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P. Clay Stephens
Massachusetts Department of Public Health

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U.S. Women and HIV Infection

P. Clay Stephens, P.A.

Women are inadequately provided with HIV services and education and are differentially denied access to these. Divisions of race, ethnicity, economic class, and religion, among others, are compounded by sexual discrimination within each of these categories.

Review of current data on women with AIDS reveals that the reporting methods used convey a false impression that women are not at significant risk. Moreover, the persons indirectly affected by AIDS are predominantly women — mothers, sisters, partners, family members, teachers, and human service workers. Thus, AIDS is more of a women's issue than the statistics imply.

Women, as a gender-defined class, face major cultural obstacles to service, beginning with their characterization as "vessels of infection and vectors of perinatal transmission." Women are considered not as individuals worthy of attention, but merely as sources of the infection of others, that is, men and children.

Examples of barriers to service, of SOP (standard operating procedure), are explored through focusing on specific groups of women and their concerns: the unique peri-treatment issues of women intravenous drug users and their minority status among male users; the inability of mainstream health promotion campaigns to adequately address the gender differences within the minorities; the disregard for the reproductive rights of the mother in the rush to protect the fetus from HIV infection, and the lack of supportive care for the woman who chooses to continue her pregnancy; the blame placed on women prostitutes for "heterosexual spread," hiding the reality of their risk level and obstructing their utilization as models and instructors of risk-reduction activities; and the hostility and twin burden of sexual discrimination and homophobia directed toward lesbians (including those working in AIDS service organizations), which deny these women the ability to access and eliminate their own risk, if any.

The last section of the article explores gender-specific approaches to service delivery and proposes formats for change.

The opinions expressed herein are the personal opinions of the author and do not necessarily reflect the policies of the Massachusetts Department of Public Health.

P. Clay Stephens, P.A., is the coordinator of AIDS Resource Development for the AIDS Program at the Massachusetts Department of Public Health. She was previously involved in clinical HIV research at the Fenway Community Health Center in Boston and is a volunteer with the AIDS Action Committee of Massachusetts. Ms. Stephens has presented both nationally and internationally on women and AIDS.

The bulk of HIV-related services and education in the United States has been aimed at persons whose sex is consensual, whose use of drugs is recreational, and whose language is English; who have the resources to seek and choose their source of health care and counseling; and who have enough control over their own life and their family's lives to make the changes necessary to prevent infection, or to prolong their life and the quality of that life if they do become infected.

The people not yet reached are those whose sex is not or is only marginally consensual; for whom drugs are a lifestyle; who have diminished literacy; who are separated from the dominant culture by racial, ethnic, economic, and religious differences; who do not have access to the health care deemed standard in this society; and who, owing to institutionalized discrimination based on race, sex, and economic class, are not in control of their own and their family's future.[1]

This is not an accident. Most of the AIDS service organizations and the local, state, and federally funded services that followed were initiated by the gay male community or were a result of the lobbying efforts of that constituency. Beset both by a strange disease and by the effects of homophobia, this community began by taking care of its own. Although gay and bisexual men still represent the largest portion of persons with AIDS (PWAs),[2] these agencies have now included services for the full range of those affected by HIV infection. In January 1986, Richard Dunn, executive director of Gay Men's Health Crisis (GMHC) in New York City, described that organization's original client profile as a thirty- to thirty-five-year-old, middle-class, employed, white, gay male earning $35,000 or more per year. By late 1985 the typical GMHC client was a Black or Hispanic, twenty-two- to twenty-nine-year-old, unemployed, possibly Spanish-speaking, IV-drug-using mother of two.[3] In other words, a woman.

Outside the New York/New Jersey area, the change has been less dramatic but is still evident. Realizing that in most instances there would be few others ready and able to care for these nongay and nonmale groups, the AIDS service organizations (ASOs) have created minority and intravenous drug user (IVDU) programs within the scope of services originally designed for gay and bisexual men. Yet the flavor of the early orientation lingers. Programs developed for "single"[4] middle-class white men simply do not fit persons outside these bounds, however well intentioned these programs may be.

Whether speaking of women as a class, as a portion of those persons using IV drugs, or as members of the minority communities or other HIV-affected groups, they do not fit into the services designed for men belonging to these latter communities. The situation is aggravated by the realization that a woman seeking HIV-related services is usually seeking services for her children or other family members as well. (The persons and story described in the following vignette, and in the other vignettes throughout this article, are real; the names and identifiers have been changed to protect confidentiality.)

> Two babies, John and Marcus, tumble over one another, sharing toys, bottles, and occasionally their grandmother's lap. Portia's daughter died six months ago, leaving behind the twins and three older children. Portia feels very lucky that her grandchildren are well and that she has been able to keep them together. The oldest child, Nevita, has been having problems at school. The nurse at her new junior high insisted that she show proof that she is free of HIV infection even though her mother became infected from a transfusion she received after the twins were delivered.

From the perspective of cultural and racial minorities, Mario A. Orlandi discusses the "barriers to intervention experienced by population subgroups when the majority is targeted."[5] Design of prevention strategies must include recognition of the following:

> Language — failure to appreciate health promotion messages when language or symbols are used that are not understandable or are misunderstood by the subgroup;
>
> Reading level — using printed materials that are too sophisticated or beyond the reading level of the subgroup members;
>
> Models — using endorsements for the health promotion campaign from prominent individuals or organizations that are not well known to the subgroup members:
>
> Inappropriate messages — using motivational messages that are not salient to subgroup members;
>
> Motivational issues — the fear that the primary motivation for the health promotion campaign is the desire to control the subculture, robbing from it the specific practices that have historically defined it;
>
> Inappropriate target — the belief that the health promotion campaign is worthwhile, but that the designers never really intended the subculture to participate or to benefit;
>
> Welfare stigma — the tendency to view the health promotion campaign as a "handout" and to avoid it as a matter of pride;
>
> Perceived responsibility — the attitude that the campaign deals with subject areas and life choices that concern the family and the individual, not the public health establishment;
>
> Relevance of health promotion — the belief that more pressing concerns such as poverty, crime, unemployment, and hunger should be addressed prior to the health promotion campaign;
>
> Entropy — the tendency for subgroup members to perceive themselves as powerless or helpless when confronted with the enormous economic and sociocultural barriers and to express a lack of motivation to engage in self-improvement activities.[6]

While Orlandi's material was developed to assist in targeting minority health promotion activities, the concepts outlined should be utilized when the target groups differ from the majority by gender or economic class, or both. To fully appreciate the obstacle to service for women affected by HIV infection, it is necessary to understand just who these women are. As of February 1, 1988, the number of women with AIDS, ARC, and demonstrated HIV infection was estimated to be between 189,550 and 379,100. Among the 3,791 women with CDC-defined AIDS,[7] the primary routes of infection are their own needle sharing during intravenous drug use and sexually acquired infection from partners who are themselves intravenous drug users.[8] Other women have become infected through blood transfusions prior to screening of the blood supply in 1985; use of blood products or components, or both, prior to screening and heat treatment begun in 1985; and as partners of infected men. A woman could become infected through sexual contact with another woman if a sufficient amount of blood or body fluids was exchanged. As of February 1988, however, no woman with an AIDS diagnosis had been infected in this manner. (Women-to-woman transmission will be discussed later in this article.)

While the proportion of women among persons with AIDS (PWAs) in the United States has ranged consistently between 6 and 7 percent, it is important to recognize that women constitute a total of 27 percent of the population of PWAs in those groups into which a woman can be placed, that is, all groups except gay and bisexual men and intravenous-drug-using gay and bisexual men. Further, this figure is on the increase, having been 22 percent in the fall of 1987. As only full-blown cases of AIDS are reported in the United States, estimates of the population of women with ARC and HIV seropositivity are derived from seroprevalence studies and are confirmed by demographical information from alternative test sites (ATSs), clinics, AIDS service organizations, hotlines, and so on.

The demographic distribution in children with AIDS parallels that of infected women. Although the number of children with CDC-defined AIDS is relatively small — 789 as of February 1, 1988 — the number of children infected may be as much as ten to fifty times greater.

Women at risk for HIV infection include intravenous drug users and other needle sharers and/or unprotected sexual partners of men using intravenous drugs; and unprotected sexual partners of gay and bisexual men, of men infected through blood or blood products prior to 1985, or of male residents living in areas where HIV infection is considered endemic.

The groups of women just described are often the only ones discussed in AIDS articles and programs. However, the largest group affected by the HIV epidemic are those women responsible for the direct or indirect care of persons with HIV infection. Included are mothers, wives, sisters, and other female family members providing care in home and hospice situations throughout the course of infection up to and including death. Involved in the medical setting, and thus at risk of HIV infection, are physicians, nurses, ancillary

Table 1

Massachusetts Females by Age and Race*

	White		Minority		Total	
Age	No.	%	No.	%	No.	%
Below 13	4	3%	7	6%	11	9%
13–19	0	0	0	0	0	0
20–29	15	13	15	13	30	26
30–39	17	15	34	30	51	44
40–49	5	4	4	3	9	8
50–59	6	5	2	2	8	7
60 plus	5	4	1	1	6	5
Totals	52	45%	63	55%	115	100%

*In this table, race is not broken down beyond minority status. This is due to the need for confidentiality and is done wherever a specific identifier is under 5 total. Thus, "minority" includes Black, Hispanic, Asian/Pacific Rim, native American/Alaskan native, and other/unknown.

Source: Jeanne M. Day, AIDS epidemiologist, AIDS Program, Massachusetts Department of Public Health.

Table 2

Infection by Risk Behavior or Route, Massachusetts and U.S., as of February 1988

	Massachusetts				United States			
	Male		Female		Male		Female	
Risk Behavior/Route	No.	%	No.	%	No.	%	No.	%
Gay/bisexual male	725	72%			3,369	70%	—	—
Gay/bisexual male using IV drugs	43	4			3,858	8	—	—
Intravenous drug user	131	13	47	45%	6,961	15	1,916	51%
Hemophiliacs	15	1	1	1	499	1	20	1
Heterosexual contact	58	6	38	37	948	2	1,110	29
Transfusion recipients	17	2	13	13	793	2	413	11
Undetermined	24	2	5	5	1,248	3	332	9
Subtotal	1,013	100	104	100	7,676	100	3,791	100
Totals, Male and Female		1,117	100%			51,467	100%	

Source: Jeanne M. Day, AIDS epidemiologist, AIDS Program, Massachusetts Department of Public Health.

Table 3

Massachusetts Cases of Adult and Pediatric AIDS by Race and Sex in Comparison with Total U.S. Cases as of February 1988

		Massachusetts		U.S.		Massachusetts % of U.S. Cases
		No.	% of Sex	No.	%	
White:	Men	738	72.8%			
	Women	48	4.7			
	Pediatrics	8	0.7			
	Subtotal	794	78.3%	31,460	60%	2.52%
Black:	Men	180	17.7			
	Women	45	4.4			
	Pediatrics	9	0.8			
	Subtotal	234	23.0%	13,177	25%	1.77%
Hispanic:	Men	90	8.8			
	Women	10	1.0			
	Pediatrics	>5*	—			
	Subtotal	100*	9.9%	7,135	14%	1.40%
Other/unknown**	Men	5	0.5			
	Women	1	0.1			
	Pediatrics	4*	0.4			
	Subtotal	10	1.0%	484	1%	2.06%
Totals:	Men	1,013	—			
	Women	104	—			
	Pediatrics	21*	—			
	Total cases	1,138	—	52,256	100.0%	2.18%

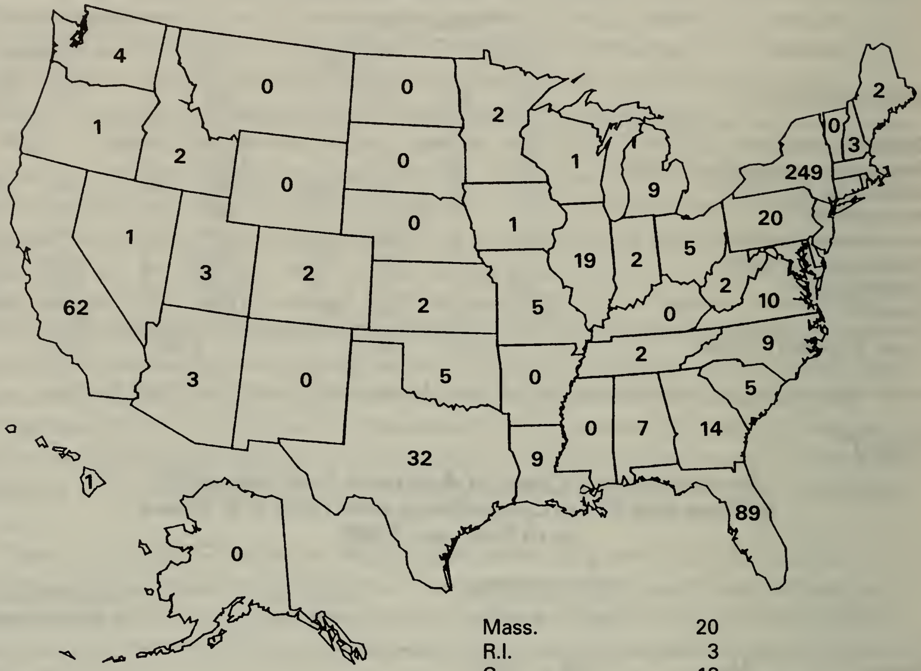
*This total is, as indicated, less than 5 and therefore not listed. The children in this category, if any, are listed in the undesignated ("other/unknown") group in an effort to protect confidentiality.

**"Other/unknown" includes but is not limited to Asian/Pacific Islanders, native American/Alaskan natives, those cases outside these categories included to protect confidentiality, and those cases where a racial factor was not known.

Source: Jeanne M. Day, AIDS epidemiologist, AIDS Program, Massachusetts Department of Public Health.

Figure 1

Pediatric AIDS Case Distribution, February 1988



Mass.	20
R.I.	3
Conn.	18
N.J.	103
Del.	2
Md.	20
D.C.	10
Guam	0
Trust Territories	0
Puerto Rico	30

Source: AIDS Weekly Surveillance Report — United States, AIDS Program, Center for Infectious Diseases, Centers for Disease Control, Atlanta, Ga., 1 February 1988.

and accessory personnel, social workers, and custodial and other institutional workers. Persons involved outside hospitals and clinics include hospice workers, home health aides and other home care staff, and visiting nurses. As women predominate in all helping professions, simple mathematics indicate that women provide the bulk of medical, home, and family care for persons with AIDS in the United States.

> Karen is a thirty-eight-year-old ICU nurse at a regional medical center. She works full-time, lives alone, and has just been hired to administrate the AIDS unit when it opens in sixty days. She says she has never been so challenged in her nursing career as she has been working with HIV-infected patients. She is never seen without a journal under her arm. Her smile widens as she tells you that when the epidemic is over, she would like to live in Florida or some other warm place. Karen has had difficulty staying warm since she was diagnosed with her first bout of PCP [*Pneumocystis carinii* pneumonia] just two months after her hemophiliac husband died.

As in other helping professions, educational and outreach workers in both public and private AIDS organizations are predominantly women, as are teachers, media specialists, and cultural, religious, and community service organization members serving the larger community in attempting to reduce the spread of HIV infection.

In a larger sense, it is women who perpetuate and teach cultural norms and who are central to the passage of those norms through child-raising activities, teaching professions, and social service activities. Women must be seen as targets of AIDS education within their instructional roles. They must be trained in the basic information as well as in techniques that will allow them to pass this information on to those around them.

Recognition of the role of women in the struggle to stop the spread of HIV infection should not be read as a belittlement of the efforts of the gay male community. Gay and bisexual men and the organizations they have formed were the first to address the issue of AIDS and as such have led the larger community in its attempts to understand the needs of PWAs and the social and political ramifications of the epidemic. The goal is, rather, to bring to light the contribution of women and to examine the burden placed on them by this disease.

What little attention has been given to women affected by HIV has been inappropriate, offensive, and a perpetuation of negative stereotypes. In Washington, D.C., at the Third International Conference on AIDS (June 1987), women were repeatedly characterized as ''vessels of infection and vectors of perinatal transmission,''[9] often by the same researchers who offered in their own work the suggestion that one must be sensitive to the differences of the particular male subculture within which their research was being conducted.

The danger of ''vessel and vector'' thinking is not only the personal and group insult delivered, but the blindness demonstrated and sanctioned therein. This results in lack of care, inappropriate services or no services at all, and inadequate funding — if any — for research and medical care. What begins as a phrase of epidemiological shorthand becomes a society-wide policy. Most of the problems are not new; they are simply viewed through another set of distorted lenses. AIDS is a paradigm for the condition of women within our society.

> Ellen lives in a small Maine community with her husband and three children, ages six, eight, and twelve. In the spring of 1983, she underwent surgery and received one unit of blood. She is a forty-mile-a-week runner and works full-time as a librarian. In October of 1986 she was notified by phone that the donor of her blood transfusion had developed AIDS and that she should be tested. She is antibody-positive. Her husband is negative and has remained so. She has since developed ITP and has to quit running, no longer works because of her fatigue, and has been on steroids for five months in an attempt to slow the drop in her platelets. She describes her life as working full-time to stay well and complains about the amount of work she must do to keep her various physicians in contact with one another and informed of new advances in HIV-related ITP treatment.

It is difficult to speak of the group of IVDUs as a community, since they are not self- or internally organized. The group has not yet come together to respond to the threat of HIV infection. Most services have been and will continue to be delivered by outsiders, whether social service personnel or recovering or ex-users who are working in their former communities.

As a group, IVDUs have a male:female ratio of 3:1 or 4:1; are undereducated and under- or unemployed; live in urban areas; are frequently members of a minority, possibly non- or minimally English-speaking; have low levels of literacy; are not available to the media; are involved in criminal behaviors aside from their drug use; and are members only of the street corner society and the drug underground.[10]

Women within this group are additionally segregated by their responsibility for family members (male partner(s), children, parents) and by their own pregnancies; are even less likely than their male counterparts to be English-speaking; are less press available; and are more likely to be working in the sex industry for drugs or money. Women are therefore involved in criminal behavior and activities and are at risk of interaction with the criminal system as well as with the welfare/social service systems.[11] The latter connection is often perceived as negative, owing to the power of social workers to remove children from their mother's custody or to interrupt the mother's financial aid as a punishment for various infractions. Even if employed, women often work at minimum wage or in unprotected occupations. Women's salaries continue to represent only 64 percent of men's wages,[12] thus furthering their poverty and alienation.

Very little research has been done on the pre-, intra-, and post-treatment differences between men and women. In preparation for a study of impaired female physicians, Carolyn A. Martin and G. Douglas Talbott conducted a survey of the literature on women and chemical dependence.[13] Although prepared for a particular class of women, their findings apply directly to women intravenous drug users. They noted:

- Women often began drinking later but sought treatment earlier, therefore accumulating fewer years of problems with drugs and alcohol. . . .
- Women's abuse is more likely tied to precipitating adult crisis. . . .
- Women have fewer persons involved in their life-support systems. Women, in fact, are often the support system for their families.
- Women have fewer financial resources.
- Women have fewer employment opportunities.[14]

Women in treatment also differ greatly in that they are in therapy singly or in small groups (unless able to enter a women-only program); are often housed separately from the male participants in inpatient settings and halfway houses; and frequently leave treatment either before completion or otherwise earlier than men, owing to family or financial pressures. Martin and Talbott wisely comment that the underlying realities "may be true for women in general — whether or not chemically dependent."[15] Upon closely observing the Georgia Impaired Physicians Program, the authors made note of intra-treatment problems facing women. Again, the setting is different, but the outcome of their review speaks directly to women intravenous drug users.

Most group treatment concepts utilize peer groups to deal with feelings, to refashion distorted beliefs, to develop nonchemical coping skills, and to establish new peer norms. Over 1,000 males but only 39 females entered the Georgia program between 1975 and 1986. While this may obviously represent problems of identification, intervention, and referral as well as the low proportion of women in the ranks of physicians, it also means that virtually no women entering the program were enrolled with true, that is, female, peers. Further, the confrontational methodology utilized may have been diametrically opposed to the needs of these women, in that women often entered already in touch with their feelings and needing to integrate diverse issues and pressures. The males conversely entered very much out of touch and needed to break down barriers and recognize diversity in themselves through techniques such as confrontation and encounter. Women's goals in treatment were as follows:

1. to trust the treatment concept and staff;
2. to open themselves to others; and
3. to cope with the realities of return to the community:
   a. that — although recovered — women drug users are seen as ''worse'' than male drug users, and
   b. that no matter how successful treatment was, women would return to a profession in which they encountered hostility and would remain a minority.

Martin and Talbott repeatedly, without naming it as such, point out the sexism and sexual discrimination that women physicians — and all women users — will continue to face before, during, and after treatment. They therefore developed a list of tasks for the treatment and recovery of women users:

1. Provision of women-only groups for the discussion of sexual and spiritual issues.
2. In groups of professional women, dealing openly with the lack of trust in each other engendered by constantly being in the minority.
3. If lesbian women are involved, provision of ground rules enforced for their safety in discussing lifestyle issues. Lesbian groups would be ideal.
4. Recognition that no treatment can change women's experience of their environment as hostile but can offer coping skills and the ability to recognize trustworthiness and support when available from women peers.

To put this in more explicit terms, there is the adage in the alcoholism treatment community that nine out of ten wives stay with their alcoholic husbands but nine out of ten husbands leave their alcoholic wives. This appears to be true in the IVDU treatment community as well. Treatment will not change these circumstances, but it is hoped that each individual woman will leave capable of coping with these stresses without having to resort to substance dependence and with the support of other women living and coping successfully with the same pressures.

Reproductive rights take on new meaning when applied to the issues of HIV infection. Often seen as a shorthand for the availability of abortion, the term *reproductive rights* is actually the umbrella concept of freedom of choice, supported by complete and bias-free information. Applied to HIV infection, it is the right of an infected or at-risk woman to obtain unbiased, factual, and up-to-date information about birth control, safer sex techniques, pregnancy, pregnancy outcome for herself and her child, and full access to supportive perinatal, pediatric, and abortion services. It is further the right of the individual woman to make her own reproductive choices and to have access to support both for her decision and for its outcome.[16]

It is not sufficient to offer the best of information and counseling and then send a woman out alone to seek care in a hostile environment. Unfortunately, early in the epidemic some abortion clinics demonstrated the same reluctance to serve HIV-infected women as did other types of medical facilities. Those clinics which did serve these women often marked charts visibly, insisted on ''spacesuit'' infection control measures, served the HIV-infected woman last during the clinic session, and kept her away from other women having procedures, thus denying her peer support.[17] Other clinics simply refused to serve any women who, by medical and sexual history, might be at risk of HIV infection. This was accomplished by stating that their clinic was not medically equipped or staffed to serve the HIV-infected woman and by providing a ready referral. Happily, instances of this policy are on the decrease, as the concept of universal precautions has become accepted and as the Centers for Disease Control (CDC), medical organizations, and associations have drafted policy and infection-control standards. What has not changed as readily is the attitude of the clinic staff, which often does not recognize that the HIV-infected woman, unlike the bulk of their clients, may be seeking termination not of an unwanted pregnancy but of a wanted pregnancy that was actively sought and that she has chosen to terminate upon learning of her infection and the possible outcomes. This situation, like that of the woman carrying a Down's syndrome child, has forced a review and subsequent change in the counseling and support offered to the HIV-infected woman in the abortion setting.

> Carol is twenty-seven, the mother of two infected children, ages two and one. She used IV drugs for a short time in 1982. She was the first known HIV-positive woman to deliver at a large urban New England hospital. After her Caesarean delivery, she and her baby were left unassisted in her room, and her meals and the baby's bottles were left on the floor outside her door. Social workers, standing gloved and masked in the doorway, berated her for ''giving her baby AIDS.'' Two years later, she and both children are doing very well. She delivered her second child at the same hospital in a warm and caring environment. Between the births she had ''starred'' in a training film for delivery room nurses dealing with HIV infection. She shared her first experience so that other mothers would not have to go through such rejection. The social workers came by during her second hospitalization to apologize and stayed to become friends.

The woman who is both HIV-infected and pregnant and who chooses to continue her pregnancy also finds it difficult to obtain adequate prenatal and delivery services that are supportive of her decision. Even if she is able to locate a clinician who has both an understanding of HIV infection and the personal ability to support her choice, she is still faced with discrimination and hostility from the other staff members. More than once, a receptionist or other ancillary staff person with access to the chart has accused a woman of willfully killing her baby with AIDS. Other women, having made the choice to continue the pregnancy, find themselves questioned repeatedly about their decision right up to the legal limit of availability of abortion. Some have even been offered the chance to abort in the third trimester only because of their HIV seropositivity.

This situation is difficult enough for the woman with the personal and financial skills to control the nature and quality of her health care. For the women most at risk of HIV infection, that is, women of color, women intravenous drug users, and women of lower socioeconomic status who may not share the language and culture of the individuals delivering counseling and care, the results are as reprehensible as those of the early seventies, when women of color and non-English-speaking women were being sterilized without consent.

This only confounds the situation of women who already have little or no access to adequate medical care during their pregnancies and whose attempts to obtain that care are met with hostility, discrimination, and disregard.

This does not occur simply at the health care delivery site but at all levels, including public policy. In early 1985, a Black physician, speaking during the question-and-answer portion of a public health issues conference, stated that ''no Black children should be born until there exists a cure for AIDS.'' Yes, he was responding to the devastating effect of AIDS-related illnesses on the community he represented, but as the Black women in the audience responded, ''No Black babies means genocide, whether we do it to ourselves or whether they do it to us.''[18]

> Doralina is struggling to tell her eleven-year-old son that she is ill and may not live through the year. He knows she has been tired and regularly sees the family doctor but he thinks she will be well soon. Every time she gets up the courage to tell him that she has AIDS and was infected by her boyfriend, who died last year, she stops. She remembers the AIDS jokes, and the derisive laughter floating up to her bedroom last summer as her son and his friends sat on the stoop.

Add the burden of current intravenous drug use to the situation, and the institutionalized hostility deepens. The typical drug treatment program does not take into account the reality that women care for children and other family members, nor does it consider that in comparison to men, women have less income and less insurance coverage for participation in drug rehabilitation programs, or that they may be pregnant at the time of seeking services. In fact, a great number of women see pregnancy as a time and a motivation either to become drug free or to go on methadone. Long waiting lists characterize drug rehabilitation and detoxification programs. Even entry into such a program does not solve a woman's problems. Once in, she must try to avoid any situation or circumstance that might cause her to leave. But not every woman can. For instance, let's suppose that a woman who has been on a waiting list for many months to enter a methadone maintenance program is notified that she may now begin treatment. Having placed her children in the care of her mother, she enters the program and is doing well as a resident, but then learns that one of her children has become ill. In order to meet the needs of that child, she may have to leave the program, even though doing so could jeopardize her chances of returning. Reentry might involve penalties — such as increased chores and delayed or withheld privileges — or being placed again at the bottom of a lengthy waiting list. This can happen and has happened even to pregnant women, who are thereby forced back onto street drugs.[19] Other women find that in order to have their rehabilitation program paid for by the state or local government, they must give up or sign off custody of their children; if a woman should subsequently leave the program, regardless of the reason, her children may be taken from her.

As the result of these and other instances of standard operating procedure (SOP), the very women who need the services most are prevented from obtaining them. Social commentators have remarked that SOP will kill us all, and the statement may never have been so true as in the fight against AIDS.

> Thea is a family practitioner who has for many years shared a practice with another GP to allow her time to work both medically and politically with women working in

> the sex industry. With the AIDS epidemic came an increased involvement in the sharing of safer sex techniques and a concentration on the civil rights of sex workers. Later this year, she will leave her current practice to join that of another friend, which has become exclusively HIV-oriented. She will continue her political work and has begun a support group for family practitioners working with PWAs.

Even the most enlightened and exceptional programs can be handicapped by rules and regulations. In The Hague, the Netherlands, a needle exchange program operates between 1:00 and 5:00 in the afternoon, Monday through Friday. In Great Britain, heroin prescriptions for registered addicts are available Monday through Friday. On Friday, when the addict receives a three-day dose, it is usually taken or sold immediately, thus putting the addict back on street drugs for the weekend.[20, 21] In the United States, safer sex information is printed in slick brochures, clinical language, and, for the most part, only in English. AIDS service providers can be and are prevented by their funding sources from using vernacular; printing explicit materials; providing condoms, dental dams, and needle cleaning supplies;[22] mentioning abortion as a reproductive option; referring to birth control services;[23] speaking about sex or drugs to anyone under age eighteen;[24] discussing same-sex and nonmarital sexual activities; or offering alternative or non-Western medical treatment options.[25] Individuals and agencies can be forced to spend as much time justifying their services as they do delivering them. Creativity is stifled by a funding process that is both lengthy and ornate. Individuals, groups, and associations informally delivering services are often passed over in favor of established agencies even though they have no hands-on AIDS experience.

HIV counselors have related cases in which women clients have listed other infected or at-risk women as their only possible source of infection. Numerous letters in medical journals have postulated this route, but none of the letters, as written, withstand scrutiny.[26]

Prior to 1985, the word ''AIDS'' or the thought of HIV infection was rarely, if ever, associated with the word *lesbian.* This invisibility stemmed both from the lack of recognition of women's contribution to AIDS service organizations and from the conspicuous absence of lesbians from the Centers for Disease Control Risk Group list. The fall of 1985 was the beginning of a new era of recognition: lesbians were proclaimed to be ''God's chosen children''[27] and to be free of any fear of HIV infection. As with most stereotypes, this proclamation was no blessing. Half the lesbian community celebrated their ''immunity'' by continuation of all sexual and drug-related behaviors without scrutiny, while the other half wondered, ''If we are so free, why do we feel so bad?''[28] Thus began a conflict that continues to the present: how to educate the lesbian community about the realities of HIV infection without creating hysteria; how to be recognized by gay men and the heterosexual community without inviting further homophobia and discrimination; and how — within the gay community and the AIDS service organizations — to address the misogyny and oppressive behaviors directed at women. The resolution of this conflict is hampered by the dismal lack of understanding of lesbian sexual practices and the social consequences of living a lesbian lifestyle.

Within the lesbian and gay community, gay males are the prime targets in AIDS public education activities sponsored by AIDS service organizations. Male educators often regard lesbian risk as trivial compared to their own, or, as mentioned above, nonexistent. Lesbian sexuality — and women's sexuality in general — is perceived as boring at best and contemptuous and disgusting at worst.[29]

By 1988, the seventh year since the recognition of the syndrome, only eight women with AIDS have identified themselves as lesbians; two other women identified themselves as engaging exclusively in same-sex activity.[30] All of these women are or were intravenous drug users or transfusion recipients whose sexual identity and practices had nothing to do with their route of infection. As the number of CDC-defined adult AIDS cases in the United States was 51,467 as of February 1, 1988, the total lack of woman-to-woman transmission of infection is profound.

It must be remembered, however, that in the United States only cases of full-blown AIDS are reportable; thus, if there are any cases of ARC or HIV seropositivity in lesbians, there is no documentation of them. Personal communications and letters to medical journals have filled this gap. Lesbian health care workers and AIDS service providers have discussed two sets of lesbian partners in which one woman was infected through IV drug use and her partner became infected through significant contact with the other's menstrual blood.[31] Additionally, a letter to the *Journal of the American Medical Association* in December 1986 attempted to document woman-to-woman transmission via ''traumatic sexual activities.'' This particular case was originally reported by Sabatini and Hirschman in the 1984 *AIDS Research Journal.*

Marea Murray exhaustively dissected the *JAMA* letter and the original report in the July 31, 1986, edition of the Boston newspaper *Bay Windows.* This same analysis appeared in *Gay Community News,* another Boston publication, the following month. Murray concluded that the newly infected woman had a much greater chance of having been infected by her two male sexual partners than by her woman partner, given the dates of appearance of symptoms. The point is not to argue ''medical'' events, but to note that the researchers' lack of understanding of female/female sexual activity led them to discount behavior that has led to transmission many times over in favor of behaviors that, though exotic to these physicians, have yet to be shown to be more than a theoretical risk. Murray further pointed out the following:

> Lesbians do need to consider our own behaviors and decide for ourselves, between ourselves, with our partners whether to engage in safer sex and which behaviors that might include as well as what changes we wish to make (if any). No one is immune here and as women and lesbians (or bisexuals) we are the least likely groups to be addressed, considered, or informed about how to be safer.[32]

A lesbian is at risk of HIV infection, as is any woman, only to the extent of her risky behavior. Her identity is neither protective nor condemning. Once again it becomes clear that it is particularly important to discuss specific practices rather than personal sexual/political identity and that the discussion must be free of prejudice toward particular sexual activities.

> Claire is bored, lonely, and disgusted. Last night she met a nice woman at the alcohol/chemical free women's dance and invited her home for the night afterward. After a cup of tea, Claire explained to Shirl that she needed to use safer sex. Shirl got upset — practically screaming — calling her ''stupid, paranoid, and male-identified'' for thinking that two women could transmit HIV to one another. ''I thought you were strange when you said you volunteered at the AIDS project,'' she said when she was asked to leave. A recovering needle user, Claire hopes someday to meet a woman who understands and believes safer sex is the right thing to do. Until then, she'd rather be lonely.

Actual infection, however, is not the only risk this epidemic brings to lesbians. AIDS phobias have contributed to an increase in discrimination, gay-bashing, and an organized assault on the civil rights of the entire homosexual community, lesbians included.

Lesbians are often the recipients of this backlash in that the media has not until recently discussed HIV infection in broader than ''gay'' terms. Hearing this term repeatedly, the general public does not distinguish between lesbians and gay and bisexual men.

The recently experienced increase in homophobia and violence is dramatic. In a Boston gay-bashing incident in early 1987, the defendants excused their attack on two young lesbians by stating that they thought the ''girls'' were ''faggots.''[33] This was offered as a legitimate apology, as if to say that their actions would have been excusable if the ''girls'' had actually been ''faggots.''

Situations such as these have led some individuals to discuss the safety of ''out'' lesbians, especially those living in small communities or in neighborhoods where bashing has occurred. The repeal or failure of passage of civil rights laws, the reinstitution of sodomy laws or defeat of repeals, and the continued struggle over child custody, foster care,[34] and adoption have led women to believe that the heady time of gay and lesbian rights which followed Stonewall[35] is over.

The AIDS epidemic is not occurring in a vacuum, but in the laboratory of society and culture. Thus, this same homophobia has caused some AIDS service organizations that had begun as grassroots responses to the crisis to ''become a business''[36] and attempt a single-focus response. While concentrated effort can be laudable, it is ironic that most of the struggles that are dropped in favor of AIDS-only activities are those which affect women's lives: reproductive rights; child-care provisions; birth control and abortion; foster care and adoption; the Equal Rights Amendment; welfare; and health care. While some of the single-issue impetus stems from the misguided concept that if the gay-run agencies ''behave'' they will continue to be funded, the stance is based partly on a disinterest in and lack of knowledge of women's issues and is held together by internalized and institutionalized homophobia within the service agencies themselves.

> Harriet was infected by her bisexually active husband. She had known about his attraction to men for years. She and Ted had a wonderful relationship, two great teenagers, and a wide spectrum of professional and personal friends. The instant that they heard about the sexual transmission of AIDS, Ted stopped his risky behaviors with men and Harriet and he limited their own sexual activity to safer practices. When the HIV antibody test became available in 1985, they both tested antibody-positive. Ted now has ARC and Harriet is asymptomatic. Both volunteer their professional skills to the local AIDS service organization.

From the beginning of the epidemic, prostitutes have been implicated in the spread of AIDS. Sex workers are often the first ones blamed and the first to be restrained physically or legally during spread of a sexually transmitted disease.[37] Prior to the availability of HIV antibody testing, prostitutes were predicted to be the main source of AIDS spread into the ''general population,'' and as such were listed among the groups at high risk. Forgotten were the thousands of male IVDUs and their sexual partners among the ''general population.'' Also forgotten were the ranks of heterosexually identified men living comfortable lives in the cities, suburbs, and countryside, replete with wives, children, jobs, and churches, who have same-sex encounters on business trips, over weekends, or at sex shops/movie houses. Prostitutes were not listed to notify them of their own risk, but to place the rest of the community on notice that, as always, one must avoid wicked women if one desires to stay clean.[38]

With the advent of the HIV antibody test, evidence has begun to accumulate that, indeed, the exchange of money does not spread AIDS. Diane Richardson states in *Women and AIDS:*

> Studies suggest that ''unless a prostitute injects drugs she is unlikely to be infected with HIV. Although only a minority of prostitutes are IV drug users, some women who are ''on the game'' use prostitution as a way of getting drugs or money to pay for drugs. In New York, for instance, injecting drugs is reported to be most common among the group of prostitutes known as streetwalkers. It is estimated that in the United States about 10–20% of prostitution involves street prostitutes. These are women who pick up their clients on the street rather than through, say, an escort agency. As a high proportion (some estimate as many as half) of the city's injecting drug users are believed to be infected with the virus, this may explain why some street prostitutes in New York, and cities like it, are reported to be at risk.[39]

Richardson goes on to delineate the confounding issues of race and economics:

> A large number of street prostitutes are working class and black women. While this is partly related to poverty, it is also due to the racism which prevents black prostitutes from working indoors in brothels and casinos, or for escort agencies. It is street prostitutes who, because they are more ''visible,'' have particularly suffered from increased harassment . . . one result of blaming prostitutes for spreading AIDS.[40]

Rarely is concern for the prostitute herself mentioned outside the women's and feminist press. Most outreach projects have been designed to keep the sex worker from infecting others rather than from becoming infected herself. Heterosexual transmission studies have attempted to document female-to-male transmission and thus permanently afix blame. Robert R. Redfield, M.D., has repeatedly blamed women for transmission of HIV infection to men, and, thus, for infection among military men. After his article appeared in 1985 in the *Journal of the American Medical Association,* many people began to dispute his premises. Priscilla Alexander writes in *Sex Work:*

> A series of letters have been published in *JAMA* disputing [Redfield's] findings for a variety of reasons, including the consequences of admitting to homosexual activity and/or IV drug use in the military. Interestingly enough, when the United States Army tested fifteen prostitutes near a US Air Force base in Honduras and found that six of the women were seropositive, and then claimed the study as proof that prostitutes were infecting GI's, Redfield disputed their claim. He said that the direction of transmission was more likely to be from the GI's to the prostitutes, because none of the women in the study used IV drugs.[41]

Few have recognized sex workers for what they are: a multifaceted community of women — and men — who, through their provision of sexual services, are experts at sex. By concentrating on the street worker — the woman most likely to use IV drugs, most likely to be a partner of a male IVDU, and most susceptible to economic pressure from her customers to not use a condom — the media and others have ignored the larger population of sex workers. It is this group that can serve as ''sex experts'' and assist in the design of relevant safer sex materials for the larger community. It is this group of women who can, working together with AIDS service organizations, design projects that will educate and support street workers so that they can institute safer sex guidelines and avoid the risks of needle use and sharing of those needles. Again, Richardson sums this up well:

> In many ways it is ironic that prostitutes have been scapegoated for AIDS. Contrary to popular belief, prostitutes are among the best informed as to how to protect themselves and others from sexually transmitted diseases, including AIDS. After all, it makes good business and health sense for them to know. While it is a common assumption that prostitutes spend most of their time engaging in high-risk sex with their customers, few studies exist of what men specifically pay prostitutes to do for them.[42]

In Africa, prostitutes are being used as sex educators in a condom-use campaign aimed at married heterosexual couples.[43] In the Netherlands, the women of Red Thread and Pink Thread, organizations of sex workers and women working with and in support of sex workers, respectively, organize condom-use campaigns among ''window'' prostitutes and help women to find work only in those brothels which support condom use.[44] In California, wine, cheese, and safer sex materials are served to working women during educational sessions held in the ''trick hotels,'' and the women leave with condoms and other safer sex equipment.[45]

> Jacqueline does not consider herself a prostitute but occasionally refers to her lunchtime activities as ''hooking.'' She earns $250.00 a day performing oral sex on ten to fifteen ''johns'' cruising in their cars during the noon hour. She always uses a condom, placing it on their penis with her mouth. The john rarely knows it is in place until after his climax. Still she worries about AIDS, wondering how she would support her kids and her disabled brother without this income. Pretending to her family that she is a secretary, she spends a great deal of time reading in the public library. Lately she has read more about HIV infection and is not amused at the blame placed on sex workers. ''So why don't the police arrest johns who try to pay us girls more to skip the rubber?''

Women, as a class defined only by gender, are as varied, as different as can be imagined. What we share is the experience of living in a society that systematically denies our reality, or world view. It is not sufficient simply to provide child care at every AIDS meeting and service if we can't get to the meeting because of economic, class, educational, cultural, and language barriers. The situation requires an overhaul of the very basic concepts of health care and social service. In planning for the future, it is imperative to struggle against these old ways of being and to ensure that changes are made in the manner and style of service delivery. Each program must incorporate the following concepts or activities:

1. Women's caucuses should be established to design, implement, and monitor all women's AIDS/HIV services and projects. Minority women should constitute at least 51 percent of these caucuses.

2. All written and audiovisual material must be culturally sensitive, and should ideally be produced by members of the community at which the material is aimed. The material must be composed in language and vernacular that are understood by the community and must take into account the level of literacy of the target group. Cultural roles must be respected,

and material must be made accessible to those persons, especially women, who occupy specific modeling roles. These materials must be available to an individual without causing him or her to be identified as personally ''AIDS-concerned'' by other members of the neighborhood or community. Moreover, not all members of a particular group are identical. Materials should reflect, for instance, the differences between Hispanics on the East Coast who have come from Puerto Rico and those on the West Coast who identify as Chicano. Terminology, religious orientation, roles, role models, and many other determinants may vary.

3. Projects for education and risk reduction should follow the same guidelines as those listed in item 1 above. Additionally, funding should be in the hands of the communities affected, enabling persons to work within their own community. Assistance should be available at the governmental funding level to assist new community groups, organizations, agencies, and associations that previously have not received large-scale funding so that they can equip themselves with the knowledge and expertise necessary to administer these projects.

4. Materials and equipment needed for risk reduction should be readily available at no cost and in a manner (place, time, and situation) which is supportive of their use. This includes a broad range of personal sexual risk-reduction materials, such as condoms, dental dams,[46] and spermicide as well as IV-drug-related materials, such as bleach, water, and clean needles and syringes (''works''). Gloves, face masks, plastic barriers, needle disposal containers, and other equipment that contributes to the home and community-level care of infected individuals must similarly be available.

5. Women must have readily accessible entry into drug and substance abuse programs that are designed around the concerns and issues of women and that provide child care or incorporate the family unit into the care facility program. A wide range of programs must be made available so that a woman can choose to protect herself and her family from HIV infection *now* and yet choose to deal with aspects of her drug dependence at a later date. No longer can we require a woman — or a man — to come to grips with addiction as a condition of access to life-saving HIV risk-reduction materials.

6. Custody, adoption, and foster care procedures and regulations must be revised to allow a woman the right to designate who will care for her children, and in what manner, at her death or the point at which she cannot provide care herself, while allowing her to retain custody up to that point.

7. Antidiscrimination laws concerning HIV infection, risk of HIV infection, and testing must be enacted and enforced. Antidiscrimination laws

pertaining to sex, race, ethnicity, and language must be enforced to provide access to vital information and services for disenfranchised groups. Public health regulations and reportable disease regulations must be applied carefully and with the recognition that confidentiality is relative[47] and that anonymity is optimal. Public accommodations and employment nondiscrimination clauses must be enforced.

8. Same-sex sexual practices, sex in exchange for money, and IV drug use must be decriminalized so that individuals engaging in these practices can come forward and seek care without constraint.

9. Shelters, halfway houses, residences, and hospices must be available in every community for women and children. Children in AIDS-affected families who are themselves uninfected must receive appropriate support and hospice services, as do their infected siblings and other family members. The family unit must be protected and supported even during the course of disintegration under the weight of HIV infection. The family members should not be forced to separate from each other in order to receive services.

10. School curricula concerning HIV infection must be developed for all school levels to alert children of the effects of AIDS and its strains on our communities and to provide them with personal risk-reduction information. Moreover, as infected children, born of infected parents — not only children who are hemophiliacs or transfusion recipients — will be attending school in increasing numbers, these curricula can pave the way toward inclusion by their peers in all school activities while also teaching the concepts of infection control in both a home and school setting.

11. Communities must be helped to provide HIV-specific services to the citizenry, but must also integrate HIV-infection awareness into every level of community activity. Each service must be available to each citizen in an appropriate and sensitive manner, whether or not that person is HIV-infected.

12. Participation in medical research and access to experimental treatment and drugs must be increased for women. Research efforts must not continue to focus on women only in their reproductive capacity.

Finally, more individuals and groups must broaden their focus to include the struggle for civil rights, health care, and support for women, people of color, IV drug users, lesbians, children, gay and bisexual men, and all those threatened by HIV infection.

> Sherry is seven years old. Her mother and her little brother died last year. She doesn't know what happened to her father. She goes to the same school she has always attended but lives with her grandparents a few blocks from her old house. Most afternoons she stays inside after school. The kids in the neighborhood think she will make

> them die just like her mom and her baby brother. Her only playmate is eight-year-old José. His mother has AIDS, so he isn't afraid to be around her.

While many ills of society must continue to be addressed, there remains but one overriding agenda: the halting of the AIDS epidemic and the end of the discrimination that has furthered its spread and increased the suffering of our entire community.

Notes

1. It is the intention of the author to accord the communities of women — and men — addressed herein the recognition and respect they deserve. Thus, each reference to a specific community, the lesbian, gay, Black, women's, and so on, was capitalized as an indication of that recognition. Most of these capitalizations have been removed in the interest of stylistic consistency with the rest of this journal. Might this, though small, be a part of the SOP (standard operating procedure) that diverts us from validating the lives and world view of others?
2. *AIDS Weekly Surveillance Report — United States,* AIDS Program, Center for Infectious Diseases, Centers for Disease Control, February 1, 1988.
3. AIDS and Public Policy Conference, New York City, January 1986.
4. Gay and lesbian couples have yet to receive the status and recognition accorded heterosexuals. Thus, gay men are listed as single in most discussions of demographics. Pertinent to this article is the fact that, regardless of relationship status, gay men rarely have sole custody and responsibility for children.
5. Mario A. Orlandi, "Community-Based Substance Abuse Prevention: A Multicultural Perspective," *Journal of School Health* 56, no. 9, November 1986, 394.
6. Ibid., 397.
7. *AIDS Weekly Surveillance Report — United States,* February 1, 1988.
8. Ibid.
9. "Open Letter to the Planners of the International Conference on AIDS," International Working Group on Women and AIDS, Washington, D.C., June 1988.
10. Sam Friedman and Don Des Jarlais, "AIDS and the Social Organization of Intravenous Drug Users," presented to the American Anthropological Association, Philadelphia, December 1986.
11. P. Clay Stephens, P.A., "Politics of Women and AIDS," Women and AIDS Conference, Boston, October 1986.
12. United States Department of Labor, 1987. Please note the increase from 59 cents for every male dollar earned.
13. Carolyn A. Martin and G. Douglas Talbott, "Special Issues for Female Impaired Physicians," *Journal of the Medical Association of Georgia* 75, August 1985, 483–488.
14. Ibid., 484–485.
15. Ibid., 485.
16. P. Clay Stephens, P.A., "Reproductive Rights and AIDS," Women and AIDS Conference, Boston, October 1986.
17. David Polando, personal communication, May 1986.
18. AIDS and Public Policy Conference, New York City, January 1986.
19. "Sarah," personal communication, August 1987.
20. Michael Adler, editorial: "AIDS and Intravenous Drug Abusers," *British Journal of Addiction* 81, 1986, 307–310.

21. D. Colin Drummond et al., "Replacement of a Prescribing Service by an Opiate-Free Day Programme in a Glasgow Drug Clinic," *British Journal of Addiction* 81, 1986, 559–565.

22. Judy Spiegel, "Addictaphobia in AIDS Client Advocates," National Lesbian and Gay Health Foundation Conference, Washington, D.C., March 1986.

23. In roundtable discussions with ATS (alternative test site) counselors and HIV educators, these restrictions have been the most troublesome.

24. Hotline counselors are required, in many cases, to inquire about the age of the caller before answering explicit questions or mailing out explicit sexual risk-reduction guidelines.

25. Spiegel, "Addictaphobia in AIDS Client Advocates."

26. Debbie Law, speaking as a member of a panel entitled "Lessons from the Recent Past: What Gay Men and AIDS Service Providers Might Learn from the Women's Health Movement." Moderated by Urvashi Vaid and presented by Debbie Law, Veneita Porter, Suzann Gage, and Suzanne Farr, National Lesbian and Gay Health Foundation Conference, Los Angeles, March 1987.

27. Marshall Forstein, M.D., AIDS and Mental Health Conference, Boston, May 1986.

28. Suzann Gage and Lisa Tackley, "Lesbians: STD's, AIDS, and Safer Sex," National Lesbian and Gay Health Foundation Conference, Los Angeles, March 1987.

29. Veneita Porter, speaking as a panel member, "Lessons from the Recent Past."

30. George Seage, M.P.H., senior AIDS epidemiologist for the Boston Department of Health and Hospitals, personal communication, June 1987.

31. Participants, "Lesbians Working in AIDS Organizations," National Lesbian and Gay Health Foundation Conference, Los Angeles, March 1987.

32. Marea Murray, letter to the editor, *Bay Windows,* 4, no. 31 (July 31, 1986).

33. *Gay Community News,* "News Notes," August 1986.

34. In Massachusetts in 1985, two foster children were removed from the home of a gay male couple. There were no problems with the placement; the removal occurred solely on the basis of the couple's sexuality. Regulations were then passed requiring that placement in traditional families be given priority, thus essentially eliminating the possibility of a placement in the home of any single person or any gay or lesbian couple. A state advisory committee later recommended that this restriction be lifted. The governor has yet to act on the recommendation. The matter is currently in the courts.

35. Stonewall, a drag bar in New York City, has given its name to the riots that marked the beginning of the Gay and Lesbian Rights Movement of the last twenty years.

36. David Polando, HIV counselor, Portsmouth Feminist Health Center, Portsmouth, N.H., personal communication, May 1986.

37. Vern Bullough and Bonnie Bullough, *Women and Prostitution: A Social History,* Prometheus Books, Buffalo, N.Y., 1987.

38. Marjo Meyer, M.D., "Red Thread and Pink Thread," National Lesbian and Gay Health Conference, Los Angeles, March 1987.

39. Diane Richardson, *Women and AIDS,* Methuen Press, New York City, 1988, 43.

40. Ibid., 43–44.

41. Frederique Delacoste and Priscilla Alexander, *Sex Work,* Cleis Press, Pittsburgh, Penn., 1987, 254.

42. Richardson, *Women and AIDS,* 44.

43. "AIDS in Developing Nations," roundtable discussion, Third International Conference on AIDS, Washington, D.C., June 1987.

44. Marjo Meyer, M.D., "Red Thread and Pink Thread."

45. Gloria Lockett, "Women and AIDS," Homosexuality, Which Homosexuality Conference, Free University, Amsterdam, the Netherlands, December 1987.

46. A dental dam is a square of latex approximately six by six inches, typically used during dental procedures as a barrier. As condoms are useful only for sexual activities involving a penis or a penis-shaped sex toy, individuals have used dental dams as a safer sex barrier during oral-genital female-receptive and oral-anal sexual contact.

47. Although medical and professional ethics regulate confidentiality, and although some states, such as Massachusetts, have HIV confidentiality laws or regulations, the protection is only as good as the individuals and agencies participating. There exists, as well, a tension between the duty to warn and the obligation to honor confidences in the medical arena. Anonymity is preferred, in that with no identifying information there can be no breach.

Additional References

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