CALIFORNIA MODELS FOR WOMEN`S AIDS EDUCATION AND SERVICES

by

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Introduction: The AIDS Epidemic

To say that the AIDS epidemic continues to grow is to repeat an obvious fact. Yet the growth must be observed and understood in order to develop policies and programs which can meet and respond to the specific groups (including certain subsets of women) affected by this serious new illness.

Between January 1979 and December 1984, a five-year period, 8,954 AIDS cases were reported to the CDC. The case reports multiplied at a steady rate, as indicated in Table 1. As of June, 1985, 49% of those stricken had died.

Date of diagnosis		No. of cases	No. of deaths	Case fatality rate
1979	Jan.-Jun.	1	1	100%
	Jul.-Dec.	10	8	80%
1980	Jan.-Jun.	19	15	79%
	Jul.-Dec.	28	28	100%
1981	Jan.-Jun.	81	71	88%
	Jul.-Dec.	174	145	83%
1982	Jan.-Jun.	353	267	76%
	Jul.-Dec.	626	443	71%
1983	Jan.-Jun.	1163	789	68%
	Jul.-Dec.	1507	984	65%
1984	Jan.-Jun.	2256	1190	53%
	Jul.-Dec.	2728	929	34%

Table 1: Number of reported AIDS cases by half-year of diagnosis. 1979-84. Data from Centers for Disease Control, June 3, 1985. Surveillance Report.

The number of cases per million has risen steadily. Between January and June of 1985 alone, the number of cases per million nationally has risen from 35.1 to 46.9. In San Francisco the rate has climbed from 287.9 to 384.2. (1) The illness has also spread to new locations and populations. Initially concentrated in a few major metropolitan areas, it is now in all 50 states. The percentage of total cases in the major cities is shrinking and the proportion in more rural states and districts is growing. Table 2 indicates this trend during the first six months of 1985.

SMSA or Residence	Dates of Diagnosis					
	1/1/81 - 1/21/85			1/1/81 - 6/3/85		
	N	%	cases p. million	N	%	cases p. million
New York, N.Y.	2855	36	313	3615	33.9	396.4
San Francisco, Ca.	936	12	287.9	1249	11.7	384.2
Miami, Fl.	305	4	187.6	368	3.4	226.4
Newark, N.J.	217	3	110.4	270	2.5	137.3
Elsewhere	3668	46	14.7	5176	48.5	23.9
Total U.S.	7981	100	35.1	10678	100.0	46.9

Table 2: Comparison of AIDS cases by Standard Metropolitan Statistical Areas in January and June, 1985. Source: CDC Surveillance Reports of 1/21/85 and 6/3/85.

N = no. of diagnosed cases
% = % of total U.S. cases
cases p. million = no. of cases per million inhabitants

Although the cities with the highest rates of AIDS cases continue to have more illness diagnosed (e.g., the case per million rate in San Francisco has jumped from 284.9 to 384.2 between January and June of 1985), the distribution is broader. The cities listed in Table 2 (among the top five in terms of cases per million at both countings) now have a lesser share of the total number of cases than they did in January. This change demonstrates the continuing rapid spread of the epidemic. The implication for preventive education and for services is that these also must become more widely distributed outside the major metropolitan areas.

While AIDS has always affected both men and women and persons of all sexual orientations, its sexual spread has previously been more rapid among gay men than among the heterosexual population. Epidemiological evidence indicates, however, that as a sexually transmitted disease AIDS is currently spreading among heterosexuals at a progressively faster pace. As Table 3 indicates, the number of AIDS diagnoses for which heterosexual contact was the primary risk factor rose from 59 in January 1985 to 97 by June 1985, a 64.4% increase. The number of cases where homosexual contact was the suspected route rose from 5,748 to 7,732, an increase of 34.5% The heterosexual rate of increase was 1.86% times that of the homosexual contact rate of increase.

	Suspected Route of Transmission	
Date	Male-Male Contact	Male-Female Contact
1/21/85	5748	59
6/3/85	7732	97
Numerical Increase	1984	38
% Increase	34.5%	64.4%

Table 3: Number of AIDS diagnoses by suspected route of sexual transmission. Data source: CDC Surveillance Reports, 1/21/85 and 6/3/85.

Interestingly enough, the rates of increase in diagnoses for men and women during the same period are both around 34%, although the rate is slightly higher for women. The difference is not statistically significant.

	Gender (Adults & Adolescents)	
Date	Male	Female
1/21/85	7375	511
6/3/85	9869	689
Numerical Increase	2494	178
% Increase	33.8%	34.9%

Table 4: Rates of increase in reported AIDS diagnoses for men and women between 1/21/85 and 6/3/85. Source of data: CDC Surveillance Reports. Calculations by author.

Comparisons of Tables 3 and 4 indicate that the rise in AIDS diagnoses attributed to heterosexual contact is not simply a matter of more women being diagnosed. It reflects more heterosexual transmission for both women and men.

The incubation time between infection and the emergence of AIDS-defined illnesses can be from a few months to many years. The lengthy incubation-healthy carrier phenomenon, combined with a lack of AIDS awareness in the general population, means that the illness rates are only the tip of the iceberg of AIDS infection among heterosexual men and women.

In response to the spread of AIDS, including the rise in heterosexual cases and the steady increase in numbers of women and infants with the illness, this report will concentrate on the impact of AIDS on women. It will include an outline of prevention strategies utilized in California, which may be able to slow the increase of cases, and lessen the morbidity and mortality for those women who are exposed to or infected by the HTLV-III virus.

I. Women and AIDS: Transmission and Demographics

As of June 3, 1985, 738 females in the United States had been reported to the CDC as having AIDS. The best estimate of women with AIDS-Related Conditions (ARC) is approximately six to ten times greater than the number with AIDS, 4,428 - 7,380. The best estimate of those with the virus in their system is 60 to 80 times the number with AIDS: 44,280 - 73,800. (2) Women comprise 7% of the national population of AIDS patients and probably a similar proportion of those with ARC or the virus. If the category "gay and bisexual men" is excluded, as many as 20% of AIDS cases are female. Still, as the figures cited above indicate, there are thousands of women already infected. They, their sexual partners, and their infants are at immediate risk of developing the fatal illnesses associated with AIDS.

Sources of Transmission

Table 5 indicates the major routes of transmission for AIDS for women.

AIDS Diagnoses Among Women

	U.S. [1]		California [2]		San Francisco [3]	
Patient Groups	N	%	N	%	N	%
I.V. Drug User	374	50.7	5	21.7	2	22
Hemophiliac	3	.4	-	-	-	-
Heterosexual Contact	88	11.9	2	8.7	1	11
Transfusion	63	8.5	5	21.7	3	33
Parent at Risk	43	5.8	2	8.7	2	22
None Apparent/Unknown	167	22.6	9	39.0	1	11
Total:	738	100%	23	100%	9	100%

Table 5: Reported AIDS cases among women, by patient group (suspected route of transmission) for U.S., California, and San Francisco since 1981. (On account of rounding, not all percentages add up to 100.)

1 from CDC Surveillance Report, June 3, 1985

2 from California AIDS Activity Office data, 1/7/85. Author's calculations.

3 from San Francisco Department of Public Health, 4/30/85. Author's calculations.

General Issues

The most common route of transmission for women is IV drug use and shared needles (50.7%). This is a significant risk factor nationally, in California, and in San Francisco. (Because the state and city numbers are so small, they must be treated with caution when making generalizations and predictions.) Of the other identified routes, heterosexual contact is the next most important nationally. Although a substantial number of women have contracted AIDS through blood or blood products, this risk factor has essentially ceased to be a threat on account of blood bank use of virus antibody tests.

A striking number of women (22.6% nationally, 39% (9) in California, and 11% (1) in San Francisco) are listed as being at risk for "no apparent" or "unknown" reason. The comparable category ("unknown, other") for males is only 5.6% nationally (June 3, 1985 -- CDC). Some of these women may be recent Haitian imigrants. Haitians in Haiti and recently emigrated to the U.S. are reported to be AIDS-antibody postive at a rate of 2%. Haitians are currently listed as "unknown/other", unless in other risk categories. Some women in the "unknown" category may have never been adequately questioned. There may be a sophistication in surveillance with male cases, which came about as the numbers grew, that has not fully developed in the surveillance of female cases. Although women comprise the bulk of health care workers serving patients with AIDS, there are no reported cases of transmission to females (or males) associated with exposure to blood, urine, saliva, or mucous during nursing or other medical care. Neither superficial contact nor more direct contact, including needle sticks with contaminated blood, have resulted in AIDS, or even in positive antibody test results.

Sexual Transmission

More women than men are reported to have contracted AIDS through heterosexual contact. This could be a sign that AIDS is more easily transmitted from males to females. If so, the role of tissue trauma during vaginal and/or anal intercourse might be a factor together with the dosage transmitted via semen. This can be compared to the lesser potential for trauma to the male during intercourse and the more limited opportunity for direct passage of vaginal and cervical secretions into the male`s body.

On the other hand, the male-female difference in rates of heterosexual contact leading to AIDS may be a result of the much higher numbers of men already infected with the virus. On the

basis of AIDS diagnoses, we can estimate that there are over 10 times as many men infected with the virus as there are women. While many of these men have contracted AIDS via homosexual contact, a substantial proportion has been infected via drug use. Bisexual males and a number of gay-identified men have sexual contacts with women. But even if one excludes both gay and bisexual men from AIDS statistics, 80% of the diagnosed AIDS cases are male. These figures mean that a woman is much more likely to meet an infected person of the opposite sex than is a man. Consequently, her chances of being exposed to the AIDS virus via heterosexual transmission are currently greater than a man`s.

While there is a tendency for some to focus on the risks of prostitution, all women who have multiple sexual partners increase their chances of AIDS virus exposure. Coyote, a national prostitutes` organization, reports that nationally nine prostitutes are known to have contracted AIDS. It is unknown whether these women were also IV users. There is no direct evidence that U.S. prostitutes or other sex workers, such as sex therapists and sex surrogates, have contracted AIDS as a result of their sexual activity. As Coyote argues in Appendix 1, sex workers are often more careful of disease transmission than is the average citizen.

Prostitutes (both male and female) who sell sex to finance IV drug use may be exposed to the virus via shared use of needles. They are then capable of transmitting the virus to others sexually. Historically, female prostitutes have been blamed for the existence and spread of sexually transmitted diseases in the general poulation, even when there is contrary evidence. Coyote`s position paper (Appendix 1) attempts to address this scapegoating phenomenon in such a way that the commonality between those paid and those not paid for sex will be understood. Coyote`s goal in this paper is a response based strictly on health concerns.

IV Drug Use and Women

Drug use with shared needles is the most important source of transmission of the virus to women. As Table 5 indicated, it is especially important nationally, although less so in California. Current estimates, however, are that approximately 10% of the opiate using population of San Francisco is HTLV-III antibody positive. (3) If this figure continues to rise, and if the figure is determined to be similar with other, non-opiate, IV drug use, the spread into the general population will accelerate, both through shared needles and through sexual contact. Figures from the San Francisco Department of Public Health from May 30, 1985 demonstrate the important role IV use may play in AIDS infections, regardless of gender or sexual activity. (See Table 6.)

Gender	Reported Drug Use
Male	
Gay	13%
Bisexual	26%
Heterosexual	46%
Female	22%

Table 6: Gender and sexual orientation (where known) of San Francisco AIDS cases with I.V. drug use reported by patient or physician, regardless of suspected route of transmission or primary risk factor. Data from San Francisco Department of Public Health, May 30, 1985.

Prognosis for AIDS is poor in IV users, with a higher death rate (51.7%) than for AIDS cases overall (49%). (4)

IV drug use is more heavily concentrated in non-white communities in the United States than it is among whites. The economics and social consequences of racism, together with criminal justice legislation and enforcement policies have produced a situation in which the poorer Black and Hispanic communities of the United States are suffering from an epidemic of drug use. This epidemic, combined with that of AIDS, is having a devastating impact already in the New York-New Jersey area. With reports that as many as 80-90% of opiate users in Manhattan are antibody positive and knowing that these are not sexually closed populations, we can see the seriousness of the community-wide impact of AIDS on Black and Hispanic populations. Table 7 indicates the ethnic distribution of IV drug users who have been diagnosed with AIDS.

Race	N	%
White	264	19%
Black	692	50%
Hispanic	433	31.1%
Native American	3	.22%
Asian	-	-
Unknown	11	

Table 7: Racial distribution of diagnosed AIDS cases with I.V. drug use as primary risk factor, U.S. Data source: CDC, 2/1/85.

These figures lead us to a general consideration of ethnicity and AIDS in women

Ethnic Distribution of AIDS in Women

Nationally, women of color have been far more likely to be diagnosed with AIDS than are white women. Table 8, which compares California and the rest of the nation, makes this clear.

Female AIDS Cases by Race

	Region		
	Ca.	Elsewhere	All
Patient Race/Ethnicity	N	N	N
White	26	149	175
Black	6	340	346
Hispanic	3	149	152
Other/Unknown	-	9	9
Total:	35	647	682

Table 8: National Distribution of female AIDS cases by race, as of May 28, 1985.

From a quick review of this table, one might incorrectly conclude that AIDS is not especially a problem for ethnic minority communities in California; however, the Pacific Center AIDS Project in Alameda County has found that 17.21% of California AIDS cases are in minority communities. (5) In Alameda County itself, the figure is 32.5% (6). Table 9 inidcates that ethnicity varies among the patient groups (another term for "risk categories").

Race

Patient Groups by Risk Factor

	Male Gay/Bisexual		I.V. Use		Hemophilia		Heterosexual Transmission		Transfusion		Maternal Transmission		Other/ Unknown		TOTALS By Ethnicity	
	N	%	N	&	N	%	N	%	N	%	N	%	N	%	N	%
White	992	90	2	25	-	-	1	25	4	80	-	-	1	25	1000	88.9%
Black	43	4	4	50	-	-	2	75	-	-	2	100	2	50	53	4.7%
Hispanic	56	5	2	25	-	-	-	-	-	-	-	-	1	25	59	5.2%
Asian	6	.5	-	-	-	-	-	-	1	20	-	-	-	-	7	.6%
Other (incl. Am. Indian)	4	.3	-	-	-	-	-	-	-	-	-	-	-	-	4	.4%
Unknown	2	.2	-	-	-	-	-	-	-	-	-	-	-	-	2	.2%
Totals (by patient group)	1103	100%	8	100%	-	-	3	100%	5	100%	2	100%	4	100%	1125	100%

Table 9: AIDS patient groups (primary risk factor) by ethnic origin is San Francisco between Jan. 1, 1981 and May 30, 1985. Data Source: from San Francisco Department of Public Health.

Furthermore, when one analyzes the ethnic distribution of heterosexually contracted AIDS cases in San Francisco, a broad ethnic spread immediately emerges, as indicated in Table 10.

Ethnic Group	Heterosexual males and all females- AIDS Diagnoses	
	N	%
White	8	36
Black	10	45
Hispanic	3	14
Asian	1	5
Other	-	-
Total:	22	100%

Table 10: Ethnic distribution of AIDS diagnoses in San Francisco among (self-identified) heterosexual males and women (all sexualities), regardless of risk factor. Data source: San Francisco Department of Public Health.

The figures in Table 9 make clear that any educational campaign in San Francisco intended to have an impact beyond the gay community must reach beyond the white population to the Black, Hispanic, and Asian communities. This comment does not imply that the same multi-ethnic approach should not also be used in education and service for gay San Franciscans. I merely wish to emphasize the special importance of multi-ethnic work to reach women, either directly or through their male partners.

Lesbians and AIDS

As of May 30, 1985, there had been no documented cases of sexual transmission of AIDS virus between lesbians. There are, however, a small number of cases of women who define themselves as lesbians who have contracted AIDS through shared IV needles and through heterosexual contact. Until further research on female transmission is complete, the risks of lesbian sexual practices as transmissors of the virus are essentially unknown. The paucity of research on sexually transmitted disease among lesbians makes most projections highly speculative.

If the virus is found in vaginal and cervical secretions, and/or the menstrual blood of infected women (as is to be anticipated), then it is as important for women as for men to avoid these fluids when their partners are infected or possibly infected.

Two studies currently under way, the AWARE project on AIDS seropositivity in women, conducted by Wofsey, et al. at UCSF, and a project at the San Francisco based Lyon-Martin Clinic on

sexually transmitted diseases in lesbians, may help answer some of these questions. For a description of the AWARE projects, see their attached research proposals (Appendix 3).

Donor Insemination

A major issue confronting lesbians as well as some other couples with fertility problems is donor insemination. There have been no documented cases of AIDS virus transmission through donor insemination. This does not mean that semen without "sex" is safe. Rather, it may reflect precautions taken by sperm banks and individuals to avoid donations from persons who might be virus carriers. It may also be related to other factors, such as the minimal tissue trauma or limited dose with planned insemination. However, until more data is collected (and given the knowledge that the virus can be contracted from heterosexual transmission of semen), most physicians and sperm banks advise against insemination with a donor in a risk catefory. One strategy for protection in donor insemination is use of the antibody test when the donor has possibly been exposed or infected. The Alternative Test Site brochures of the San Francisco AIDS Foundation (Appendix 4) explain why such screening is important.

Pregnancy and Maternal Transmission

Women are unique in their ability to become pregnant and bear children. This special capacity also renders them capable of passing the AIDS virus on to their unborn children. Of the 124 pediatric AIDS cases reported to the CDC by June 3, 1985, 90 (73%) are the result of maternal transmission. The mothers were infected via shared needles or sexual contact. Most appeared healthy during their pregnancies. The maternal infections were passed on, however, to the infants, transplacentally, or at birth, and in some possibly through nursing. The infants with AIDS, the many others with ARC, and those children carrying the virus can anticipate greatly shortened lives with high susceptibility to opportunistic infections and cancers. Prevention of maternal transmission can only be accomplished through education of women at risk for AIDS infection. As will be discussed in the "Programs" section, such education will require the combined efforts of health departments, community service agencies, and health care providers to women. Antibody screening programs for women at risk can only be one component in this process.

Pediatric AIDS is a phenomenon more common to other areas of the U.S. than to California. However, nine cases have been reported in California, two of them in San Francisco. Ethnic minority children comprise a substantial porportion of the cases -- 33% in California and 78% nationally. The pediatric AIDS demographics mirror the female demographics, for obvious reasons.

II. Current AIDS Prevention Programs for Women

It is universally acknowledged that education is the key to stemming the spread and mitigating the effects of AIDS. The

education must include health providers as well as people who have been, or might be, exposed to the AIDS virus. Additionally, multiple services, ranging from information and referral through social service and case management to a full range of medical services, are acutely needed for people with all stages and types of illness and incapacity associated with AIDS. As the previous section indicates, a growing number of women will be needing both education and health services. To date, woman-focussed and/or woman-sensitive AIDS resources have been quite limited.

In this section we will review such resources and programs in Northern California on a county-by-county basis, beginning with San Francisco, where the greatest number of women`s educational, resource, and research projects are to be found. Most of these programs can be adapted to other counties and adjustments can easily be made for urban, suburban and rural conditions.

San Francisco City and County

A. Women`s AIDS Network

The Women`s AIDS Network (WAN) is a volunteer organization grounded in San Francisco. Its active members come from most Bay Area counties (San Mateo, Santa Clara, Alameda, Marin, Sonoma) as well as Sacramento. It draws subscribing members from as far away as New York, Texas and Georgia.

Formed at a national AIDS meeting in 1983, the Women`s AIDS Network initially saw itself as a national organization. When this proved impractical, it gradually settled into an educational and advocacy role in Northern California. Its members are predominantly women health professionals (physicians, therapists, educators, nurses, researchers, social workers, etc.) working in AIDS organizations.

For its members, WAN provides a location to exchange information and ideas. Some of the issues which the organization has addressed include:

1. members` experiences as women in predominantly male organizations

2. emotional issues of working with people with AIDS and ARC

3. networking opportunites for referrals, advice, employment, planning

4. recommendations for coordinated, non-duplicative resource development

5. information sharing concerning research, new programs and policies, potential speakers for forums, workshops, etc.

6. resource sharing, e.g., loans of audio-visual media

WAN has provided a variety of services to the broader community by sponsoring educational forums, and by preparing and distributing brochures about women and AIDS. WAN sponsored the first Women and AIDS forum for the general public in the Bay Area in 1983. In 1984, with the assistance of the San Francisco AIDS Foundation, it sponsored and organized its second Women and AIDS forum, this one for health care providers. Continuing Education credit was available for nurses. The syllabus for this forum is attaching in Appendix 5. The brochure "Women and AIDS" was written by two members of WAN, and then funded, printed and reprinted by the SFAF (Appendix 6). Currently (June, 1985) WAN is completing its first newsletter to the general public. The newsletter will have an initial circulation of 3,000 copies.

Funding for WAN activities hasbeen generated by dues, forum fees, and a small grant. The organization is currently planning a

benefit for newsletter expenses and is selling buttons which say "AIDS: Not Just a Man`s Issue -- Women`s AIDS Network". (See Appendix 7 for WAN membership form.)

WAN provides a model which can have a significant impact on health care providers and on consumers. It developed in an area with many AIDS cases (most of which are male). The region may also have been conducive to organizational creation. The San Francisco Bay Area is a region with an established history of women organizing around health, gay and feminist issues. Still the network approach can be a strategy worth considering in outlying counties, as a mode to generate awareness of AIDS, and as a way of linking the women health workers of the county into an active force around AIDS issues. Major values of this approach are that it is fairly economical, it breaks down isolation, and it can grow indefinitely.

B. Women`s Program, San Francisco AIDS Foundation

In October, 1984, the San Francisco AIDS Foundation (SFAF) received a grant from the State Department of Health to develop a pilot program on Women and AIDS. This project is the only government funded educational program in the U.S. which is explicitly focused on AIDS and women. The Foundation hired a half-time development coordinator (the author of this report). Building on earlier work at SFAF, the program has developed an experimental multi-faceted approach to education, referrals and resource devlopment concerning women and AIDS. It has taken San Francisco and nearby California counties as its main focus. Its work between November 1984 and June 1985 is described below.

1. Forums

The November 1984 "Women at Risk" forum for health care providers attracted over 100 participants. The Women`s Development Program has also been involved in a number of other forums and workshops. These have been directed at three audience categories: health professionals, women at risk, and the general public.

Forums and workshops for health professionals included Continuing Education credit wherever possible to encourage attendance by nurses and other persons for whom certification credits are important. A forum conducted for the San Francisco Health Department focused specifically on women and AIDS, with special presentations on women and drug use, heteroseuxal and maternal transmission, and criminal justice concerns. Workshops on "Women and AIDS" were also incorporated into other AIDS and women`s health meetings and forums, thus enabling the program to reach a broader segment of care providers, many of whom might not attend a meeting or forum exclusively focused on women or on AIDS or on "women and AIDS".

Presentations for the general public were conducted at U.C. Berkeley, as part of an all-day forum on AIDS, and to

predominantly lesbian and gay audiences in San Francisco and Santa Cruz.

Presentations to women at risk through IV drug use and/or multiple sexual contacts were prepared in cooperation with the San Francisco Pretrial Diversion Program and a San Francisco Jail Medical Service social worker. The first workshop, held in May 1985 at the County Jail, utilized a slide presentation, brochures, Hotline flyers, and a question and answer format for an audience of 20 female inmates.

The goal of the Women`s Development Program in regard to education of women at risk has been to train service agency staff and/or members of the at-risk group to do trainings themselves. At the Family Addiction Center for Education and Treatment (FACET), staff were trained by the program coordinator; at the jail the initial program for inmates involved both jail and SFAF staff. The latter is preferable when developing materials for a new audience, as it gives the program developer more direct opportunity to judge the effectiveness of various educational strategies.

2. Information and Referrals

The women`s program also provided up-to-date information on women and AIDS to SFAF Hotline callers, SFAF staff, health care professionals, and researchers. In order to provide such information, an agency or program will need to set aside staff time to collect the information. Existing women`s organizations and services should be surveyed in regard to their abilities to provide AIDS services, while existing AIDS organizations must also be reviewed in terms of their service to women. At the SFAF, the women`s program coordinator went to the International AIDS conference in Atlanta in May 1985 as one part of this process. Access to a good medical library and knowledgeable individuals are also crucial factors in providing accurate information to the public.

An additional information gathering strategy used by the women`s program was the development of an organizational network among professional AIDS researchers working with human subjects. While the research network was much broader in scope than "Women and AIDS", it did include all Bay Area research projects working with women. It was also responsive to research issues affecting female subjects.

Distribution of information can be a time consuming process. The SFAF Hotline, which is a primary source of public information on AIDS in Northern California, uses numerous volunteers. The value of a hotline approach is that individualized education, directly responsive to the concerns of the caller, can be provided. At the SFAF, the Hotline is supplemented wit6h brochures and other materials that can be sent to the caller. Additional mass media and group approaches for more general public education are also pursued by the Foundation.

The SFAF Hotline was developed to serve three basic classes of people: the general public, people at risk for AIDS, and people with AIDS and ARC. The women`s program provided additional training and resource lists to the Hotline staff and volunteers to help them respond more accurately and sensitively to women`s issues within the three general categories. (See Appendices 8 and 9 for support group and drug rehabilitation resources listings.)

3. Advertising

As a component of the provision of information to the general public, the women`s program prepared specific advertising to encourage women and the non-gay-identified population to call the Hotline. (See Appendix 10 for advertising copy.) To reach the multi-ethnic population of women at risk, advertising was prepared in Spanish and English. Ads were placed in the Black, Hispanic, Asian and white press, as well as the gay and lesbian press and in papers read by prostitutes.

4. Multi-Ethnic Outreach

In addition to the bilingual, multi-ethnic advertsing campaign for the Hotline, the program distributed "Women and AIDS" brochures in Spanish ("Mujeres y AIDS", see Appendix 11) and recruited Black, Spanish-speaking and bi-cultural volunteers to work on various outreach projects. Consultation and a proposal were also provided to the San Francisco Department of Public Health concerning a possible mult-ethnic educational program for teenagers (see Appendix 12). The Women`s Program Development Coordinator also participated in the ethnic outreach committee of the SFAF.

Where specific ethnic and/or racial populations are at risk for AIDS, special advisory committees and outreach work are necessary. Programs should provide routine Spanish-language outreach in advertising, written materials, and educational events wherever there is a significant Hispanic population.

5. Work with Special Groups of Women at Risk

Prostitutes, women in jail, IV drug users, and women facing pregnancy after possible AIDS virus exposure: these groups of women have special needs for AIDS services. The SFAF Women`s Program developed separate files general of information, health, social services and legal resources, education programs, and specialists who could work with individuals or groups. The file development was prepared by literature review and contact with organizations working with women in these groups. The files were then available when requests for assistance or resources arrived from health care providers, the general public, and the women at risk.

6. Networking and Volunteers

One person can only accomplish a limited amount. Networking and volunteers can be important extenders. Both approaches were integral to the SFAF Women`s Development Program.

Networking was accomplished through the Women`s AIDS Network, the San Francisco and East Bay Perinatal Forums, SFAF contacts, Coyote, the Coalition for the Medical Rights of Women, the Bay Area AIDS Research Consortium (founded by the SFAF), and gay and lesbian organizations.

The SFAF volunteer network and volunteer coordinator were used to recruit volunteers. From San Francisco State University, two Women`s Studies interns and five Health Education interns donated various amounts of time. One volunteer came through an alternative sentencing program. Several volunteers either had ARC or were otherwise exposed to the AIDS virus. Another worked in an AIDS-related job. Among them, these volunteers contributed over 450 hours of work in six months.

Each volunteer had a clearly defined task which was pursued over several weeks or months. Two developed a multi-ethnic advertising campaign; one prepared translations and typed; another handled a mailing list and information requests; four prepared a grant proposal; and two developed a major listing of women`s health care providers. In only one case did a person stop working before a project ended and then the work was substantially complete.

7. Future Plans

The Women`s Development Program was charged by the State Department of Health Services with the development of pilot programs and preparation of proposals for future work. It is anticipated that the program will continue its existing educational work, networking, and consultations. The Women`s Program also prepared several proposals for future work:

a. Outreach to Women`s Health Care Providers

A Program intern prepared a county by county listing of women`s health care providers in Northern California. The listing includes all obstetrician/gynecologists, women`s health clinics, and women`s substance abuse programs in San Francisco, Alameda, Contra Costa, Lake, Solano, Mendocino and San Mateo counties. The listing will be used to contact these providers to begin comprehenisve educational programs about women and AIDS in these counties. This plan was begun after it was realized that very few women`s health care settings have literature on AIDS and women. Existing literature and patient education programs which touch on sexually transmitted diseases have not yet been updated to include AIDS. THe primary goal of this plan is to begin to change this situation. Implementation of the plan will

require extensive local organizing and cooperation. (See Appendix 13 for a partial county by county listing.)

b. "Women and AIDS -- Straight Talk"

A second proposal prepared through the program is a heterosexual education project designed to foster the use of condoms. This proposal, "Women and AIDS -- Straight Talk", was prepared by San Francisco State University Health Education students. It is attached in Appendix 14.

c. "AIDS Teenage Awareness Program"

A third proposal was prepared in draft form for the Community Services of the San Francisco Department of Public Health. This proposal was for a multi-ethnic approach utilizing adult community leadership to educate teenagers about AIDS (see Appendix 12).

These projects are mentioned here, not only because they were generated by the Women`s Program of the SFAF, but alsobecause they can be used as models in other cities, counties, or states which are developing AIDS awareness and prevention programs to protect and serve women.

C. AWARE

The AWARE research project is funded through the University of California, San Francisco, out of California AIDS research funds. It is mentioned here because its goal is the generation of knowledge about women and AIDS and because it provides education, counseling and referrals to its research subjects, all of whom are women.

AWARE is the acronym for Association for Women`s AIDS Research and Education. The emphasis is on research, with the study essentially focused on seropositivity prevalence among women at risk through heterosexual contact. Copies of the project`s research proposals are appended (Appendix 3).

The AWARE project is the first to systematically study women at risk. It is also the product of cooperative planning and interaction among physicians, epidemiologists, health service providers, and advocates for women. It is thus a thoroughly objective but somewhat unusual scientific enterprise. Both its research methods and its style of working with subjects could be usefully replicated in other cities. Additional research projects connected to the AWARE study are investigating the role of donor insemination, the psychological impact of antibody test result information, and the AIDS antibody status of women partners of men with hepatitis B antibodies.

D. AIDS Support Resources for Women in San Francisco

There are a number of health organizations in San Francisco which either serve women primarily or have special programs for women. These organizations are listed in Appendices 8, 9, and 13. Of special note in regard to AIDS services are the support groups for women developed by Shanti and the AIDS Health Project. The AIDS Health Project provides eight-week structured educational support groups in which participants assess their response to AIDS and develop health maintenance strategies.

Both Shanti and the AIDS Health Project were pressed to provide special services for women. Both report a limited demand. It is possible that as AIDS antibody testing becomes more widespread and more women discover they are antibody postive, the demand will increase.

In the area of susbstance abuse resources, services are limited. The AIDS Health Project provides some out-patient support groups. There are few residential drug rehabilitation programs for women. Many programs will not take children; still others exclude pregnant women. Currently, only one residential program in San Francisco will provide accommodations throughout pregnancy and for women with children. This is the Pomeroy House of the Women`s Alcoholism Center. Although Pomeroy House requires that the client`s major problem be alcohol, it will admit women with polydrug dependency including opiate use. The staff has also completed a process of in-service training concerning women and AIDS. Pomeroy House provides an important model for education and rehabilitation of women at risk for AIDS on account of IV drug use.

In addition to the special programs for women noted above, all the AIDS organizations in San Francisco -- e.g., Hospice, Shanti, Mobilization Against AIDS, and the SFAF -- make their general services available to women. The SFAF, for example, offers comprehensive case management through a social services department; it also provides a food bank for people with AIDS or ARC, and general referrals. Hospice provides housing services for people confronting death and dying. Shanti provides a variety of counseling and support for individuals and their loved ones facing life-threatening illness and bereavement. Mobilization Against AIDS is an advocacy organization which monitors legislation and secures funding for AIDS research and services.

E. San Francisco Public Health Department

The Health Department has begun to apply traditional communicable disease tracking and education to heterosexual AIDS cases in San Francisco. Persons with AIDS (not persons with positive antibody test results) are asked to notify their recent and current sexual partners. Alternatively, if the patient is uncertain about making the personal contact, a Health Department Communicable Disease Officer will make the contact instead. The goal of the program is

to stem the spread of AIDS through individual education about safe sex practices.

The Department of Public Health also provides extensive funding for general education and for the Alternative Test Site Centers for anonymous antibody testing. This is in addition to its funding for direct medical, mental health and other services needed by people suffering from AIDS-related illnesses.

F. Medical Services in San Francisco

The bulk of Northern California medical services for people with AIDS and ARC is located in San Francisco. This results from several factors: the size of the San Francisco gay community, the local concentration of AIDS cases, and a pre-existing density of health services, physicians, research facilities, and medical schools. If special services for women with AIDS were to develop in California, one would expect them to occur first in San Francisco. To date the number of adult female patients has been low -- seven with AIDS, and an unknown number of women with identified ARC symptoms. Lyon-Martin Clinic, a San Francisco women`s clinic originally founded to serve lesbians, has trained its staff, with the help of AIDS outpatient clinic staff from San Francisco General Hospital, to be a pre-screening clinic for AIDS. The AIDS screening clinics in the city`s Public Health Centers, as well as all other AIDS medical services, are also available to women. The Lyon-Martin model represents the addition of AIDS-related services within a woman-focussed organizaiton. The Health Center model represents a similar expansion of AIDS services for both male and female clients. In both cases, special training for physicians in diagnosis and treatment is required.

Services for pediatric AIDS patients are limited; referrals are being made to the pediatric immunology service at the University of California San Francisco Medical Center.

Because AIDS is a chronic debilitating disease, specialized supplemental services are required for comprehensive care in addition to the traditional physician services. With women as clients, additional needs, such as those associated with dependent children and pregnancy, must also be addressed. Planning for clinic and other medical services for women should take these special needs into account. Section D, above, describes some of the supplemental services available to women in San Francisco.

Overall, of the Northern California counties, San Francisco has the greatest variety of educational and service programs directed at women. We will now briefly examine some of the outreach and special services to women in other counties. All the counties listed are in the state service area of the San Francisco AIDS Foundation. They receive assistance in program development. Where no organized program exists, the Foundation has provided some direct education.

Alameda County

Aside from services provided through the Health Services Agency, the major AIDS organization in Alameda County is the Pacific Center AIDS Project. The Pacific Center provides an information and referral service, a variety of education programs, and support groups for people with AIDS as well as for friends, family and lovers. The Center has initiated several projects specifically addressing the needs of women:

1. "Women Concerned About AIDS" discussion group -- meets once a week, includes women working in the field, women at risk, and those with friends or family with AIDS.

2. An evening drop-in women`s group -- for lesbians, straight and bisexual women.

The Center has also been involved in several outreach projects which touch on the special needs of women:

1. "Talking with Our Kids and Other Parents About AIDS~ -- an evening forum.

2. An elimination and prevention of racism project (see "Pacific Center AIDS Project Statement on Racism and AIDS Work", Appendix 12).

Several forums on AIDS in Alameda County have included workshops on women and AIDS.

The Pacific Center AIDS Project is a more typical AIDS organization for California than is the SFAF. It has less AIDS funding and a smaller overall budget. Consequently it provides fewer AIDS-specific services. Similar to many AIDS organizations throughout the country, it is based in an insititution which was initially and is primarily focussed on the needs of the gay and bisexual community.

Other Northern California counties with AIDS education projects provide even fewer services and educational programs specifically for women.

Marin:

Marin AIDS Support Network, the Health Department and the AIDS Advisory Committee are the primary AIDS education organizations in Marin. Woman focussed work in the county includes distribution of brochures on women and AIDS.

Marin AIDS Support Network has a female staff member (volunteer) and female board members. The Support Network has publicly raised issues of women and AIDS in educational

and media settings. No special forums concerning women have been held.

Sonoma:

Programs for women have included:

A forum on AIDS for the lesbian community

A section on women and AIDS provided in a recent educational forum on AIDS for health care providers

In July, 1985 River Community Services will be holding a one-day forum on women and AIDS

"Women and AIDS" brochures are distributed regularly

River Community Services has had female staff who have helped focus activities on women as well as men

Contra Costa:

Contra Costa has very limited AIDS services, primarily provided by the Pacific Center and the SFAF. The Health Department in Contra Costa has played a very limited role.

"Women and AIDS" brochures have been distributed

Discussion about women and AIDS has been incorporated into general AIDS education, including several forums for substance abuse professionals

Lake:

The primary AIDS organization in Lake County is the Health Department

Brochures on women and AIDS have been distributed

Discussion about women and AIDS has been incorporated into general AIDS education

Mendocino:

The primary organization for AIDS education is the Health Department

Brochures on women and AIDS have been distributed

Discussion about women and AIDS has been incorporated into general AIDS education

Napa:

The primary AIDS organization is the Health Department

Brochures on women and AIDS are being distributed

Discussion about women and AIDS has been incorporated into general AIDS education

Solano:

The Health Department is the primary AIDS organization in Solano. There is also an active group of lesbian and gay volunteers

Brochures on women and AIDS are being distributed

Discussion about women and AIDS has been incroporated into general AIDS education

As the above survey indicates, when one leaves the Bay Area, educational, social and medical services for women with AIDS concerns thin out quickly.

III. Conclusions and Recommendations

As Part One of this report makes clear, the AIDS epidemic is spreading rapidly into new populations. Women and infants will be affected in increasing numbers. Because progress toward either vaccination or cure is slow, education is one of the most important strategies available to limit the spread of the illness. Yet educational programs for health providers, the general public, and people at risk are extremely limited. With the exception of San Francisco and Alameda counties, where limited women`s outreach projects have begun, there are essentially no on-going educational projects specifically designed to educate women and their health providers about AIDS. Few programs exist to involve women or their health care providers in the process of stopping the spread of the illness.

Several California projects which do address these concerns are described in Section II. It is still too early to assess their effects thorougly. The study conducted in March 1985 by San Francisco State students found that 47 out of 100 women did not know they could contract AIDS. A total of 64% did not know any risk reduction measures. (7) On the other hand, in a focus group of nine women at risk convened in San Francisco in May 1985 and including IV users and sexually active women, all were aware that women could get AIDS and most knew some risk reduction strategies. Most had also changed their behavior on account of AIDS, although few could be said to have completely protected themselves (see Appendix 15). Both these women and those in the San Franicsco

State study wanted more information. Research in New York and San Francisco has demonstrated that AIDS education programs can change behavior and consequently reduce the rate of the epidemic. (8)

AIDS education programs for women present special challenges. Women are an aggregate group of individuals. They do not belong to one community, culture, class or location. Instead, their lives are organized through a variety of family allegiances, ethnic groups, residence patterns, and life styles. These differences mean that programs oriented directly toward women will be most successful if they build on and utilize this diversity, rather than attempting to ignore it.

In some cases the educator may be able to reach a woman through ethnic media or social organizations; in another case, her life style of drug use may be the key; for yet another, awareness of sexually transmitted diseases can be the first step to AIDS awareness.

At the same time, efficiency demands that some commonalities be introduced into educational planning. The education of health and social service providers, as well as community leaders, can save time for the AIDS educator. Mass media campaigns (such as the one described in Appendix 14) are also crucial. A "Women and AIDS" program can pass on basic AIDS information to health providers; at the same time, it should provide awareness that special strategies are needed to educate clients, patients and community members in a culturally relevant manner.

Recommendations

The following recommendations are guidelines for developing AIDS awareness and service programs directed at women. They are based on a county/city model. None of these recommendations can be implemented without a basic program of AIDS education and services. Many counties have no organized AIDS programs. As these basic programs are initiated, they should incorporate the following suggestions.

RECOMMENDATION I: Comprehensive AIDS education campaigns are needed on a county-by-county basis. A needs assessment should first be conducted which evaluates community awareness, estimated numbers of AIDS and ARC patients as well as antibody positive individuals. Variables, such as IV drug use, sexually transmitted disease patterns, and out of wedlock pregnancy and teen parent rates, should also be reviewed in order to plan appropriate and effective AIDS prevention campaigns which will reach women as well as men and people of all ages. Public education and health agencies as well as community organizations should be surveyed to assess current service provisions. Assessments concerning women`s risks and needs should be incorporated in any broader AIDS-related needs assessment.

RECOMMEDNATION II. Local Health Departments should initiate reviews of AIDS education, health, and social services. These reviews should incorporate women`s needs.

Questions important to service for women include the following:

Are health care providers educated about AIDS and women?

Do they need additional training?

Is there an AIDS screening clinic or a referral list of knowledgeable physicians, including family physicians, OB/GYNs, and pediatricians?

Are appropriate medical services available for people with ARC and/or AIDS?

What are the special needs of women? Are they being met?

What services, if any, exist for the woman drug user? Are they appropriate?

RECOMMENDATION III: Basic AIDS education Programs for health care providers, for people at risk or with AIDS, and for the general public should be initiated.

Following a needs assessment, an educational strategy can be developed. Planners may find the book Health Education Planning: A Diagnostic Approach helpful. (9) The first step will be the establishment of educational priorities, secondly adequate funding, staffing, authority and coordination must be assured. A basic level of community awareness, i.e., knowledge that the program exists, should be established. Planners should develop a long-term strategy as well as short term realizable goals.

A variety of specific educational strategies for women have been described in Section II. They include:

Outreach to health providers (see Appendices 5, 7, 13 and 14)

Development of an advocacy and information network of women working on AIDS issues (see Appendix 7)

Direct media advertising (see Appendix 14 for an educational model incorporating advertising; also see Appendix 10 for advertising models.)

Use of existing community institutions -- including health agencies as well as social service, ethnic, religious or other cultural groupings

Materials development in appropriate languages. In some cases it may be more efficient to incorporate material about AIDS into existing material, e.g., into media concerning sexually transmitted diseases.

Education of community leaders (Appendix 11 presents one model for this approach.)

Specific strategies selected will depend on the community. What is most important is that a planned program be initiated.

RECOMMENDATION IV: Where appropriate, new services should be initiated. This will involve development of a funding base as well as public and private involvement in planning and provision. The types of basic services that will be needed include:

1. Anonymous AIDS antibody testing sites
2. AIDS screening services
3. Low-cost and free medical care for persons with AIDS or AIDS-related illnesses
4. Comprehensive social services, including mental health, welfare, disability, food stamps, SSI, unemployment, housing, legal assistance, nursing care, hospice arrangements, religious support, counseling and support groups for family, lovers and close friends
5. Services should be made available directly or by referral through traditional health care providers. For women, these providers include obstetrician/gynecologists, family practice physicians, pedicatricians, and health clinics (see listing in Appendix 13).

RECOMMENDATION V. Because of the diversity that women represent, all educational campaigns and services for them should be sensitive to multi-ethnic, multi-class issues as well as to lifestyle diversity.

RECOMMENDATION VI. Because of women`s unique reproductive roles, AIDS programs for women should take reproductive issues into account. The issues include:

1. birth control
2. genitally transmitted diseases
3. donor insemination
4. conception and safe sex
5. antibody screening and pregnancy counseling
6. maternal transmission of the AIDS virus
7. pediatric AIDS, whether caused by maternal transmission or other routes
8. maternal issues with older children, born before the mother`s illness
9. reproductive freedom -- including the right to have or reject an abortion

Pursuit of the above recommendations could be a first step in meeting the needs of women and the needs of the larger community, both gay and straight, young and old -- for a safer way of living during the era of AIDS.

Footnotes

1. CDC AIDS surveillance reports of 1/21/85 and 6/3/85.

2. These estimates are based on studies which indicate that for those persons whose blood was antibody positive five years ago, 5 to 10% have developed AIDS; another 20% have developed ARC; while approximately 70-80% remain healthy.

3. Estimates from medical staff at Haight-Ashbury Free Clinic and Bay Area Addiction Research and Treatment (BAART) program serving methadone clients. May, 1985.

4. Data from CDC, Feb. 1, 1985.

5. Pacific Center AIDS Project Statement on Racism and AIDS Work. See Appendix 2.

6. Ibid.

7. Cf. "Women and AIDS -- Straight Talk", Appendix 14.

8. Research and Decisions Corporation, "A Report on: Designing an Effective AIDS Prevention Campaign Strategy for San Francisco: Results from the First Probability Sample of an Urban Gay Male Community," San Francisco, 1984; S. Schultz, S. Friedman, A. Kristal, D.J. Sencer, "Declining Rates of REctal and Pharyngeal Gonorrhea among Males -- New York City," MMWR, 33:21, 6/1/1984.

9. This test, by Lawrence W. Green, Marshall W. Kreuter, Sigrid Deeds, and Kay Partridge (Palo Alto, Mayfield Publishing, 1980) provides a practical analytic approach to values, beliefs attitudes and perceptions which can facilitate or hinder personal motivation for change.

List of Appendices

1. "Coyote Convention -- San Francisco, CA, May 30-June2, 1985"
2. "Pacific Center AIDS Project Statement on Racism and AIDS Work"
3. AWARE research proposals for 1984-5 and 1985-6
4. Alterhnative Test Sites for AIDS Antibody Test
5. Syllabus -- Women At Risk: Strategies for AIDS Education and Prevention, Nov., 1985
6. "Women and AIDS" brochure
7. Women`s AIDS Network membership form
8. "Current Support Groups and Assistance for Women exposed to AIDS -- San Francisco Area," May, 1985
9. "Rehabilitation Resources for Women with IV Drug Dependencies" February, 1985
10. Advertising for AIDS Hotline directed at women and/or general public
11. "Mujeres y AIDS" brochure
12. "AIDS Teenage Awareness Program: A Multi-ethnic Strategy"
13. "Women`s Health Services Listing"
14. "Women and AIDS -- Straight Talk"
15. "San Francisco health crisis focus group with women at risk," memo, Research and Decisions Corporation, June 21, 1985