low risk" be able to protect themselves and those they love.

### **Lesbians with AIDS**

In order to justify the inclusion of lesbians in HIV

prevention models, most journals, educators, scientists, and funding sources want numbers. How many lesbians have AIDS? How many lesbians are HIV infected? The latter question has not been answered adequately for any group, but the Centers for Disease Control (CDC) has consistently estimated that 1 to 1.4 million people in the U.S. are infected.<sup>3</sup> There is no way of knowing how many of these people are lesbians.

The CDC defines a lesbian as a woman who has reported "sex relations exclusively with females since 1977." According to the CDC, as of September 30, 1989, there were 79 reported cases of lesbians with AIDS; there have been 103 reported cases of AIDS in bisexual women (women who reported sexual contact with both males and females after 1977). There have also been 1,242 women with AIDS, who could not be classified as lesbian, bisexual, or heterosexual because of incomplete responses.<sup>4</sup>

The CDC uses a hierarchy of exposure categories to determine HIV transmission data of AIDS cases in the U.S. If a woman has more than one possible exposure, she will be categorized by the highest risk only. If a man has more than one possible exposure from drug use or sexual contact, he will be listed in an exposure category, such as: IV drug use (heterosexual) or male homosexual/bisexual contact and IV drug use.<sup>4,5,6</sup> The CDC's hierarchy of exposure for women is as follows:

1. Intravenous drug use.
2. Recipient of blood products.
3. Heterosexual contact with an HIV-infected partner (or having specific risk for HIV).
4. No identified risk.<sup>4</sup>

If a lesbian is raped, she does not stop being a lesbian, but if that lesbian develops AIDS, she is not counted as a lesbian with AIDS.

Female-to-female transmission is not classified as a possible exposure category in CDC surveillance data. Even though a case of female-to-female transmission was reported as early as 1984, such cases are counted in the "no identified risk" category. It is important to note that the percentage of "no identified risk" for women is *double* that of men.<sup>4,7</sup> Clearly less is known about women's risk than about men's risk.

The only existing references the authors have found on female-to-female transmission have been in letters or short monographs printed in medical journals.<sup>8,9,10,11</sup>

Anecdotally, however, the authors, most women's AIDS organizations, large AIDS service providers, and long-time HIV counselors have seen cases in which female-to-female transmission has occurred.<sup>1</sup>

### **Isolation and Lesbian Communities**

In communities long disenfranchised from the health care system, single-issue HIV/AIDS prevention programs are not working. Blacks, Latinos, Native Americans, Asians and Pacific Islanders have eloquently challenged the public health establishment to recognize that effective HIV/AIDS education must not ignore key survival issues, such as poor health care, unemployment, drug dependency, poverty, and violence. All lesbians belong to racial and ethnic communities, but their particular experience of being a lesbian in those communities may not be reflected in the communities' culturally-appropriate HIV/AIDS prevention strategies. The degree of invisibility and isolation that lesbians confront in the racial, ethnic, and religious communities from which they come, and in the health fields, has put lesbians with AIDS and HIV infection in tremendous crisis.

Recognizing cultural diversity has become an essential tool for developing effective HIV/AIDS education. To recognize a culture is to recognize the community's particular social mores, as well as its relationship and contribution to the world. It is important to acknowledge lesbian culture as reflected in the many, and varied, lesbian communities throughout the country. As throughout American society, there are deep divisions among these communities along racial, class, and generational lines, and there are further divisions because of different abilities and sexual practices. Lesbian communities and racial and ethnic communities may also overlap and intersect. In addition, there are lesbians who do not identify with any community. One of the challenges in targeting lesbians in HIV/AIDS education is to develop ways of addressing all women who engage in sexual activities with other women, whether they identify with a community or not.

By ignoring, not only the complexity of the lives of lesbians, but lesbians themselves, AIDS educators and community organizers help perpetuate a long history of neglect, by the society in general, and by the medical and scientific research establishment in particular. The little attention that has been paid lesbians in the past has usually been biased, and for lesbians with or at risk for HIV/AIDS, such bias and stigma can be life-threatening.

Most HIV/AIDS prevention education is based on assessing one's risk and then reducing that risk in the future. For those officially at "low risk" the options have yet to be elaborated. In the early 1980s, public health officials assumed that groups of easily-labeled individuals: gay men, Haitians, men with hemophilia, and intravenous drug users (IVDUs) would develop AIDS.<sup>12</sup> By the end of the decade, health officials accurately asserted that behavior, not identity, was the key to risk assessment, nonetheless the legacy of 'risk groups' labeling has remained entrenched in the public's imagination. Most people still believe that if they know or limit the number of partners they have, they will not be at risk for HIV. Learning the facts about HIV/AIDS has

proved to be a much easier task than connecting that information with one's own risk.

A lesbian's false sense of security, that she belongs to a safe group of people who are not and cannot become infected, is perpetuated by almost everyone working in AIDS prevention. Stephen Joseph, former health commissioner of New York City, stated, while in office, that the New York City Department of Health Surveillance Unit keeps no statistics on lesbians, and does not intend to, because they are not at risk.<sup>13</sup>

### **Lesbians At Risk for HIV/AIDS**

Public health educators and counselors continue to believe that lesbians do not engage in behaviors that put them at risk for HIV. They and others believe a number of dangerous myths that lead to lesbians receiving little or no HIV/AIDS education. Among them are:

1. Lesbians do not have much sex.
2. The kinds of sexual activity lesbians engage in are not risky.
3. Lesbians do not have sexual intercourse with men.
4. Lesbians do not become pregnant.
5. Lesbians do not use drugs.
6. Lesbians do not trade sex for money or drugs.

Although some lesbians do not frequently engage in sexual activity as myth number one suggests, a study of 800 women, 400 of whom self-identified as lesbians, stated, "Lesbians reported having sex more often...and with a greater number of partners."<sup>14</sup> This study, in fact, found that lesbians had twice as much sexual contact as nonlesbian women, and had 15 times as many partners as nonlesbian women.

**Sexual Contact with Women.** Theoretically, lesbians can be at risk for HIV transmission from a variety of sexual activities with HIV-infected female partners because of the exchange of infected blood and vaginal secretions.<sup>10,15</sup> A commonly identified lesbian sexual practice is cunnilingus. Many lesbians engage in cunnilingus during menstruation. For some lesbian couples oral sex is a mutual act, while for others only one partner is active. According to one study of 286 women, 87% have tried tribadism (genital to genital stimulation) and 25% have had experience with sadomasochism.<sup>16</sup> Many lesbians use and share dildos and other sex toys, engage in vaginal- and/or anal-digital intercourse, vaginal and/or anal fisting, rimming (mouth to anus), full body rubbing and more.

**Sexual Contact with Men.** A less-recognized route of transmission for self-identified lesbians is their sexual contact with HIV-infected males. In a recently published study of 262 self-identified lesbians, 75% had engaged in sexual intercourse with men during their lifetimes; 46% of those since 1980. Of the lesbians who reported engaging in vaginal-penile intercourse since 1980, less than 6% reported using condoms every time; of the 36 lesbians who reported engaging in anal-penile intercourse since 1980, only three always used a condom. The study also revealed that 32% of the lesbians who reported sexual contact with men indicated that they had engaged in vaginal and anal intercourse with gay and bisexual men

## OBSTACLES FACED BY LESBIANS AND ALL WOMEN INFECTED WITH HIV

All women infected with HIV face enormous obstacles. It is the authors' belief that women take care of the world, but the world does not take care of women. The inadequate medical response to women facing HIV/AIDS has only recently become public knowledge. The full range of issues faced by women deserves much more elaboration than the scope of this article can provide, but we will try to outline some of the most pressing issues. Here are the facts:

1. For every month a white gay male lives following diagnosis, a woman will live only a week.<sup>17,18,19</sup>
2. Women are systematically excluded from nearly all clinical trials for experimental AIDS treatments, for fear of fetal injury if she becomes pregnant.<sup>20</sup>
3. Women are systematically excluded from many treatment programs for alcohol and other drug treatment programs.<sup>21,22,23</sup>
4. Women are poorer than men, often have no, or inadequate, health insurance, and bear the majority of child rearing responsibilities.<sup>24,25</sup>
5. Women are diagnosed much later in the course of HIV illness than men.<sup>26</sup>
6. Very little research has been done on the course of HIV illness in women, which may be quite different than the much-studied male HIV illness, e.g., often appearing as aggressive yeast or PID infections or rapidly developing cervical cancers.<sup>27,28</sup>
7. Doctors may take women's symptoms less seriously than they take men's symptoms.<sup>29,30,31</sup>
8. Women are more likely to be misdiagnosed because it is often assumed that women do not get HIV/AIDS. (Between 1981 and 1988, there was an unexplained and significant increase in female deaths from pneumonia and influenza in many large eastern cities that may have been HIV-related.)<sup>32</sup>
9. Few AIDS services are designed to meet the needs of women.<sup>33</sup>

For a lesbian facing AIDS and HIV infection, there are additional obstacles as well:

1. Because doctors and lesbians alike do not believe that *lesbians have AIDS*, lesbians may be misdiagnosed or diagnosed even later in the course of HIV infection than other women.
2. There is a federal law to protect people with AIDS from discrimination, but only 11 cities in the U.S. protect a woman from losing her job, home, children, etc., because she is a lesbian.
3. The few places that offer women-specific services may not be lesbian-sensitive. Her isolation can be overwhelming.
4. Her parents and siblings may have previously severed any relationship because of their inability to accept her sexual orientation.
5. Her lover may be excluded or made to feel uncomfortable in family support groups, and the lack of recognition within the gay and lesbian community that lesbians can be HIV-antibody positive may make seeking support even more difficult.

To insure inclusion of all issues for women confronting HIV/AIDS, lesbians with AIDS and HIV infection — regardless of how they became infected — must be welcome in the development of all HIV/AIDS prevention strategies and follow-up support services.

since 1980.<sup>34</sup>

For the purposes of discussing AIDS education, it is important to recognize that sexual differences are particularly difficult for lesbians to discuss. For example, if a lesbian chooses to have intercourse with a man, she may not suddenly identify herself as a bisexual. The choice of a male sexual partner, or the "bisexual" label, may be perceived by her lesbian friends as an attack on the lesbian community. As a result, many lesbians therefore hide their sexual relationships with men. Similarly, choices about sexual practices, such as sadomasochism

or using sex toys, have also divided lesbians.

**Artificial Insemination.** Another risk of HIV infection for some lesbians is from artificial insemination. There are four documented cases in Australia and several in this country.<sup>35</sup>

**Drug Use.** Some lesbians are drug users.<sup>36,37</sup> "While the number of HIV-infected lesbian IVDUs may be relatively small, lesbians are in fact a significant subpopulation of IVDUs in many cities, one which may not be reached by prevention efforts aimed at either gay men or women in general."<sup>37</sup> The sharing of an IV needle with

an HIV-infected individual is a highly-recognized transmission risk, but snorting, drinking, injecting, popping, and smoking cocaine, alcohol, heroin, barbiturates, marijuana, and more, are often overlooked contributors to HIV transmission.<sup>38</sup> Judgment, control, ability, and the necessity for the drugs can be severely altered by the use of, and desire for, these substances. The ability or means to negotiate safe drug hygiene, i.e., clean needles, as well as safer sex, can be impaired. It is not uncommon for lesbian partners to share needles with each other because of cost, availability, and companionship.<sup>39</sup> Many drug users have learned ways to reduce the risk of HIV infection, but many more have not been reached by HIV education efforts. Little outreach has been targeted to lesbians with addiction problems, and few lesbians feel comfortable joining support groups that are heterosexually-identified or homophobic.<sup>40</sup>

**Homelessness.** As HIV counselors in New York City shelters, the authors have estimated that one-third of the female clients they have seen have been lesbians. Most of these women identified a primary relationship with a woman, but indicated that they had also exchanged sexual intercourse for money or drugs with men.

There is a disturbing silence about the number of homeless lesbians, which encourages the discrimination and neglect of a significant number of women. There have been no studies about homeless lesbians, but in her work with homeless gay and lesbian adolescents, Joyce Hunter of the Hetrick-Martin Institute in New York offers some clues as to their disproportionately high numbers. Many lesbians, she suggests, leave home because of their fear of, or experience with, physical, psychological, and sexual abuse which often stems from the abuser's knowledge of the adolescent's sexuality or they are forced out of their homes by their families.<sup>41</sup>

Abuse, addiction, poverty, and homelessness are a cyclical pattern, difficult to treat in the most supportive environment, and impossible to treat in a hostile one.<sup>42</sup> The level of hatred and bigotry directed toward lesbians in shelters, and on the streets, makes it nearly impossible to break this cycle. Many of our lesbian clients became HIV-infected while homeless. It is important, therefore, that lesbian HIV/AIDS prevention strategies include "the homeless cycle" as a transmission cofactor.

**Lesbians in Prison.** The level of bigotry is perhaps the highest towards lesbians in prison. The perception that if a woman engaged in sexual activities with a woman in prison, she was either forced (raped by a "lesbian rapist"), or was only going through a phase until free to engage in "real sex" with men on the outside, has encouraged no HIV/AIDS education or latex (dental dams) for women while incarcerated. There is also a conspiracy of silence surrounding the exchange of drugs for sexual favors with prison guards.<sup>43</sup> For incarcerated women with HIV/AIDS, treatment resources are severely limited. As an article by women prisoners notes: "Medical facilities [in prison] start out understaffed and ill-equipped, and the AIDS crisis escalated these problems enormously."<sup>44</sup> Much more advocacy is needed to provide HIV services for lesbians and nonlesbians in prison.

**Sex Workers.** Because health and sexuality educators usually do not use the label "lesbian" for a woman who continues to engage in sexual intercourse with men, sex workers (prostitutes) are rarely identified as lesbians. For the lesbian sex worker, the women's community may not be a source of support or comfort because: "We face attitudes that suggest we're either 'traitors to the women's cause' or not 'real lesbians.'"<sup>45</sup> Lesbians who exchange sexual intercourse with men for money are still lesbians. Many sex workers are well informed regarding safety issues on the job, but may be less informed about safety issues at home, particularly if they are in lesbian relationships.

### **Where Lesbians Go for Health Care and HIV Information**

Lesbians go for health care where many women go for health care: family planning clinics, neighborhood and women's health clinics, private practitioners, and emergency rooms.

In the absence of lesbian-sensitive health care, many lesbians do not seek services or choose not to disclose their identity. If a lesbian does disclose her sexual identity to a health care provider, the results may be disastrous. Many practitioners have told their lesbian clients that their religion does not approve of lesbians, but they are professional, and are thus willing to answer their questions. End of conversation. Some health care professionals, who are aware of dental dams, begin AIDS education with a quick explanation of what one looks like and how difficult they are to find. Questions about sexual, drug, and pregnancy histories are no longer considered relevant when a lesbian self-identifies, because the term "lesbian" infers only one thing: this woman engages in sexual activity with women. End of conversation. Some say: "Lucky you are a lesbian because they are not at much risk." End of conversation.

Very few family planning, neighborhood, or women's health clinics have acknowledged their lesbian clients in services, grant proposals, written materials, staff hiring, or trainings. Until agencies openly use the word *lesbian*, they will not be safe places for lesbians to work or seek services.<sup>46</sup> The fear of simply acknowledging lesbians who need health care and education puts many women at significant risk, not just for HIV/AIDS, but for other STDs, cancer, depression, alcohol and other drug dependencies as well. Agencies should make efforts to use self-identified lesbians to help create and determine the effectiveness of HIV/AIDS materials designed to reach women.

### **Safer Sex Models Needed: Designed By and For Lesbians**

As the challenging discussions about cultural diversity have pointed out, the communities themselves must develop relevant prevention models.

The sex-affirming, gay-affirming, and male-affirming, eroticizing-safer-sex-for-gay-men workshops, posters, and pamphlets were the first public health campaign aimed at changing sexual behaviors, completely defined by the target group itself. The choices about how, and with whom, to have sexual contact, as well as the definition of what was "safe," were decided by gay men for gay

## STORIES FROM THE FRONT: Lesbians Seeking HIV Education

Many health facilities serving women deny the existence of lesbian clients. The following are our personal experiences as AIDS educators and counselors in New York City at family planning clinics, AIDS hotlines, prisons and prenatal shelters for homeless women.

**A 35-year-old African-American woman**, with four dependent children came to a family planning clinic for her yearly pap smear. She had been coming to the clinic for five years and was given contraceptive pills, a fistful of condoms and a lecture on how to use them. She asked some questions about AIDS and was sent to the HIV counselor. The counselor had a Keith Haring poster on her wall about coming out. The woman asked about the poster and the counselor explained that she had it on the wall in hopes that lesbians would feel safe enough to talk about the reality of their lives. The client began to cry and said that she had been living with a woman for 10 years and was sick of the condom lecture. She had lost a brother-in-law to AIDS and was very worried about her sister. She had slept with two men since 1980 who now have AIDS and she had not thought much about her own risk until recently. She had no idea that women could pass the virus to each other through sexual contact. She did not want to be tested. She and one of her sons were in treatment for depression and classes for the learning disabled. She thought she could not yet deal with being positive in case she was. She thought it would be difficult to introduce safer sex into her relationship with her lover because they had never talked about sex with each other. She became uncomfortable; thanked the counselor for the information and left. She plans to return next year for another pap smear. Last time she skipped a year.

**A 42-year-old Caucasian woman** explains in her pre-test counseling session that she is a lesbian, has had three female lovers, and is planning to get pregnant if she tests negative. She is slightly worried because she inseminated with the sperm of three different gay donors and she is concerned about long-term seroconversion because her latest donor is her new girlfriend's best friend, a gay man who did not use condoms until 1988. The counselor laughs, and says that there is no place on the counseling form to check off any of the client's risks.

**A 42 year-old Latina** in a shelter explains that her girlfriend of many years threw her out because of her crack habit. Living on the street, she traded sex for drugs, got pregnant and now she is in a shelter that offers no drug treatment. The counselor offers her condoms but she does not want them because she really does not like men, she was just lonely and drinking a little too much. Now, she is afraid her girlfriend will not take her back.

**A lesbian AIDS educator** was invited into a psychology class for inmates in prison to talk about safer sex and AIDS.

She was told by their teacher that: "this group of women was particularly hostile about homosexuality so it would be best not to tell them that you're a lesbian if you want to leave the prison alive." Regardless, she told them she was a lesbian, and many of the women said they were too, "and this is my girlfriend," they said, pointing to the woman sitting next to them. A lively, interesting discussion about the problems all women face trying to negotiate safer sex with their partners followed. The fact that condoms (for sex with the guards) and dental dams for sex with women were considered contraband and therefore not available was the only hostile part of the workshop.

**A 39-year-old homeless African-American woman** reveals in her HIV counseling session, which is part of her prenatal care, that she has three other children who are in foster care. She planned this pregnancy "to have this one for my girlfriend. She is older and wants one so bad." She has been with her lover for many years and feels they can survive anything after all the trials they have been through. Her main worry about AIDS is that her lover, who shot up in the past, was mandatorily tested in prison and might find out any day that she is HIV-antibody positive. The prison is two hours from the shelter and she does not want her lover to find this out alone.

**A hotline counselor** picks up the phone that has begun ringing several minutes before the 9:00 a.m. opening. Before she can even say, "Good morning," a woman's voice starts yelling: "What the hell are you people doing over there? Why didn't anyone tell me? Why isn't anyone talking about this? You're killing women, you know! My girlfriend tested positive a year ago, and now I just did. No one told me! No one, not her doctors, no one I spoke to, and now I've got it! How can you sleep at night? Someone should have told me..."

**An African-American woman** at a homeless shelter is not too worried about AIDS because the men who gang-raped her and impregnated her were "just kids." She is very worried about her lover of several years, an ex-IVDU, who keeps promising to get tested, but does not get around to it. She is panic-stricken at the idea that her girlfriend might have it, and is angry at her for not testing. The counselor tells her that she is at risk from her lover, which surprises her. When the counselor suggests barrier methods such as saran wrap or condoms cut in half, she says: "You have got to be joking."

men. The need to feel good about one's gayness was as important to survival as stopping the transmission of HIV. The success of the gay male safer sex campaigns, which began in 1982 in San Francisco, can be measured by the declining incidence (as early as 1983) of rectal gonorrhea among gay men that continued to drop through most of the decade.<sup>47</sup>

With the growing public awareness of the increasing numbers of HIV-infected women, came safer sex workshops and information campaigns specifically targeted to women. But instead of creating new models, the gay male safer sex model — assume your partner is HIV antibody positive whether he has been tested or not and *always* use a latex condom — was simply adopted and

directed toward women. This model ignores the many safety issues a woman may face, including sexual abuse, domestic violence, pregnancy, financial dependency, and more, and addresses only one: HIV infection. This model is particularly irrelevant for lesbians because most lesbians do not assume their partners are infected, and there is no latex shield made specifically to cover the vulva during cunnilingus.

Effective HIV prevention models for lesbians will be developed when the health profession allows each woman to assess her own personal risk — based on all known information — and fully supports any personal choice affecting her well-being. This would mean every organization with women clients would have to become aware of all available information on lesbians and HIV, advocate for more serious study, become comfortable in discussing lesbian sexuality, find ways to intelligently and clearly communicate all information, attempt to rid the agency of homophobia, treat each woman equally as a unique individual capable of making her own choices, and offer institutional, financial, and personal support for those choices.

### In Conclusion

Lesbian communities have continued to survive and thrive in spite of great odds. Homophobia and sexism in public health has threatened that survival with 10 years of neglect during the decade of HIV/AIDS. Lesbian-positive HIV/AIDS education and services can no longer be withheld because of numbers, or be dismissed because of arguments of religious and cultural sensitivity. It is long overdue that health educators take lesbian sensitivity and appropriateness seriously and begin the work of creating health education materials and messages that address their myriad health concerns.

*Rebecca Cole was previously the assistant director of the National AIDS Hotline and an HIV/AIDS educator and counselor in family planning clinics, prenatal shelters, and prisons. Sally Cooper was previously an HIV/AIDS counselor for prenatal shelters and the National, and New York City Department of Health, AIDS Hotlines.*

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# Audiovisual and Book Reviews

## WOMEN AND AIDS:

### A SURVIVAL KIT

1989, 22 mins., 1/2"/3/4" video \$195, rental \$35. University of California Extension Media Center, 2176 Shattuck Avenue, Berkeley, CA 94704; 415/642-5578.

This multicultural video covers a wide range of topics concerning HIV and heterosexual women using many different approaches (enactments, commentary from PWAs, creative graphics, and information from experts). This expansive variety of issues and approaches makes *Women and AIDS* an attention-getting videotape. The video can be shown in sections in counseling and/or educational settings, which may be the most practical way of using it, as it is a bit too long.

As female experts in the field provide evidence of the seriousness of the AIDS issue, viewers become aware of the problems faced by black, Latina, and white women who are confronting HIV infection and AIDS. The experts come from different communities: Shirley Gross, Bayview-Hunters Point Foundation; Constance Wofsy, University of California/San Francisco; Lauren Poole, Project Aware; and, Concha Saucedo, Instituto Familiar de la Raza. As Saucedo says, HIV "is an affirmative action virus."

Most powerful is the testimony of women who are living with AIDS. One HIV-antibody-positive woman addresses the issue of denial within this community, saying, "The heterosexual community really needs to band together, to bang their heads on the wall to realize, yes, it is happening to us." Another woman, who is HIV-antibody positive and pregnant, says incredulously, "It happens to other people, right?" Hopefully, the audience will begin to understand that HIV can happen to anyone who engages in risk behaviors or who has unprotected sexual relations with someone else who does.

The most important feature of this video is that it deals with qualities that are deeply ingrained in women. Trust, for example. Traditionally, because women are raised to be trusting, they trust that "their men" are remaining monogamous, that they are not using drugs, and that they will protect them. Whatever the trust level is within a relationship, honest communication is encouraged throughout the video. One woman, whose husband is HIV-antibody positive, said that she trusted her husband, but unbeknownst to her, he

was using IV drugs, and although she had told her friends to question their partners, she had not considered questioning her husband. She explained that she had no idea of the extremity of her risk (identifying herself as "a middle-class housewife"), and that "when drugs are involved, there is no trust."

Also touched upon are issues of control, empowerment, and safety. Most importantly, the videotape emphasizes the value of life. At the conclusion of the video, a woman living with AIDS, states simply: "Not many people appreciate life, but they should."

The two drawbacks of *Women and AIDS: A Survival Kit*, is that it is somewhat long but, as mentioned earlier, it can easily be used in sections; also HIV is never mentioned as such, but is only referred to as "the AIDS virus." It is important for all people to understand the differences in the range of the disease, from HIV infection to an AIDS diagnosis.

Reviewed by Carolyn Patierno, AIDS Associate, SIECUS.

## DIANA'S HAIR EGO:

### AIDS INFORMATION UPFRONT

1989, 28 mins., 1/2" video, institutions \$125, individuals \$59.95, 3/4" video \$200, rental \$50. Video Data Bank, 37 South Wabash, Chicago, IL 60603; 1-800/634-8544.

This audiovisual, produced by Ellen Spiro, provides a valuable chronicle of one grassroots organization's fight against the AIDS epidemic. As it opens, the viewer steps into DiAna's Hair Ego, a hair salon in Columbia, SC (also known as the South Carolina AIDS Education Network/SCAEN), where one is immediately confronted with a "skeleton tree," festooned with syringes and scores of miniature skeletons symbolizing people who have died from AIDS. "Bigger ones for the adults, and tiny ones for the children," explains DiAna. The viewer then steps into a friendly space crammed with AIDS educational materials: a VCR that plays videos, racks of brochures, a basket of free condoms (many gift-wrapped by DiAna's four-year-old niece), and a children's corner, which offers crayons and AIDS prevention coloring books by, and for, black children.

While fixing her customer's hair, DiAna listens to their concerns, and provides them with down-to-earth information about how to protect themselves against AIDS.

Since 1986, two black women, DiAna and Dr. Bambi Sumpter have led what may be one of the most effective AIDS prevention projects in South Carolina, which uses the beauty salon as its home base.

Their work in the South is particularly

important in light of recent warnings from the National AIDS Commission concerning the "ruralization of AIDS." Findings in rural Georgia have brought to light the fact that HIV is spreading among women — particularly black women — at the same rate as in big cities, like Atlanta, leading officials to speculate that heterosexual transmission is increasing. (Heterosexual transmission among black women is eight times as frequent as among white women, according to *The New York Times*, April 18, 1989.)

SCAEN's approach to HIV/AIDS education is unorthodox. As one SCAEN Board member comments in the video: "Health education through the official channels is a health department lecture. Now the people who give the lectures are very nice and very sincere. But the approach to health education is just like when I was in the sixth grade, with diagrams of fallopian tubes and vas deferens. That was not what I or any other sixth grader was interested in." In contrast, DiAna's Hair Ego documents an approach that is down-to-earth, practical, and sexuality-positive: "We have told people for long enough about what they *cannot* do, now we have to help them figure out what they *can* do."

SCAEN also runs tupperware-style safer sex talk parties for women. The goal of these gatherings is to desensitize women in the face of powerful taboos against talking about sexuality: if women cannot even use the words, how can they negotiate safer sex in a real sexual encounter? To convey a positive message, SCAEN also has tapped the creativity of young singers, artists, and others, in order to alert the black community to how it can protect itself.

DiAna and Dr. Sumpter are shown speaking at high schools, the Business Women's Association, the Hair Dresser's Association, and at churches. Wherever they speak, they forcefully argue that HIV/AIDS is not "someone else's problem. It could be you, it could be your father or your mother or your sister. We cannot quarantine them or throw them away...we have to take off our blinders and talk about AIDS." Challenging parents to go further in supplying information to their children, SCAEN has videotaped 3,000 children asking questions about HIV/AIDS. At the same time, they try to dispel HIV/AIDS hysteria: "If you knew more, you would not be so afraid."



Because SCAEN carries out safer sex education, rather than simply calling for abstinence, the project has been repudiated by some local public health officials. Their grassroots approach has been attacked for being unprofessional: "We got criticized because the lady who volunteered to come in at night to type our AIDS brochure did not use all capitals in the word 'AIDS.'"

The video closes with the fact that, since 1986, the entire project has operated solely on tips from the beauty parlor; the program has received little funding. Like the gay community before it, all too often the black community has had to educate and organize itself, in the face of official indifference or hostility. Confronting the interlocked epidemics of HIV infection, racism, sexism, and homophobia, SCAEN, however, is demonstrating the power and creativity of people at the grassroots. Because it portrays a community education model that works, Diana's Hair Ego is a very useful tool for college and high school HIV/AIDS classes, and for health educators and peer educators. In fact, it is useful for anyone interested in ending the epidemic.

*Reviewed by Vicki Legton, health educator, Northwestern University, Evanston, Illinois.*

### **RISKY TIMES: HOW TO BE AIDS-SMART AND STAY HEALTHY** **A Guide for Teenagers**

Jeanne Blake  
New York: Workman Publishing Company, 1990,  
158 pp., \$5.95.

I wish that I had written this book.

Over the past five years, I have probably read hundreds of books and pamphlets for teens on AIDS and HIV infection. *Risky Times* is one of the very best that I have reviewed.

Written by Jeanne Blake, a television news medical reporter in Boston, this easy-to-read, attractive paperback addresses basic information about HIV/AIDS, transmission, and prevention. Decision making about sexual and drug behaviors are addressed in separate chapters, and there is a chapter on condom use. Six teenagers provide commentary throughout the book on adopting and practicing safe behaviors, and offer excellent peer role modeling on difficult issues. Stories about people with HIV infection and AIDS are sensitively portrayed, and the reader is encouraged to feel compassion for people who are ill and to adopt behaviors to protect themselves. Statements from teen-oriented celebrities, such as Joe Montana, Cher, Matthew Broderick, Brooke Shields, and Eddie Murphy are sprinkled throughout the book, encouraging young people to adopt the celebrities' compassionate responses to the HIV epidemic.

The emphasis in the book is on behaviors, not on the provision of information. It addresses each of the goals I have outlined for HIV prevention: it will reduce myths about the disease; help young people resist the pressures to become prematurely involved in sexual intercourse and drug experimentation; promote safer sex among teenagers, including noncoital behaviors and condom use; and help teenagers develop empathy for people with HIV disease. The book also includes an excellent section encouraging teenagers to volunteer time to help fight the HIV/AIDS epidemic.

An excellent short guide for parents accompanies the paperback, written by former SIECUS Board Member Beth Winship, who is known for her popular syndicated column, "Ask Beth." Parents receive straightforward, helpful information on providing information about sexuality and AIDS to their teenage children. Ten copies of the parent guide are available for the remarkably low price of \$2.

*Risky Times* will help young people celebrate their sexuality while adopting responsible behaviors, I plan to buy a copy for all the teenagers on my gift list.

*Reviewed by Debra W. Haffner, SIECUS' executive director.*

### **The National Hemophilia Foundation's Women's Outreach Network**

Traditionally, hemophilia comprehensive care was an entity that involved men with hemophilia to the exclusion of the women in their lives. Many men felt that hemophilia was their private affair. When clotting factor products were introduced in the early 1970s, the resulting advent of home care gave those with hemophilia greater independence: the infusions necessary to maintain bleeding episodes were easily administered and many learned how to self-infuse at a very young age. There was no apparent need to involve family members in caregiving at that time.

However, when the HIV/AIDS crisis struck this community, many of the women were on the fringe of the epidemic and were poorly informed. Sons/brothers/husbands/boyfriends received information when visiting the Hemophilia Treatment Center (HTC), but how much of it was then passed on to women was unknown. Health-care professionals soon became aware of the importance of including women in the HTC information and counseling system.

Two issues, nonetheless, still make it difficult to include women in any network of information: confidentiality and demographics. There are approximately 20,000 people with hemophilia in the U.S. Although there is a greater concentration in urban areas, those with hemophilia are widely dispersed throughout the country. In

some areas, families may be hundreds of miles away from each other, which makes the development of support networks difficult. In addition, men with hemophilia tend not to involve their partners in their health care and, because of this, their partners have had no reason to visit HTCs. No one knows, at present, how much information women really are receiving, if any. Moreover, for confidentiality reasons, health-care professionals have been limited in the amount of outreach they can do in the broader hemophilia community, beyond the person with hemophilia to whom they directly provide care. In response to this situation, the Women's Outreach Network of the National Hemophilia Foundation (WONN) has been created in order to support the women of the hemophilia community in their efforts to launch individual support networks in their communities. Each region now has three to four contact women who can assist in finding women in specific areas who can offer support. In addition, coordinators act as technical resources in aiding women in developing support groups, workshops, and various other projects.

A training workshop was held in October 1990 in Denver, Colorado for 22 regional coordinators, which covered issues such as outreach, communication skills, support strategies, and sexuality. Regional meetings will take place throughout the country in 1991. For more information, contact Suzanne Broullon at the National Hemophilia Foundation: 212/219-8180. — *Carolyn Patierno, AIDS Associate, SIECUS*

## HIV/AIDS Recommended Resources

**HIV INFECTION AND AIDS: A Report to Congress on the USAID Program for Prevention and Control, July 1990** (64 pp., 8 1/2 x 11 report) prepared by the U.S. Agency for International Development. This report, a good resource for someone with little knowledge of HIV/AIDS, offers a global overview and makes some not-often-thought-of points, as it describes the efforts USAID has made in helping developing countries (50) prepare national AIDS prevention plans and build long-term programs. USAID provides technical assistance in public education, social mobilization, and prevention counseling; technical assistance in disease surveillance, blood transfusion screening, control of STDs, and the distribution of badly needed supplies and equipment; and helps health-service providers analyze costs so they can better allocate scarce resources to ensure the sustainability of their programs. "And we support a variety of private voluntary organizations because they have a remarkable capacity to act rapidly and catalyze community response in times of crisis." *Dr. Jeff Harris, Room 703, SA-18, U.S. Agency for International Development, Washington, DC 20523-1817; 703/875-4494. Free.*

**INFECTION, YOUR IMMUNE SYSTEM AND AIDS** (1989, 52 pps., 8 1/2 x 11 magazine format student booklet) written by John Lord, published by Enterprise for Education, in association with the Massachusetts Medical Society, with the help of an advisory committee that included SIECUS Executive Director Debra W. Haffner. Nicely organized and illustrated, it discusses infection and becoming infected; the immune system, how it fights a pathogen, and how HIV destroys the immune system; epidemics and epidemiology; living with HIV/AIDS; testing, treatments, and developing a vaccine; how HIV is and is not transmitted; HIV/AIDS and young people, avoiding infection, safe sex, and using condoms properly. A *teacher's guide* contains additional background information, reproducible masters of readings, quizzes, overhead transparencies, and citations for the text of the student booklet. *Enterprise for Education, 1320-A Third Street #202, Santa Monica, CA 90401; 213/394-9864. Price: \$26.95, plus \$3 p/b.*

**ME FIRST!: Medical Manifestations of HIV in Women** (1990, 8 pp., 7x9

*booklet*). This well-written and unusually informative booklet, produced by the New Jersey Women and AIDS Network (NJWAN), opens with: "Nationally and internationally, women are the population being infected with HIV at the fastest rate. Yet, because women may manifest different symptoms of HIV infection than men, HIV infection in women frequently is not recognized, especially in the early stages of the illness. For many women, the survival time from an AIDS diagnosis to death is half that of men. When women do seek treatment, they are more than twice as likely as men to present with opportunistic infections that may be missed or misdiagnosed because HIV infection is not suspected. If they are not properly diagnosed with AIDS, women cannot qualify for treatments and services that depend on an AIDS diagnosis. Because women are likely to be underrepresented in the official 'count' of people with AIDS, funding is not accurately apportioned to meet their needs." The brochure has been designed "to survey what is different and important about HIV infection in women. It will assist nurses, primary care physicians, ob-gyn specialists and allied health providers in identifying and treating women with HIV infection. Women and their health-care providers must become informed about female-specific symptoms of HIV infection. Together, they can break the cycle that has kept women invisible in this epidemic." It includes sections on: Women with HIV Infection and Those at Risk; Underdiagnosis of HIV and AIDS in Women; Primary Care and Public Health Guidelines; Medical Manifestations of HIV Infection in Women; Sexually Transmitted Diseases (STDs); Pregnancy; Patients Rights; and additional sources of information. *Price: \$.30 each, \$6 p/h per 100 or less.*

**ME FIRST!** (1990, 4x9 pamphlet). This very clearly presented pamphlet although targeted to New Jersey women will be useful to women everywhere. It begins: "Some people don't realize that women get AIDS or are infected with HIV. And most people, including health-care workers, don't know that when women have these illnesses they may show different symptoms than men do. Sadly, many women don't get the medical treatment they need to help them stay healthy. *You can make a difference* by learning about the signs of HIV infection. This booklet will help you take care of *your health*. Share it with others — your friends, family, doctor or clinic counselor so they can learn about HIV infection in women too! Also if you are thinking about having a baby, are now pregnant or breastfeeding, you need to know how HIV infection and AIDS can affect you and your

baby. Learning about AIDS and HIV infection is one way to put you first." The sections include: What is HIV Infection?; Should women be concerned about HIV infection?; What are the signs of HIV infection in women?; What are my rights as a patient?; and How can I protect myself and others? *Price: \$.20 each, \$6 p/h per 100 or less. The New Jersey Women and AIDS Network, 5 Elm Row, Suite 112, New Brunswick, NJ 08901; 201/846-4462. "If any group has a need for the material and cannot afford the cost per brochure, please call us and we will do all we can to negotiate costs to accommodate you."*

**POSITIVE IMAGES: Answers for People Who Test Positive to the AIDS Virus** (1987, 8pp., 4 1/2 x 8 1/2 booklet). "You've just found out that your AIDS antibody test is positive. You're scared, confused, and you have a thousand questions running through your head. The most important thing to remember right now is: Don't panic! This pamphlet will answer some of your questions and direct you to where many more can be answered. A good thing to do for yourself right now would be to sit somewhere quiet and read this. Information is your best weapon against fear and confusion. Remember, many people who have also tested positive have learned to cope with their test result, and are living healthy and fulfilling lives. Some of them helped write what you are about to read," states this straightforward and very informative booklet. Succinct answers are given to such questions as: Does this mean I have AIDS?; Does a positive test mean I am contagious to others?; Who should I tell?; When should I see a doctor?; Could my test be wrong?; If AIDS is spread by unsafe sex, what sexual activities are safe?; How do I use a condom?; Can I have sex with another person who is positive?; Can I have sex with a person who is negative?; What else should I do to prevent spreading the virus?; What if I'm pregnant or want to have children?; How can I keep myself healthy? *Price: \$.20 each, bulk rates available on request.*

Positive Images is a support group, which meets weekly, for people who have tested positive. Group members talk about how a positive test result affects families, sexuality, jobs, insurance and relationships. Participants' names are kept strictly confidential. Among other materials available from the group is **COREY'S STORY**, (1987, 8 pp., 6 1/2 x 10 comic book) a useful HIV/AIDS prevention comic book designed for sexually-active youth. *Price: \$.50 each, bulk rates available on request.*

*Minnesota AIDS Project, 2025 Nicollet Avenue South, Suite 200 Minneapolis, MN 55404; 612/870-7773.*

**PREVENTING AIDS: The Design of Effective Programs** (1989, 304 pp., 6x9 paperback book) by Ronald O. Valdiserri, MD, MPH. Discusses "the development of programs that seek to limit the transmission of HIV, especially those that target viral transmission through sexual intercourse and through needle sharing among intravenous drug users." Valdiserri says, "Developing effective prevention programs for these targets requires that we a) recognize and understand the behaviors that transmit the virus; b) appreciate how solutions to previous epidemics of sexually transmitted diseases and past approaches to treating addictive drug use have influenced our current programmatic responses to AIDS; c) become familiar with theories that both explain and predict human behavioral change; d) develop an appreciation for the individual and group circumstances of the persons whom we wish to reach with our prevention programs; e) analyze the strengths and limitations of the specific tools available to us for developing, implementing, providing, and evaluating AIDS prevention services; and f) understand the barriers that can interfere with programmatic efforts to prevent the further spread of the human immunodeficiency virus."

The material is presented so that it will be accessible to a broad range of readers with different levels of experience and involvement in the AIDS epidemic, but the book's focus is on program development. "Regardless of the groups we consider as targets for prevention programs...it soon becomes apparent that understanding their social circumstances is essential to providing effective and meaningful prevention services....They can refer to group norms that endorse riskful behaviors or social networks through which minorities communicate. They can describe economic circumstances that limit life-choice options or value judgments about behaviors that are controversial or poorly understood.... Disease can also be viewed as a social process; it can reflect how we live as a society, what values are important to us, how well we plan and allocate resources, and how thoroughly we understand the interrelations of our social and organizational 'ecosystem.'" The book covers epidemiology; historical variables; theoretical foundations; the targets for prevention programs; planning and implementation; the role of

testing; and barriers to the evaluation of programs. The appendices list the people interviewed for the book; names and addresses of related organizations; criteria for the development of health promotion and education programs; and an example of a consent form for testing. *Rutgers University Press, 109 Church Street, New Brunswick, NJ 08901; 201/932-7764. Prices: \$38 hc, \$15 pb.*

**PROCEEDINGS: AIDS Prevention and Services Workshop, February 15-16, 1990, Washington DC** (192 pp., 8x10 paperback book) This workshop, conducted by the National Health Policy Forum, through a grant from The Robert Wood Johnson Foundation, brought selected foundation grantees — from the areas of AIDS health services, prevention, and research — together with federal health policymakers, in an effort to provide information about what the grantees had learned through their efforts to address the epidemic. It presents background on the status of the HIV/AIDS epidemic; an overview of the continuum of needs and responses by communities; the results of new studies on the special burdens on institutions; an in-depth analysis of two cities' responses to the continuum of needs; HIV/AIDS prevention for high-risk populations; community-based AIDS support services; housing and long-term care for people with AIDS; some options in new delivery and payment strategies; presentations and a panel discussion on education, treatment, and payment pressures on the federal and state governments; and an overview of AIDS policy issues. *The Robert Wood Johnson Foundation, PO Box 2316, Princeton, NJ 08543-2316; 609/243-5934. Free.*

**TRIPLE JEOPARDY: Women & AIDS** (1990, 104 pp., 9 1/2x6 paperback book). In 1989, the Society for Women and AIDS in Africa (SWAA) used the phrase "triple jeopardy" to describe the dangers women face as individuals, mothers, and carriers in the face of the AIDS pandemic. This broadbased, refreshingly crosscultural dossier, published to mark World AIDS Day 1990, focuses on women and AIDS. Medical issues are clearly laid out along with the social, economic, and political constraints on women's behavior and choices. The information, backed by extensive facts and figures, will be relevant for individuals, AIDS service organizations, and policy makers worldwide. Published by The Panos Institute, an information and policy studies institute concerned with the extent and social implications of the HIV/AIDS epidemic, the book covers the global picture; how women are at risk; choice; HIV infection, reproduction and motherhood; HIV disease in infants; who cares, who pays; and AIDS prevention and the status of women. The book mentions that: "several major studies in Europe and the U.S., in which detailed sexual histories of partners were taken, show that almost 80% of women infected sexually reported unprotected vaginal intercourse as their only risk activity," and that "studies have shown repeatedly that even people who begin by insisting on safer sex find this decision difficult to sustain. For most people, sex with someone they know and love feels safer — but may not be." *The Panos Institute, 1717 Massachusetts NW, Suite 301, Washington, DC 20036; 202/483-0044. Price: \$9.50 plus 10% p/b.*

### **CEOs Pledge Their Support to Fight HIV/AIDS**

More than 70 chief executive officers of major U.S. companies have agreed "to increase their leadership role in facing the growing challenges of the AIDS epidemic." The CEO effort was organized by John Taylor, chair, and Richard Munro, vice chair, of the National Leadership Coalition on AIDS — a nonprofit organization charged with marshalling the support of businesses and labor leaders in response to the AIDS epidemic — and Robert Haas, Chairman and CEO of Levi Strauss & Company. Represented are CEOs from Chrysler, IBM, Aetna Life & Casualty, Ford Motor Company, and Xerox. The CEOs agreed to address AIDS as a workplace issue in their companies, to make it a priority in their internal communica-

tions as well as in their civic activities within their communities. Recruitment efforts were begun following the Coalition's Spring conference at which President Bush was featured as the keynote speaker. Richard Munro said, "Just as it is important for the President to address AIDS issues publicly and positively, it is equally important for the business leaders of our country to respond to the epidemic." The National Leadership Coalition on AIDS is composed of more than 200 businesses and labor groups, as well as trade, health, and religious organizations. SIECUS Executive Director Debra Haffner was recently elected to the board of directors of the NLCOA.

# HIV PREVENTION KNOWLEDGE TEST FOR TEENAGERS

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## **I**ntrouction

The seriousness of human immunodeficiency virus (HIV) infection among teenagers has been well documented.<sup>1,2,3</sup> Studies of adolescent sexual and drug-using behaviors indicate that many youth place themselves at significant risk for infection.<sup>4,5,6,7,8,9</sup> The Centers for Disease Control (CDC) reported in September 1990 that 568 teenagers had developed AIDS. Many of the 29,609 adults ages 20 to 29 who have AIDS likely contracted HIV during adolescence.<sup>10</sup> Further, the high prevalence of other STDs among youth (75% of STD cases are between ages 15 to 24) is an indicator of risk for HIV infection.<sup>11,12</sup>

Leading authorities, such as the U.S. Surgeon General, have indicated that youth should be a major target of HIV education. The challenge of educators is to develop the most effective approach for motivating young persons to practice HIV prevention and low-risk behaviors. However, often lacking in the development and implementation of such interventions is an evaluative component. Before educational programs can be conducted, reliable and valid measures should be developed to assess the learning needs of the targeted population and the outcomes of the program.<sup>13,14</sup> This may increase the likelihood that the most desirable content and approach will be utilized. Therefore, the goal of this study was to develop an HIV measure for one component of learning — knowledge — that is designed for use with teenagers.

Several surveys of teenagers' knowledge about HIV infection and AIDS reveal cognitive deficiencies, especially concerning the prevention of HIV infection.<sup>4,7,14,15,16,17</sup> This is problematic, since misconceptions and incomplete information may lead to unintended high-risk HIV behaviors. Actually, one recent study revealed that about three-quarters of the surveyed teenagers wanted more information about AIDS.<sup>18</sup> Hence, a need exists for educational programs to correct the lack of appropriate information. Given the philosophy that proper HIV education emphasizes preventive behaviors, the cognitive component of such programs should likewise provide accurate concepts concerning prevention. A measure designed specifically to assess knowledge of HIV preventive behaviors can assist in the formative and summative evaluations of such programs.

## **M**ethodology

In developing this knowledge test for teenagers, the multiple-choice approach was utilized,<sup>19</sup> with items generated that represent both the knowledge level (HIV concepts) and application level (HIV situations) of the cognitive domain.<sup>20</sup> The major emphasis of the questions focused on HIV preventive behaviors. A pool of items based on literature<sup>13,21,22,23,24,25,26</sup> was developed according to a table of specifications containing four conceptual areas, each with specific categories: the HIV/AIDS problem: social impact of HIV/AIDS, HIV infection and AIDS; HIV transmission: sexual contact, blood transmission, mother to child, and fears/fallacies; individual HIV prevention: knowing of infection, sexual, drug use, and mother to child; and HIV/AIDS control efforts: testing/medical, education/research, individual activism, and help sources.

A panel of experts, including federal government HIV officials, health educators, and teenagers, reviewed the items, which resulted in the elimination of some questions. Attempts were made to make the reading level of the items junior high school level. A preliminary test consisting of 50 items (44 knowledge domain, 6 application domain) and 5 demographic questions was developed. This form was reviewed by a small group of eighth grade students, which resulted in further verbal clarification of some items. Subsequently, the form was administered to high school students.

The collected data were analyzed to provide evidence of reliability and validity of the test using correlation techniques, difficulty index, and factor analysis. From the item analysis, a pool of the 30 most functional items were selected for the final test. The data were then re-analyzed using only the 30 items.

## **F**indings

The sample consisted of 246 students, who were enrolled in an urban high school, located in a large mid-western city. Their ages ranged from 13 to 20 years or older; the majority of students were between 16 and 19 years old. There was a nearly equal proportion of females and males, with about 72% and 17% of the sample white and black students respectively. The data related to the preliminary and final forms were subjected to item analysis, using correlational method and difficulty level. Due to space limitations, the results are not presented

here, but they can be obtained from the authors. The initial data analysis produced a final test of 30 items (25 knowledge domain; 5 application domain) with accepted criteria. The items of the final test had the highest item correlation and were within the average item difficulty range. The mean score for the final test is 17 (possible scores being 0 to 30) with a standard deviation of 6.6. The reliability coefficient of the final test was .85 (alpha method) and .86 (Kuder-Richardson).

### Discussion

The table of specifications, along with analysis of the data, provided evidence of content validity and internal consistency of the test. Because the test largely assesses knowledge of HIV/AIDS prevention behaviors, it has application for curriculum development, and for the evaluation of educational programs designed for teenagers which emphasize HIV/AIDS prevention. The test can also be utilized for further research into the relationship of HIV/AIDS prevention knowledge, and other variables, such as the actual practice of preventive behaviors and HIV/AIDS-related attitudes and fears. Finally, the authors encourage others to develop sound HIV measures so that more accurate program evaluation can occur. Hopefully, evaluation research will then become a standard component of educational programs designed for teenagers and other populations.

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# HIV PREVENTION BEHAVIORS KNOWLEDGE TEST FOR TEENAGERS

*Note: HIV means the virus that causes AIDS (also called the AIDS virus). STD means sexually transmitted diseases, such as syphilis, gonorrhea, or herpes. IV drugs means intravenous drugs.*

**Part I. Directions:** Choose the best answer for each question.

- The *most* common way HIV has been transmitted is
  - by sexual contact.
  - by IV drug use.
  - by blood transfusions.
  - from mother to child.
- How long does it take for the symptoms of HIV infection to develop after a person becomes infected?
  - 2 to 6 weeks.
  - 1 to 2 years.
  - few weeks to 3 years.
  - \*d. few months to 10 years or more.
- The *surest* way to avoid HIV and other STD is by
  - having only one sex partner.
  - using condoms during sex.
  - carefully selecting sex partners.
  - \*d. not having sex or injecting drugs.
- Sexual fidelity is *100 percent* effective in avoiding HIV or other STD only if
  - a condom is used for every sexual contact.
  - anal intercourse is avoided.
  - \*c. neither partner was infected when sex started, and both avoid IV drugs and sex with others.
  - d. each partner states that he/she has not had sex with high-risk persons.
- Which statement concerning having an HIV infection and AIDS is *true*?
  - \*a. One can be infected with HIV without having symptoms.
  - b. Many persons with an HIV infection have recovered.
  - c. All persons with an HIV infection have developed AIDS.
  - d. Nearly all persons diagnosed with AIDS have already died.
- Which statement concerning HIV infection is *true*?
  - a. An HIV infection causes sterility.
  - \*b. HIV can be transmitted to others, even if symptoms of infection are absent.
  - c. The exact percentage of HIV-infected persons who will develop AIDS is known.
  - d. The outcome of having AIDS is *not* very severe.
- Which statement concerning HIV transmission is *true*?
  - a. HIV is transmitted like the flu or common cold.
  - b. HIV can be spread by casual contact.
  - c. HIV can be spread by mosquitoes.
  - \*d. Family members living with HIV-infected persons have not acquired HIV just by being near the person.
- Which statement concerning the HIV-antibody test is *true*?
  - a. A positive HIV-antibody test result means that the person will develop AIDS.
  - \*b. A positive HIV-antibody test result means that the person has been infected with HIV.
  - c. The HIV-antibody test can be purchased at a drugstore by anyone.
  - d. The HIV-antibody test will be positive very soon after a person becomes infected.
- Which statement concerning teenagers and AIDS is *false*?
  - a. AIDS among teenagers is increasing.
  - \*b. Teenagers are safe from HIV infection.
  - c. Teenagers can get HIV from sex and IV drug use.
  - d. Some HIV-infected people in the 20-29 age group acquired HIV when they were teenagers.
- Which statement concerning AIDS and the HIV infection problem is *false*?
  - a. There are many more persons infected with HIV than those actually having AIDS.
  - \*b. HIV infection has been limited to a few large cities.
  - c. Both sexes and children have been infected with HIV.
  - d. The number of AIDS cases is increasing in the United States.

11. Which statement concerning symptoms of HIV infection is *false*?
- Sometimes it takes a long time for symptoms to appear.
  - Early symptoms of HIV infection are like some common illnesses.
  - Most persons with HIV have periods of both health and illness.
  - \*d. A person can usually guess who is infected.
12. Which statement about having an HIV infection is *false*?
- Many HIV-infected persons do not know they are infected until symptoms appear.
  - HIV itself usually does not kill the person.
  - \*c. Only a small percentage of HIV-infected persons will develop AIDS.
  - Persons with HIV may get severe illnesses healthy persons do not get.
13. Which statement concerning HIV transmission is *false*?
- There have been very few female-to-female sexual transmissions of HIV.
  - \*b. HIV is transmitted only if the infected person has been diagnosed as having AIDS.
  - A person with an STD has a greater chance of getting HIV if he/she has sex with an HIV-infected person.
  - d. HIV probably can be transmitted by oral sex.
14. Which statement concerning blood donation and transfusion is *false*?
- \*a. One can get HIV from *donating* blood.
  - It is very unlikely to get HIV from blood transfusions.
  - All donated blood is tested for HIV antibodies.
  - d. Persons who might have HIV should not donate blood.
15. Which statement concerning multiple sex partners is *false*?
- Condoms reduce the risk of acquiring HIV or other STD if a person has multiple sex partners.
  - The more sex partners a person has, the greater the chance of getting HIV.
  - \*c. There is little chance of getting HIV or other STD from multiple partners if all are heterosexual.
  - d. There is a risk of getting HIV or other STD from having multiple sex partners even if you know each partner.
16. Which statement concerning HIV-infected women and pregnancy is *false*?
- \*a. All children of HIV-infected women are born with HIV.
  - It is risky for an HIV-infected woman to breast-feed.
  - The HIV-infected woman should delay pregnancy.
  - d. Babies born with HIV usually die within two years.
17. Which statement concerning the fear of getting HIV or other STD is *false*?
- Some people should fear getting HIV or other STD.
  - Myths about the transmission of HIV and other STD have increased people's fear.
  - \*c. For most people, fear of getting HIV or other STD is justified.
  - d. There is nothing to fear about acquiring HIV or other STD from just being around others.
18. Which statement concerning HIV-infected persons is *false*?
- HIV-infected persons should practice sexual abstinence or low-risk behavior.
  - \*b. HIV-infected persons should avoid donating blood, but they can donate body organs and semen.
  - HIV can be transmitted soon after a person becomes infected.
  - d. HIV-infected persons should never share IV drug needles.
19. Which statement concerning the prevention of HIV and other STD is *false*?
- The precautions for avoiding HIV infection also prevent other STD.
  - Some behaviors that prevent HIV and other STD also prevent unwanted pregnancy.
  - \*c. Scientists are unsure about how a person can avoid HIV and other STD.
  - d. Individual prevention is the most important solution to stopping HIV and other STD.
20. Which statement about preventing HIV and other STD by sexual fidelity is *false*?
- \*a. Sexual fidelity works only if it is practiced in marriage.
  - Uninfected partners who practice sexual fidelity will avoid HIV or other STD from sex.
  - Sexual fidelity works unless one's partner uses IV drugs or was infected when the relationship started.
  - d. It is sometimes impossible to know if a partner is sexually faithful.
21. Which statement concerning the selection of new sex partners is *false*?
- \*a. Insisting that new sex partners get tested for HIV and other STD *eliminates* the risk of becoming infected.
  - It is difficult to know for sure if a partner is infected.
  - It is impossible to determine who is uninfected just by looking at the person.
  - d. A person thinking of having sex should consider that anyone could be infected.
22. Which statement about using condoms for preventing HIV and other STD is *false*?
- \*a. Intercourse is the only sexual activity for which condoms are needed.

- b. Each condom should be used only once.
  - c. An empty space should be left at the end of the condom when it is used.
  - d. A condom should be used even if one carefully selects sex partners.
23. Which statement concerning the HIV-antibody test is *false*?
- \*a. All persons with positive test results have AIDS.
  - b. Persons having a positive test result can transmit HIV.
  - c. Test results may be negative shortly after a person has become infected with HIV.
  - d. The test results are very accurate, but not perfect.
24. Which statement concerning calling the National AIDS Information Line is *false*?
- a. The hot line is available 24 hours daily.
  - b. The caller will not be asked his/her age or phone number.
  - c. The person answering will not ask for the caller's name.
  - \*d. The call will be charged as a long distance call on the telephone bill.
25. Which statement concerning the medical treatment of AIDS patients and persons with HIV is *false*?
- a. Some drugs improve the health of persons with AIDS.
  - \*b. An HIV infection can be cured.
  - c. There is no vaccine to prevent an HIV infection.
  - d. Drugs that help restore the immune system are being tested.
- Part II. Directions:** Read the HIV life situations below and answer the questions concerning them.
26. Margarita and Carlos have decided to have sex with each other. But they want to avoid getting HIV or other STD. Both have had sex with other people. What would be their *wisest* choice to avoid HIV or other STD?
- a. Both would urinate and wash their genitals after sex.
  - b. Margarita would take the birth control pill.
  - \*c. Carlos would wear a condom during all sexual activity.
  - d. Both would not have sex with other people.
27. Naoko thinks she might be infected with HIV or another STD. But, she does not have symptoms. She wants to do something about her concern. Which behavior would be the *wisest*?
- \*a. She could immediately talk to a health counselor.
  - b. She could ask her sex partners if they have symptoms.
  - c. She could wait to see if she develops symptoms.
- d. She could take some medicine she got from a friend.
28. Stacey and Daryl are high school students who are dating each other. They are considering having sex, and have decided to talk about HIV and other STD. Some of their statements are correct and others are incorrect. Which statement is *incorrect*?
- \*a. It would be safe for us to have sex, since neither one of us looks like we are infected.
  - b. If we have sex, Daryl should use a condom.
  - c. Even though neither one of us is homosexual, there is still a chance of getting HIV or another STD.
  - d. It is impossible to know for certain if there is no risk of HIV or other STD, since we cannot be perfectly sure of each other's past.
29. Chris and Paul sometimes shoot IV drugs together and with their friends. Often they share the drug needles. However, they do not have sex with each other. They have certain beliefs about their lifestyle and HIV infection. Which belief listed below is *incorrect*?
- \*a. We have no chance of getting HIV, since we are shooting drugs only with friends.
  - b. We should get counseling about whether we should take the HIV-antibody test.
  - c. It would be wise to stop sharing needles, even if we shared them before.
  - d. We could be infected with HIV, even though we do not have sex.
30. Jamal and Cantrise are students in the same high school and have dated each other for a long time. Jamal uses IV drugs, but Cantrise does not. They had too much to drink at a recent party, and afterwards had sex for the first time. Cantrise had some beliefs about their relationship and HIV infection. Which of Cantrise's beliefs is *incorrect*?
- a. Women have acquired HIV from men who use IV drugs.
  - b. If we continue to have sex, I should insist that Jamal use a condom.
  - \*c. I have no chance of getting HIV if we have more sex as long as I do not use IV drugs.
  - d. I have a chance of getting HIV.

\* This is the correct answer.



# CHILDREN, ADOLESCENTS AND HIV/AIDS EDUCATION

## A SIECUS Annotated Bibliography

This annotated bibliography profiles HIV/AIDS resources targeted for children and adolescents. In the face of this devastating disease, it is imperative that young people be educated on HIV transmission and sexuality at a young age. Education must continue throughout the elementary grades and high school in comprehensive programming. The bibliography includes resources for preschoolers through high school students.

Although SIECUS does not distribute any of the materials listed in the bibliography, they are available for use within our

reference library.

This bibliography has been prepared by Carolyn Patierno, SIECUS' AIDS associate, and is funded through a cooperative agreement with the Centers for Disease Control. It can be reproduced, as long as SIECUS is acknowledged (please send a copy to the Publications Department for our records). A single copy can be obtained, free upon request, with a self-addressed, stamped, business envelope by writing to: Publications Department, SIECUS, 130 West 42nd Street, Suite 2500, New York, NY 10036, or by calling 212/819-9770.

### BOOKS

#### AIDS: TRADING FEARS FOR FACTS— A GUIDE FOR TEENS

*Karen Hein, MD & Theresa Foy  
DiGeronimo*

The authors, writing especially for teens, are sensitive to the needs, fears, and concerns of this age group. Pronunciation of medical terms is given as the terms are introduced in the text for discussion, and photographs are effectively used. Includes a resource directory. 1989, 206 pp., \$3.50.

*Consumer Reports Books, 51 East  
42nd Street, New York, NY 10017; 212/  
983-8250.*

#### BE SMART ABOUT SEX: FACTS FOR YOUNG PEOPLE

*Jean Fiedler & Hal Fiedler*

This book, containing anecdotal information from young people, fosters a better understanding of the realities of HIV/AIDS. Chapter topics include: Expressing Sexual Feelings; Thinking About Sexual Decisions; Facts About AIDS; and Four Rules for Safer Sex. 1990, 128 pp., \$17.95.

*Enslow Publishers, Bloy Street &  
Ramsey Avenue, Box 777, Hillside, NJ  
07205; 201/964-4116.*

#### CHILDREN AND THE AIDS VIRUS: A BOOK FOR CHILDREN, PARENTS, AND TEACHERS

*Rosemarie Hausberr*

Utilizing beautiful black-and-white photos, this book explains the facts about HIV/AIDS and its transmission. Large print is used for younger children, and in-depth discussions in smaller print are included at the bottom of the page for older children. 1989, 48 pp., \$4.95.

*Clarion Books, 52 Vanderbilt Avenue,  
New York, NY 10017; 212/972-1190.*

#### FRIENDS FOR LIFE: THE KIDS ON THE BLOCK BOOK SERIES

*Barbara Aiello & Jeffery Shulman*

This story, in which the advisor of the student video club is discovered to have AIDS, examines the varied responses of the community, the students, and the advisor. Eventually, there is a positive outcome, but not before some difficult issues are confronted. For grades 4 to 6. 1988, 48 pp., \$12.95.

*Twenty-First Century Books, 38 South  
Market Street, Frederick, MD 21701; 301/  
698-0210.*

#### LOSING UNCLE TIM

*Mary Kate Jordon*

Beautifully written and illustrated, this book deals with the loss, grief, and fear children can experience after losing a family member to AIDS. Daniel experiences his Uncle Tim's illness in the beginning of the story, and his subsequent death toward the end, as well as his funeral and the reading of his will. An important book, as more and more children are having to deal with the emotional ramifications of death and dying due to HIV/AIDS. For grades K to 3. 1989, 26 pp., \$12.95.

*Albert Whitman and Co., 6340 Oakton  
Street, Morton Grove, IL 60053; 1-800/255-  
7675.*

#### RAPPIN', TEENS, SEX AND AIDS

*Sala Udin*

The two black and Latino characters in this empowering comic book — written in language that speaks clearly to teen readers — visit the school's health educator, who talks to them about peer pressure, sexuality, and empowerment. 1988, 7 pp., \$1.

*Multi-Cultural Training Resource Center,  
1540 Market Street, Suite 320, San Fran-  
cisco, CA 94102; 415/861-2142.*

#### RISKY TIMES, HOW TO BE AIDS- SMART AND STAY HEALTHY: A GUIDE FOR TEENAGERS

*Jeanne Blake*

This attractive, easy-to-read book includes chapters on: How You Can't and Can Get Infected; Condoms; Decisions; and Questions. Six teenagers provide personal insights on each of the issues presented. Quotations from famous performers and athletes appear throughout the book. A sensitive and informative companion guide for parents, written by syndicated columnist Beth Winship ("Ask Beth"), accompanies the book. 1990, 158 pp., \$5.95.

*Workman Publishing Co., Inc., 708  
Broadway, New York, NY 10003; NY,  
212/254-5900, elsewhere, 1-800/722-  
7202.*

### AUDIOVISUALS

#### AIDS, NOT US

Five young men, growing up in the city, struggle with their personal risks for HIV infection — each with a different perspective on the issue. The video covers condom use, homosexuality, dealing with a family member living with AIDS, and communication skills. For junior and senior high school-level students. 1989, 36 mins., \$125 plus \$5 p/h.

*HIV Center Video Library, PO Box  
050-168, Staten Island, NY 10305; 718/  
720-4488.*

#### AIDS: ALLIE'S STORY

Allie Gertz is a young woman who was infected with HIV when she was 16 years old. She now spends much of her time talking with young people about the disease and her experience. She comments, "In helping other people, I'm able to help myself," and

touches on such subjects as alcohol, acquaintance and date rape, and sexuality, explaining how each relates to HIV. For junior and senior high school-level students. 1990, 14 mins., \$250 (purchase), \$75 (rental).

An ABC 20/20 presentation. Distributed by AIMS Media, 6901 Woodley Avenue, Van Nuys, CA 91406, 1-800/785-4111.

#### ARE YOU WITH ME?

Highlighting the issues women face when negotiating safer sex with their male partners, this video profiles a mother and her teenage daughter — both sexually active — and their frank and honest discussions with one another. The daughter's discussions with her partner are more candid than the mother's, and the resulting tensions and interchanges between the two encourages discussion. For junior and senior high school-level students. 1990, 17 mins., \$65 plus p/h.

Produced by AIDSfilms. Distributed by Select Media, 74 Varick Street, Suite 305, New York, NY 10013; 212/431-8923.

#### THUMBS UP FOR KIDS

Using song, dance, rap tunes, and visual effects, a group of children learn that it is hard to become infected with HIV, and that it is safe to play with someone who has AIDS. One of the little boys in the group has AIDS and talks about it with the rest. Division into three segments allows for discussion between each. For preschool and early elementary school children. 1990, 23 mins., \$250 (purchase), \$75 (rental).

AIMS Media, 6901 Woodley Avenue, Van Nuys, CA 91406, 1-800/367-2467.

#### SAVING A GENERATION

For teachers of grades 4 to 12. Offers strategies to help reach students and implement HIV/AIDS programs. The package comes with two video tapes; a teacher's guide that provides preparation for addressing facts about HIV/AIDS; criteria for evaluating curricula and resources; solutions for overcoming personal barriers; and suggestions for dealing with sensitive issues. 1990, each 27 mins., package, \$95 plus \$10 p/h.

Select Media, 74 Varick Street, Suite 305, New York, NY 10013; 212-431-8923.

### CURRICULUM AND GUIDELINES

#### AUNT RITA'S PATIENT: A STORY ABOUT AIDS

St. Paul Area Chapter of the American Red Cross

An AIDS prevention program for children grades 4 to 6. In the activity book, which also includes a glossary, Melanie and Paul's Aunt Rita, a doctor, has a patient with AIDS. As she learns more about the disease, she shares her knowledge with Melanie and Paul. A Teacher's Guide accompanies the book. 1990, 40 pp., student activity book, \$1, teacher's guide, \$3.

St. Paul Area Chapter, American Red Cross, 100 South Roberts Street, St. Paul, MN 55107; 612/291-6711.

#### BUILDING BLOCKS: AN AIDS CURRICULUM GUIDE FOR EARLY ELEMENTARY EDUCATORS

St. Paul Area Chapter of the American Red Cross

Contains lessons for grades K to 3. Topics include: germs, staying healthy, sickness, and AIDS. The third grade program includes additional lessons on being different, the immune system, and communicable diseases. Each grade level includes an evaluation mechanism for the students. 1990, 126 pp., \$5.

St. Paul Area Chapter, American Red Cross, 100 South Roberts Street, St. Paul, MN 55107; 612/291-6711.

#### ON THE ROAD TO HEALTHY LIVING: A BILINGUAL CURRICULUM ON AIDS AND HIV PREVENTION FOR MIGRANT STUDENTS (GRADES 6 to 12)

Villarreal Analytical Management and Organizational Services for the National Coalition of Advocates for Students

Available in both Spanish and English, this curriculum consists of five 45-minute lessons on HIV. It presents decision-making, communication, and assertiveness skills, as well as basic information on HIV. Uses a cooperative learning approach: small group activities, role playing, and demonstration. Provides information on migrant Latino communities that impacts on HIV education. Offers very thorough information for teachers. 1990, 345 pp., \$12.95, \$2.00 p/h.

National Coalition of Advocates for Students, 100 Boylston Street, Suite 737, Boston, MA 02116; 617/357-8507.

#### LOOKING INTO AIDS

William Yarber

Much of the discussion in this curriculum, which is designed for middle school, is dedicated to self-esteem, assertiveness skills, and IV drug use. Includes an instructor's guide and a student handbook. The instructor's guide provides worksheets, "learning opportunities," and ways to implement an HIV/AIDS curriculum. 1989, instructor's guide, \$9, student handbook, \$2.

Phi Delta Kappa, PO Box 789, Bloomington, IN 47402; 812/339-1156.

#### PREVENTING AIDS: A GUIDE TO EFFECTIVE EDUCATION FOR THE

#### PREVENTION OF HIV INFECTION

Nicholas Freudenberg

This guide is divided into two sections — Planning AIDS Education Programs and Reaching Out: How to Educate Specific Population Groups about AIDS. Each chapter includes tables that provide clear information, and guidelines on the most effective and creative means for developing programs. 1989, 217 pp., \$22, \$17.60, APHA members.

American Public Health Association, 1015 Fifteenth Street NW, Washington, DC 20005; 202/789-5600.

#### SUMMARY OF THE NATIONAL FORUM ON HIV/AIDS PREVENTION & EDUCATION FOR CHILDREN & YOUTH WITH SPECIAL EDUCATION NEEDS

Association for the Advancement of Health Education

Presents the conclusions of the forum, which had as its objectives: determining the extent to which this population is at risk; identifying the most appropriate curricular delivery approaches; and determining the extent and methods by which HIV prevention education, and general health education needs, are currently met. 1989, 38 pp., free.

Association for the Advancement of Health Education, 1900 Association Drive, Reston, VA 22091; 703/476-3437.

#### TEACHING AIDS: A RESOURCE GUIDE ON ACQUIRED IMMUNE DEFICIENCY SYNDROME

Marcia Quackenbush & Pamela Sergent

This resource guide assists teachers in integrating AIDS information into existing courses. Includes lesson plans that cover the medical, social, and legal aspects of AIDS, and provides worksheets, trouble-shooting tips, and a resource listing. 1988, 159 pp., \$19.95 plus 15% p/h.

Network Publications, PO Box 1830, Santa Cruz, CA 95061; 408/438-4080.

#### TERRY & FRIENDS PRESENT AIDS EDUCATION

Creative Graphics

Activity book for grades K to 3 and 4 to 6, with teacher's guides. Each curriculum provides eight lessons. Learning modules, designed as single concept units, present basic information, lessons on germs, staying healthy, HIV/AIDS, on being different, refusal skills, and self-esteem. Illustrations present people of different races, and various family configurations are acknowledged. 1988, K to 3 and 4 to 6, \$95, complete package, \$175.

Creative Graphics, 127 South Main Street, Mt. Vernon, OH 43050; 614/392-4327.

## Conference and Seminar Calendar

**13TH ANNUAL NATIONAL CONDOM WEEK, February 14-21, 1991.** Sponsored by the Condom Resource Center. AIDS education organizations, universities, family planning centers, and public health agencies will staff information tables, organize events, and sponsor safer sex condom workshops to promote this nationwide celebration and educational campaign. Oakland, California. Contact: Condom Resource Center, PO Box 30564, Oakland, CA 94604, 415/891-0455.

**NATIONAL FAMILY PLANNING AND REPRODUCTIVE HEALTH ASSOCIATION'S 19TH ANNUAL MEETING, "PARTNERS IN PROGRESS: NFPHRA AND TITLE X," February 19-22, 1991.** Will feature a rally on Capitol Hill, the NFPHRA Awards Luncheon, workshops, roundtables, and professional papers sessions. Mayflower Hotel, Washington, DC. Contact: NFPHRA Annual Meeting, 122 C Street NW, Suite 380, Washington, DC 20001-2109, 202/628-3535.

**VII ANNUAL NATIONAL CONVENTION ON CHILDREN OF ALCOHOLICS, "DISCOVER YOUR MAGICAL HEART: THE HEALING JOURNEY HOME," February 24-27, 1991.** Plenaries will include Women and Self-Responsibility, Overcoming Perfectionism: Giving Up the Super-Human Syndrome, and The Miracle of Recovery: Turning Losses Into Lessons. Twin Towers Hotel and Convention Center, Orlando, Florida. Contact: U.S. Journal Training, Inc./Orlando, 3201 SW 15th Street, Deerfield Beach, FL 33442-8190, 1-800/851-9100.

**CHILDREN'S DEFENSE FUND ANNUAL NATIONAL CONFERENCE, "WHAT WORKS: BRIDGING THE GAPS FOR AMERICA'S CHILDREN," February 28-March 2, 1991.** Workshops include Coordinated Services for Minority Teen Parents and Pregnant Teens, Meeting the Needs of Homeless Families, and Developing Culturally Competent Programs for Children with Special Needs. Washington Hilton Hotel, Washington, DC. Contact: 1991 CDF Conference, c/o D&S Whyte Associates, 101½ South Union Street, Alexandria, VA 22314-3323, 703/548-2802, fax 703/683-0067.

**THIRD ANNUAL CONTRACEPTIVE TECHNOLOGY CONFERENCE, "ISSUES AND OPTIONS IN REPRODUCTIVE HEALTH CARE," March 7-8, 1991 (Washington, DC); April 4-5, 1991 (Anaheim, CA).** Sponsored by Contemporary Forums and Association of Reproductive Health Professionals. Will identify trends in contraceptive methods, and develop a comprehensive approach to contraceptive counseling. Hyatt Regency Crystal City, Arlington, Virginia; Disneyland Hotel, Anaheim California. Contact: Contemporary Forums, 530 La Gonda Way, Suite E, Danville, CA 94526, 415/820-2800.

**COMMITTEE FOR CHILDREN'S TEACHER TRAININGS, "Youth Violence Prevention," March 13-15, 1991, April 29-30; "Child Abuse Prevention," August 5-7.** Will provide the foundation for training educators in presenting curricula, such as *Talking About Touching* and *Personal Safety and Decision Making*. Seattle, Washington. Contact: Committee for Children, 172 20th Avenue, Seattle, Washington 98122, 206/322-5050.

**10% OF THOSE WE SERVE 6TH ANNUAL CONFERENCE, "TREATING LESBIAN AND GAY CLIENTS RECOVERING FROM THE ALPHABET OF ADDICTIONS: ALCOHOLISM, CO-DEPENDENCY, DEBTING...WORKAHOLISM," April 5, 1991.** Workshops will include sexual addictions, eating disorders, orientation to self-help programs, AIDS and recovery,

and incest. Keynote speaker will be LeClair Bissell, MD. John Jay College, New York, New York. Contact: Office of Gay and Lesbian Health Concerns, NYC Department of Health, 125 Worth Street, Box 67, New York, NY 10013, Michael Picucci, 212/242-5052 or Dava Weinstein, 212/799-0664.

**INTERNATIONAL FOUNDATION FOR GENDER EDUCATION'S FIFTH ANNUAL CONVENTION, "COMING TOGETHER — WORKING TOGETHER," April 8-14, 1991.** Programs designed for female and male crossdressers and transsexuals, wives and partners, friends, allied professionals, and support services. The Regency Hotel, Denver, Colorado. Contact: IFGE, PO Box 367, Wayland, MA 01778, 617/894-8340.

**THIRD NEW ENGLAND CONFERENCE ON WOMEN AND AIDS, "KEEPING WOMEN IN FOCUS," April 19-20, 1991.** Sponsored by the Fenway Community Health Center and the Boston AIDS Consortium. Will examine how sexual, political, religious, cultural, and economic factors affect women living with HIV. A Women's Health Fair will include information booths, performances, and demonstrations. The Westin Hotel at Copley Place, Boston, Massachusetts. Contact: Cynthia Rothschild, Women and AIDS Conference Coordinator, FCHC, 15 Haviland Street, Boston, MA 02115, 617/267-0900.

**SECOND ANNUAL REGIONAL CONFERENCE ON SEXUAL MINORITY YOUTH, "AFFIRMING DIVERSITY II," May 3-4, 1991.** Will focus on current methods of working with sexual minority youth and on improving techniques for youth-serving professionals. Topics will include sexual minority youth of color, street youth, mental health issues, and lesbian youth. Contact: John Barnes, AIDS Program Office, 3000 Newport Gap Pike, Building C, Wilmington, DE 19808, 302/995-8422.

**THE CENTER FOR EARLY ADOLESCENCE TRAINING INSTITUTES, "Training for Parent Educators," July 10-12, 1991 (Chapel Hill, NC), July 24-26 (San Francisco, CA), November 6-8 (Chapel Hill, NC); "Training for Program Planners and Youth Workers," April 10-12 (San Francisco, CA), May 15-17 (Boston, MA), October 16-18 (Chapel Hill, NC).** Contact: Registrar, Center for Early Adolescence, University of North Carolina at Chapel Hill, Suite 211 Carr Mill Mall, Carrboro, NC 27510, 919/966-1148.

**VII INTERNATIONAL CONFERENCE ON AIDS, June 16-21, 1991.** Florence, Italy. Contact: Giovanni B. Rossi, Istituto Superiore di Sanita, Department of Virology, Viale Regina Elena 299, 00161 Rome, Italy.

**FIRST INTERNATIONAL CONFERENCE ON SEXUAL ASSAULT ON CAMPUS, October 3-5, 1991.** Will focus on practical strategies and innovative approaches for reducing date rape, gang rape, and other forms of sexual violence against students. Orlando, Florida. Contact: Dr. Alan McEvoy, Department of Sociology, Box 720, Wittenberg University, Springfield, OH 45501, 513/327-7507.

**SOCIETY FOR THE SCIENTIFIC STUDY OF SEX 1991 ANNUAL MEETING, "RESPONSIBLE SEXOLOGY," November 7-10, 1991.** Inter-Continental Hotel, New Orleans, Louisiana. Contact: Howard J. Ruppel, Jr., Executive Director, SSSS, PO Box 208, Mount Vernon, IA 52314, 319/895-8407, fax 319/895-6203.