

MODEL PROGRAMS FOR WOMEN'S AIDS EDUCATION & SERVICES

by

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CALIFORNIA MODELS FOR WOMEN'S AIDS EDUCATION AND SERVICES

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.

<u>SMSA or Residence</u>	<u>Dates of Diagnosis</u>					
	<u>1/1/81 - 1/21/85</u>			<u>1/1/81 - 6/3/85</u>		
	<u>N</u>	<u>%</u>	<u>cases p.</u> <u>million</u>	<u>N</u>	<u>%</u>	<u>cases p.</u> <u>million</u>
New York, N.Y.	2655	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 Homosexual and Heterosexual Transmission

<u>Date</u>	<u>Male-Male Contact</u>	<u>Male-Female Contact</u>
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 (see Table 4). The difference is not statistically significant.

<u>Date</u>	<u>Gender (Adults & Adolescents)</u>	
	<u>Male</u>	<u>Female</u>
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>Patient Groups</u>	<u>U.S. 1</u>		<u>California 2</u>		<u>San Francisco 3</u>	
	<u>N</u>	<u>%</u>	<u>N</u>	<u>%</u>	<u>N</u>	<u>%</u>
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	<u>167</u>	<u>22.6</u>	<u>9</u>	<u>39.0</u>	<u>1</u>	<u>11</u>
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 data, 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 (167), 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 immigrants. Haitians in Haiti and recently emigrated to the U.S. are reported to be AIDS-antibody positive at a rate of 2%. Haitians are currently listed as "unknown/other", unless in other risk categories. Other 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

In absolute numbers, 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 U.S. 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 population, 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 their paper is to develop 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 in other, non-opiate, IV drug users,

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.)

<u>Gender</u>	<u>Reported Drug Use - SF AIDS Cases</u>
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.

Reported Drug Use - US AIDS Cases

<u>Race</u>	<u>N</u>	<u>%</u>
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

<u>Patient</u> <u>Race/Ethnicity</u>	<u>Region</u>		
	<u>Ca.</u>	<u>Elsewhere</u>	<u>All</u>
	<u>N</u>	<u>N</u>	<u>N</u>
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 indicates 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.

<u>Ethnic Group</u>	<u>Heterosexual males and all females-</u> <u>AIDS Diagnoses</u>	
	<u>N</u>	<u>%</u>
White	8	36
Black	10	45
Hispanic	3	14
Asian	1	5
Other	<u>—</u>	<u>—</u>
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 necessity of multi-ethnic work if one is to reach women who risk contracting AIDS, 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 transmitters of the virus are essentially unknown. The paucity of research on sexually transmitted disease among lesbians makes most projections on AIDS transmission 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 minimal tissue trauma and/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), almost all physicians and sperm banks advise against insemination with a donor in a risk category. 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 cases 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 proportion 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 opportunities 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 has been 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 the network 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 development 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 (jointly sponsored by the Women's AIDS Network) 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, heterosexual 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.

A primary 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 SF county 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. 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. 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. 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 (the Bay Area AIDS Research Consortium). 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 with 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 advertising 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 multi-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 diverse ethnic and/or racial populations are at risk for AIDS, special advisory committees and outreach work are necessary. All 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 comprehensive 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 also

because 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 an 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 Bay Area 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 positive, the demand will increase.

In the area of substance abuse resources, services for women 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 and political influence 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 organization. The Health Center model represents a similar expansion of AIDS services for both male and female clients. In both cases, special training in diagnosis and treatment is required for physicians and other staff.

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 institution 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 incorporated 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 the most important strategy 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 thoroughly. 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 Francisco 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; it should encourage culturally relevant strategies to educate clients, patients and community members.

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.

RECOMMENDATION II. Local Health Departments should initiate reviews of existing 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. Programs should acknowledge and include women as well as men.

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 and other cultural organizations.

- 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, pediatricians, 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 text, by Lawrence W. Green, Marshall W. Kreuter, Signid 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.

Determination of Knowledge, Attitude, and Risk of HIV
Infection in a Family Planning Clinic Population

Oliva, G., Di Clemente, R., Purser, S., Rutherford, G.

Presented

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In December of 1985, the Centers for Disease Control issued recommendations for the prevention of perinatal transmission of Human Immunodeficiency Virus (HIV).¹ These were prompted by increasing rates of seropositivity in women who were IV-drug users, prostitutes, sex partners of men with AIDS and ARC, and the sex partners of asymptomatic men, and the evidence of high rates of HIV infection occurring in infants born to these mothers.^{2,3} The guidelines called for counseling and encouragement of antibody testing for women in high-risk groups.

In San Francisco -- where AIDS has been predominantly a disease of gay men, with 97%⁴ of cases still occurring in this group -- little had been done in the way of community outreach and prevention education for women. With reports of unpublished studies of seropositivity in IV-drug-using women beginning to show increasing rates (from 1% to over 5%) in a methadone clinic group within a year's time⁵, Health Department personnel saw the need for an active intervention program.

Before implementing a large-scale program of health education, and especially before beginning any kind of testing program in the Department of Public Health's community clinics, it was decided to survey the women in family planning and pregnancy testing clinics to determine their current level of knowledge, attitudes, and risk status for HIV infection.

METHODS

A survey instrument was developed containing 40 questions. It was translated into Spanish and Chinese. Health educators and outreach workers from the Communicable Disease and Family Planning programs visited each County District Health Center. They greeted each client coming in for service and explained the purpose of

the questionnaire: "To help us plan a program for AIDS prevention for women." The staff assured the women that their responses were totally confidential and voluntary, and offered them assistance in explaining terms and, in some cases, reading the questions. A box was provided in which to drop the completed questionnaires.

RESULTS

The results to follow represent a preliminary analysis of the first 219 questionnaires. Of the first 237 women who were approached, only 18 (7.5%) refused to complete one. Although we had anticipated possible lack of acceptance by the clients due to the number and personal nature of the questions, the health educators reported that in fact there was considerable interest and enthusiasm expressed, and that clients readily asked for clarification and information.

The population included in this report are 219 women coming in for regular preventive health care in Women's Clinics at four District Health Centers spread geographically over the city. Their mean age was 27. The ethnic breakdown included 39.7% White, 32.4% Black, 10.9% Hispanic, 6.4% Chinese, 7.3% Filipina, and 3.3% Other.

Women were asked to select their primary source of information about AIDS. 64% responded that TV/radio (40%) and newspapers/magazines (24%) were their main sources. Only 21% responded that they got more information from health-related sources (health care professional 9.3%, AIDS pamphlet 6.1%, medical journal 5.6%). The remaining 14% chose friends (5.6%), teachers (3.7%), relatives (3.3%), and other (2.3%).

In contrast, when asked how they would like to receive information, 92% agreed or strongly agreed that the Health Department should be doing more. Selected vehicles for dissemination of this information included brochures (79.3%), one-to-one counseling (75.5%), audio-visuals (68.1%), group discussions (62.9%), and hotlines (62.4%).

A considerable number of questions were designed to assess the knowledge level of typical clinic clients. When asked to identify modes of transmission for the AIDS virus, over 90% correctly identified the primary modes (having sex with a bisexual, sharing needles, blood transfusions, transplacental). However, significant percentages incorrectly chose examples of casual contact as possible infection sources. These include kissing (38.8%), sharing utensils (36.9%), hot tubs (30.9%), and touching (11.5%). In addition, only 58.2% thought that viral transmission was possible through sex with a heterosexual, and 25.6% did not think it possible with an IV-drug user.

Respondents were asked if they had ever heard the term "safe sex" and to identify unsafe sexual practices. Although 64.2% had heard the term, only 33.6% correctly identified two or more high-risk behaviors. A significant percentage of respondents thought that known high-risk behaviors were safe -- sex without a condom (90%), oral-anal contact (36.6%), oral-genital contact (42.4%), and exchange of body fluids (28.1%).

In designing an educational intervention, it was felt that an indication of attitudes would be helpful. Women were asked whether or not they believed that HIV-infected individuals posed a risk to non-infected persons in a number of settings. 54.2% thought that HIV-infected individuals should not be in contact with others either in jobs, living situations, or caring for children.

Questions had been raised about the need to allocate resources for AIDS prevention in a general women's clinic population. Consequently, we asked women a number of questions about their own behavior. A total of 37.1% reported one or more behaviors believed to be risk factors for transmission of HIV.^{1,3,6} Specific responses included IV-drug use (11.3%), sex with a bisexual (8.1%), anonymous sex (21.9%), and sex with an IV-drug user (14.3%).

We attempted to look at some correlations between knowledge, attitudes, and behavior. Limited numbers allow only a preliminary report at this time. Although 76.6% of respondents agreed that condoms were protective, 73.9% reported rarely or never using condoms.

We compared reports of "worry" and perceived risk with reported high-risk behaviors. 43% of respondents said they were worried or very worried about acquiring HIV infection. There was a significant positive correlation ($p = < .0001$) between degree of concern and reports of whether they considered their risk of becoming infected to be very high, high, or intermediate (41%). In contrast, there was a significant negative correlation ($p = .01$) between those who perceived themselves to be at risk and those who in fact reported high-risk behaviors.

DISCUSSION

The results of this survey are extremely useful in making decisions about an AIDS prevention program for the heterosexual population using Health Department services.

Most clients are getting their information from the media where sensationalism, half-truths, and distortions are common. The great majority recognize the need for

more reliable information and would like to see the Public Health Department provide a number of vehicles for this.

Clients have significant knowledge gaps and misconceptions in the areas of casual contagion and accurate identification of high-risk behaviors. This combined with the high incidence of high-risk behaviors make the initiation of an active education program an urgent matter.

Misconceptions about the risk of contagion in work and household situations are of great concern.^{7,8} With conservative initiatives like that of LaRouche in California, voters need to have accurate information so that fear and ignorance do not result in a tragic breach of civil rights.

Of possible greatest concern is the discrepancy between knowledge and behaviors and perceived versus actual risk. Great numbers of women will need to be reassured through the provision of accessible, accurate information. However, the real challenge lies in overcoming the denial of those at risk. Obviously, pamphlets and audio-visuals will not help here. One-to-one counseling, although expensive, may be the only way to intervene.

CONCLUSION

An in-depth survey of 219 women attending public health clinics for women's health care revealed that significant numbers are concerned and in need of more information about HIV infection. The combination of lack of knowledge and participation in high-risk behaviors warrant immediate active initiation of a health education/prevention model in public health programs for heterosexual women.

1. Centers for Disease Control. Recommendations for Assisting in Prevention of Perinatal Transmission of Human T-Lymphotropic Virus-Type III/Lymphadenopathy-associated Virus and Acquired Immune Deficiency Syndrome. MMWR 1985; 34-721-6, 731-2
2. Rubenstein, A., Sickic, M., Gupta, A., et al. Acquired Immunodeficiency Syndrome With Reversed T4/T8 Ratios in Infants Born to Promiscuous and Drug-Addicted Mothers. JAMA 1983; 249:2350-6.
3. Redfield, R.R., Markham, P.D., Salahuddin, S.Z., et al. Frequent Transmission of HTLVIII Among Spouses of Patients with AIDS-Related Complex (ARC) and Acquired Immunodeficiency Syndrome (AIDS): A Family Study. JAMA 1985; 253: 1571-3.
4. Bureau of Communicable Disease Control. San Francisco AIDS Morbidity and Mortality Report. August 31, 1986.
5. Unpublished findings. Wofsy, C. and Cohen, J. Project AWARE. University of California, San Francisco.
6. Melbye, M., Ingerslev, J., Biggar, R.J., et al. Anal Intercourse as a Possible Factor in Heterosexual Transmission of HTLV-III to Spouses of Hemophiliacs. NEJM 1985; 312:857.
7. Friedland, G.H., Saltzman, B.R., Rogers, M.F., et al. Lack of Transmission of HTLV-III/LAV Infection to Household Contacts of Patients with AIDS or AIDS-Related Complex with Oral Candidiasis. NEJM 1986; 314:344-9.
8. Sande, M.A. Transmission of AIDS: The Case Against Casual Contagion. NEJM 1986; 314:380-2.

CONTEMPORARY OB/GYN

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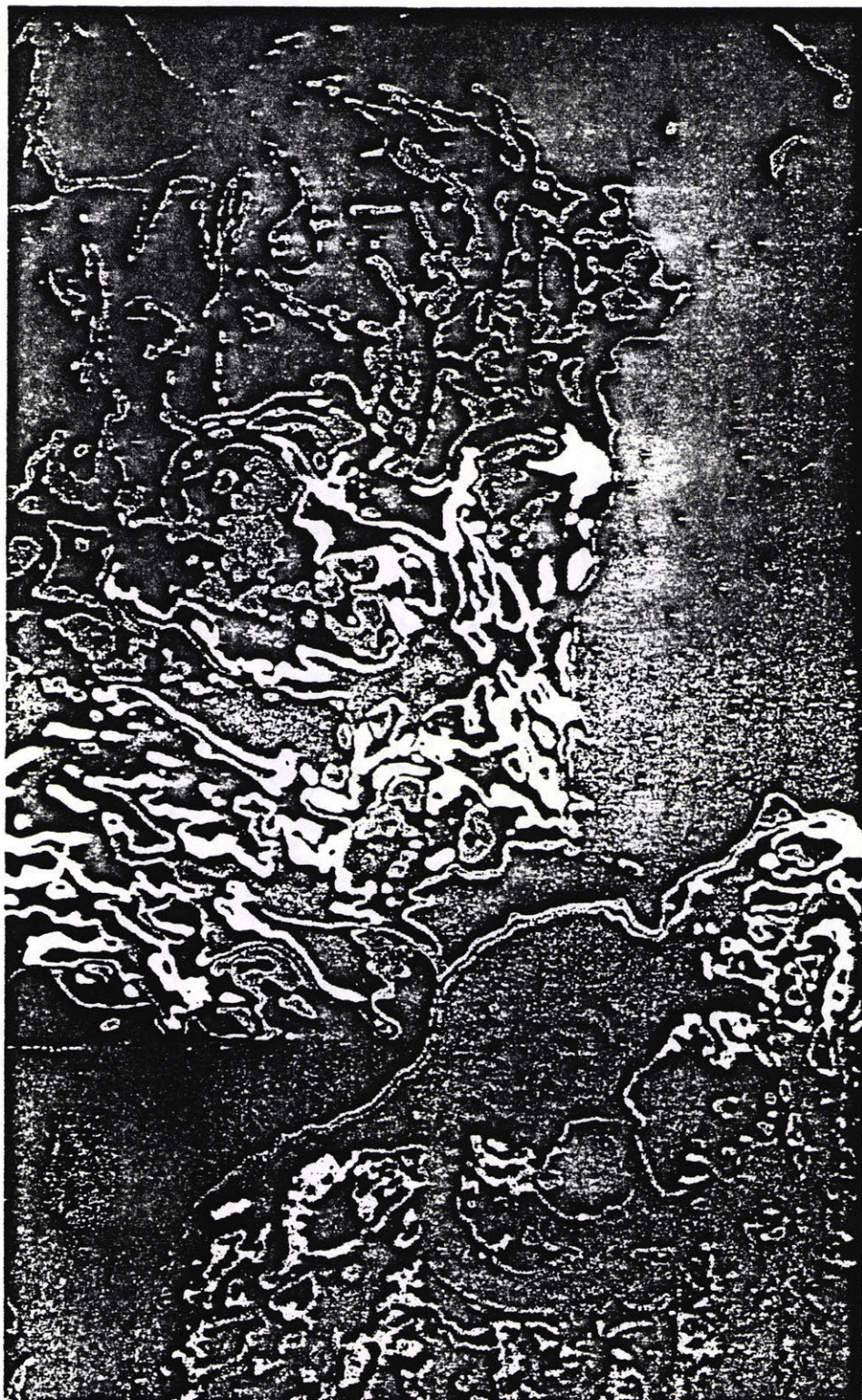
VOL. 28, NO. 4

Tort reform:
state-by-state report

ERT after
endometrial Ca
surgery?

Preventing group B
 β -hemolytic strep

What you
must know
about
AIDS



Serving your patients in the age of AIDS

By Nancy Stoller Shaw, PhD

Wherever you are located geographically, incorporating an awareness of AIDS into your practice is vital. As the primary caregiver to many women, you may be the only physician who will provide the information that permits early diagnosis. A comprehensive history is paramount.

In August 1986 the Centers for Disease Control (CDC) changed its method for categorizing the source of transmission in reported cases of AIDS. As a result, the number of women considered to have contracted AIDS from heterosexual contact rose from 16% to 27%. The number of cases listed as derived from "unknown source of transmission" accordingly dropped by the same amount.

The "new" heterosexual female cases include women who had sexual intercourse with men from countries in which heterosexual transmission is believed to play a major role in spreading human immunodeficiency virus (HIV), the up-and-coming term for human T-lymphotropic virus type III (HTLV-III). The women in question did not knowingly have sexual contact with homosexuals, IV drug abusers, people who had AIDS or AIDS-related complex (ARC), or hemophiliacs. The women did not abuse drugs themselves or report having had drug transfusions.

If the CDC were similarly to reclassify women whose sexual partners were from the US—and there are no compelling epidemiologic reasons not to—the percentage of women whose risk factor was heterosexual activity would rise to almost 40%. In addition, 9.3% of

female cases to date are the result of blood transfusions or blood products; 51.7% are from sharing IV needles or other drug paraphernalia (Figure 1).¹

Translating these percentages into numbers, we find that since 1981 more than 1,500 US women have been diagnosed as having AIDS.¹ Although figures vary considerably, most experts feel that for every current AIDS case there are five to ten cases of ARC. Observers also estimate that for every case of ARC, five to ten more people may be carrying the virus but showing no clinical signs of doing so. This projection suggests that 7,500 to 15,000 women have ARC and 40,000 to 150,000 more are carrying the virus.

The number of men who are asymptotically carrying the virus or who have AIDS or ARC is estimated to be 14 times that of women. Although many of these men are homosexual, current estimates indicate that some 160,000 to 800,000 heterosexual (not bisexual) men are also infected with the virus.

A recent study found that the nonmonogamous heterosexual population of San Francisco averages four to five partners per year.² Eleven percent are married. Almost all 400 study subjects were aware of AIDS and its routes of transmission. Nevertheless, most have made few or no changes in their sexual lifestyles since the AIDS epidemic began.

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Women who have AIDS

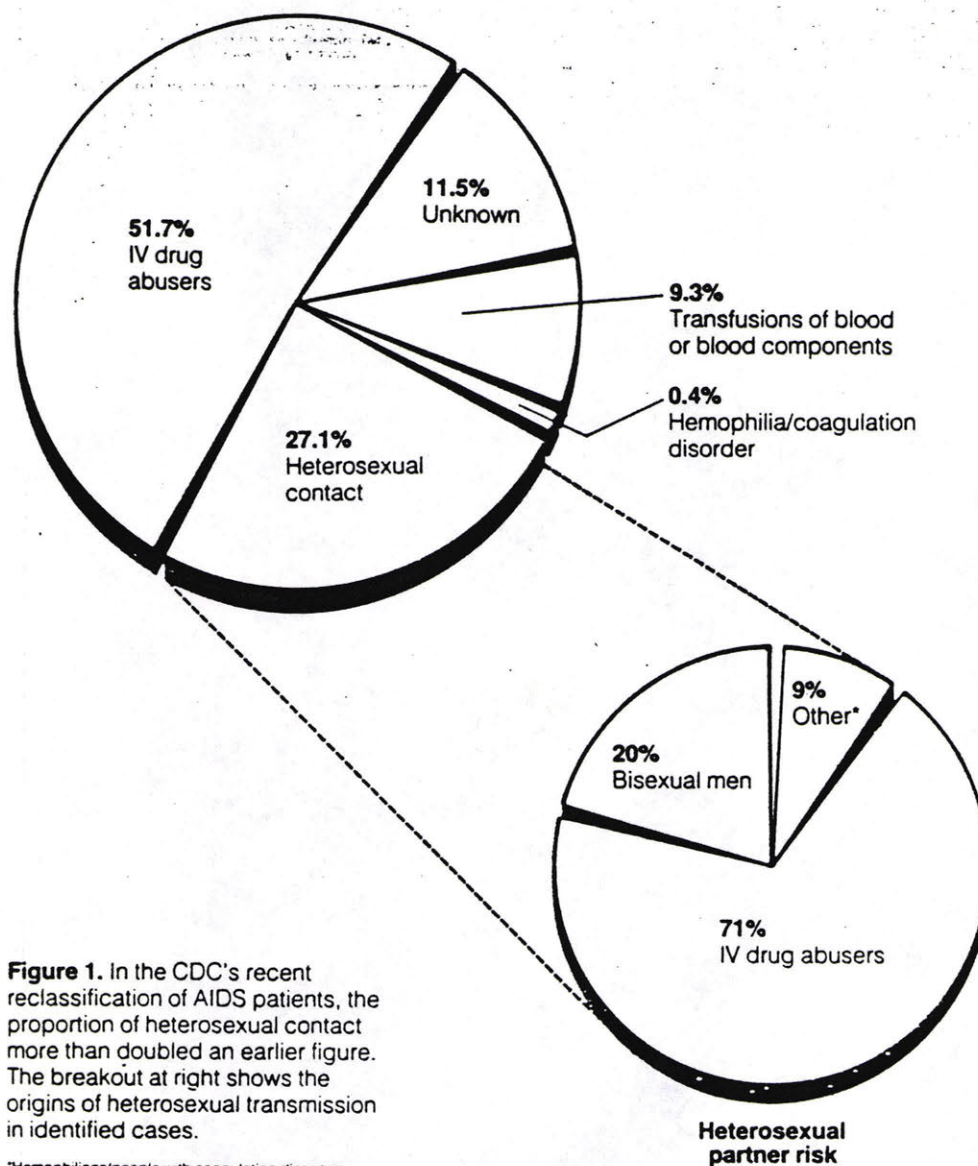


Figure 1. In the CDC's recent reclassification of AIDS patients, the proportion of heterosexual contact more than doubled an earlier figure. The breakout at right shows the origins of heterosexual transmission in identified cases.

*Hemophiliacs/people with coagulation disorders; blood transfusion recipients; men outside US.

Source: CDC.¹²

For those who have changed, the major differences have been fewer sexual partners and avoidance of those with known risk—for example, men who acknowledge their bisexuality or drug abuse. Some 2,000 to 4,000 heterosexual men and women in the city may already be infected with the virus. Therefore, the risk of transmission to the nonmonogamous het-

erosexual population is considerable. Similar risks exist in other cities throughout the US.

Demographically, 50% of US women already diagnosed as having AIDS are black; 27% are white; 22% are Hispanic; and 1% are from other or unknown backgrounds. Female cases are currently concentrated in four states: California, Florida, New Jersey, and

New York. These statistics may seem to condone relief and minimal interest in the disease by physicians in other parts of the country. It is important to remember, however, that women with AIDS are also found in other cities and rural areas across the country.

The Public Health Service predicts a continuing trend toward national dispersion of cases and an increased rate of heterosexual transmission. Thus, women with AIDS or ARC can arrive at almost any practice. How should you prepare to meet this challenge?

Educating your staff

The first step to providing adequate care is having a well-trained office staff. Basic education about AIDS should be given to all employees—including nurses, physicians, receptionists, and cleaning personnel. While the education should be appropriate to the employee's specific function, a basic feature of all training should be attention to staff fears and other feelings regarding AIDS, death, and dying. Such training will help prevent the staff from projecting negative feelings onto patients.

Resources are available through AIDS agencies, health departments, and medical centers throughout the US. These materials can be used in conjunction with inservice presentations and ongoing training programs. Education should address risk assessment and reduction, diagnosis and treatment, psychosocial issues, infection control, and legal and ethical concerns. The Women's Health Outreach, a project of the Women's Program of the San Francisco AIDS Foundation, has published a spiral-bound 356-page volume containing a wide range of information.*

Risk assessment and reduction

Because there is no cure or vaccine for AIDS, the only way to curb the epidemic is to under-

stand and prevent its transmission. The obstetrician-gynecologist's office is the ideal place to teach women about this. Current research indicates that women prefer to receive information about AIDS from a health-care professional and that family planning clinics and private physicians are their primary sources of such contact.²

The clinician can assist the patient in assessing her own risk of exposure. He or she can also educate her and her sexual partner about protecting themselves from future exposure. If the patient is already infected, the physician or other members of the health-care team can teach her how to protect a potential sex partner. All health-care workers who have direct contact with patients should be able to talk about sex and the use of condoms in specific terms and in a comfortable, nonjudgmental manner.

Women at risk who are of childbearing age should be made aware of the possibility of perinatal transmission. Staff members should be kept up to date about the changing views of researchers about such transmission. If a patient at risk is pregnant or considering pregnancy, the health-care provider should follow a protocol involving education, counseling, testing, and appropriate medical and psychological care.³

Staff should be taught to identify early indications of substance abuse. Information about reducing risks for IV drug abusers must be provided to patients in a supportive way. Long-term treatment and counseling for drug abusers are more appropriately provided by specialists in the field (see "Referral: a primer").⁴

How women with AIDS differ from men

Proper diagnosis is a key issue in managing AIDS and ARC—and no simple matter. Women may have symptoms different from those of men. For example, researchers reporting at the International AIDS Conference in Paris

**Women and AIDS Clinical Resource Guide* is available from the San Francisco AIDS Foundation, 333 Valencia St., Fourth Floor, San Francisco CA 94013. Postpaid, the book costs \$28 (\$40 for non-AIDS health-care providers).

Referral: a primer

An extensive network of community-based services has been developed in San Francisco to meet the needs of patients who have AIDS, ARC, or positive antibody test results. Those at risk of infection need special counseling, too. Other services are provided to the families, lovers, and friends of these patients.

The types of referrals suggested below are based on the San Francisco experience. Most such services can be found in any metropolitan area. Women need organizations and personnel sensitive to their special needs, including the impact of AIDS on their potential for pregnancy and mothering.

Start with your city or state health department. Each state has appointed an AIDS coordinator to remain in touch with the CDC for continual updates of information. If the contact person can't answer your questions, you may be referred to the CDC.

AIDS information and referral agencies. Some of these organizations, which are often the best source of referrals, offer specialized services for women. AIDS hotlines, found in all areas of the US, can refer you to the closest agency that has detailed information. That agency may well be the local health department.

Medical care. These services should include primary AIDS and ARC screening, conventional treatment, and alternative treatments, including chiropractic, nutrition counseling, or visualization, a form of therapy in which the patient visualizes a desired outcome, such as better health or more energy. Questions to

ask include: Is antibody testing free? anonymous? confidential?

Emergency services should be AIDS-aware. The staff should be able to provide referrals to physicians and AIDS-sensitive dentists. AIDS/ARC home care is an important feature, because many patients eventually require hospice services, public health nurses, private care, or home food delivery.

Mental health services. Facilities providing psychological services should offer support groups, a telephone network for women with AIDS or ARC, private counseling, and programs and services for community mental health, suicide prevention, and psychiatric emergencies. Counseling is crucial for grief, death, and dying.

Social services. Personnel should have listings of local AIDS service organizations; financial resources, including medical, general assistance, food stamps, and advice on social security and state disability benefits; housing counseling; legal information and advocacy; and religious services.

Alcohol and substance abuse services. Residential and nonresidential programs are available to varying extents in different parts of the US. To be sensitive to women's needs, such programs should accept pregnant women, provide child care, and be able to furnish methadone maintenance during pregnancy. Be sure not to refer patients to recovery programs that refuse clients who are antibody positive to HIV.

—N.S.S.

this summer said that chronic vaginitis was a common presenting complaint.⁵ Also, women who have AIDS or ARC are much less likely than men to have Kaposi's sarcoma or central nervous system involvement.^{6,7}

Investigators in New York City say that

AIDS is commonly reported at a later stage in women than in men. Furthermore, women enter the hospital for initial treatment when the illness is more severe; in addition, women's average length of stay is longer than men's.⁷ To prevent such delays, all staff involved in

health counseling as well as nurse practitioners, physician's assistants, and other ancillary staff should know the signs and symptoms of illnesses associated with AIDS.

Because these diseases are now being studied so intensively, treatment regimens for AIDS-related illnesses are being revised frequently. Therefore, the physician should consult with AIDS specialists before prescribing medication or establishing other treatment regimens.

Psychosocial issues

Health-care workers should identify their own assumptions and biases about the stigmatized populations to which many women at risk for AIDS belong. These include IV drug abusers, women who have multiple sex partners, and members of ethnic groups other than the provider's own. Because a woman at risk may have had a gay or bisexual partner, attitudes toward homosexuality expressed by the staff can contribute to the patient's willingness or unwillingness to confide certain risk factors.

The epidemic has elicited powerful emotional responses from the public. Physicians and other health-care workers are affected by society's attitudes. Exploring fear, grief, anxiety, and other emotions generated by the emergence of AIDS can lead to better patient care and more careful policy and practice decisions.

Women face the special stresses associated with the possibilities and uncertainties of maternal transmission.⁸ Women are also concerned with the responsibility of parenting and with the prospect of using AIDS services structured primarily for men. Nevertheless, women who have AIDS are statistically less suicidal than men who have the disease.⁷

Infection control

All staff members who have contact with patients' blood should follow standard infection control procedures similar to those used to prevent the spread of hepatitis B. Because

HIV has been cultured—with difficulty—from vaginal secretions, caution should be exercised during pelvic examinations as well.⁹ The value of taking routine precautions is to protect staff and patients against unwitting carriers of the virus. Simultaneously, the patient's privacy is not compromised by any appearance of special arrangements. The CDC recommends routine use of infection control procedures in all populations of which any member could be carrying the virus—including all ob-gyn patients.¹⁰

Specific infection control measures can be as simple as using disposable gloves, following standard procedures to avoid needle sticks, and proper handling and cleaning of soiled laundry. More detailed information is available in a recent CDC report.¹¹

Legal and ethical considerations

Medical records of women who have AIDS or ARC or who are antibody positive may require special handling. In some states it is illegal to divulge the results of an HIV antibody test without the patient's explicit consent. In California, permission must be obtained each time the information is shared.

Some states enacted such legal restrictions after patients lost jobs, housing, insurance, or other services because they had been identified as having AIDS. Before ordering a test or recording or sharing information, the practitioner should be aware of local law. Inform the patient about potential legal or social consequences and relevant legislation. A signed consent form may be appropriate or required.

Decisions about pregnancy and abortion should be examined from both medical and ethical perspectives. Although maternal transmission is well documented, the degree of risk is not certain.³ Some women wish to maintain pregnancy, others to terminate it. The physician must give accurate and sensitive advice when such a decision is necessary.

The clinician may also be asked about future

pregnancy by women who are healthy but antibody positive. The current CDC recommendation is that not only women who have AIDS or ARC but also those who are antibody positive postpone pregnancy indefinitely.

Educating patients

AIDS educational literature should be accessible in waiting and examining rooms. Because AIDS is a stigmatizing illness, women should be able to pick up this material without drawing attention to themselves.

Printed materials should be available in the languages spoken by the patient population being served. Posters and other educational graphics can be displayed on the walls to heighten patient awareness. Many such materials are becoming available, sometimes free of charge, from local health department authorities and AIDS agencies.

The medical intake form given to all patients should include questions that specifically address risk factors. These forms can also be used to determine a patient's level of AIDS awareness about preventive measures.

Information about AIDS transmission and prevention can be integrated into discussions about other aspects of health. For example, in discussing family planning, the physician might recommend the use of condoms—possibly in addition to other measures—for patients who have multiple sex partners or who are uncertain about the viral status of their steady partners. The topic of AIDS can also be raised in other discussions of drugs, sex, or pregnancy. When to bring up the subject may be determined by information on the intake and history forms, by the physical examination, and by laboratory data.

The existence of the AIDS antibody test should be made known to all patients, whether they are perceived to be at risk or not. Patients should not routinely be encouraged to take the test, however, nor should physicians order it unless they believe a woman has been

exposed to the virus. Patient literature on the test should cover such issues as anonymous testing, confidentiality procedures, and legal, insurance-related, and other potential consequences of being tested. For a 4-minute tape explaining basic lay information about AIDS, your patients may call a toll-free number set up by the CDC: 800-342-AIDS.

Because AIDS is a new, complex, life-threatening illness, no individual practitioner can expect to provide everything a patient affected by the disease will need—even if that patient is a young, healthy woman with no symptoms other than a positive antibody test. Knowledge of local resources and a good referral list are important additions to quality care provided at the office or hospital.

With proper staff training, a well-established program of patient education, and a backup list of resources and referrals, the obstetrician-gynecologist can provide primary, "first-stop" diagnosis and service to slow the AIDS epidemic and help care for those already affected by it. □

REFERENCES

1. CDC. *AIDS Weekly Surveillance Report*. Atlanta, Ga, Aug 11, 1986, p 1.
2. Research and Decisions Corp. *Designing an Effective AIDS Risk Reduction Program for San Francisco: Results From the First Probability Sample of Multiple-High Risk Partners of Heterosexual Adults*. San Francisco, San Francisco AIDS Foundation, 1986, p 18.
3. Rutherford GW, Oliva G, Grossman M, et al. Guidelines for control of perinatally transmitted human T-lymphotropic virus type III/lymphadenopathy-associated virus infection and care of infected mothers, infants and children. *San Francisco Epidemiologic Bull* 1986 2(April suppl 1):1.
4. Faltz B, Madover S. AIDS counseling strategies for the substance abuse client. San Francisco: UCSF AIDS Health Project, 1985.
5. Wright DC, Rhoades J, Redfield RH. HTLV-III disease in heterosexual women. Read before 2nd Intl Conference on AIDS, Paris, France, June 1986.
6. Kapila R, Grigori A, Kloser P. Women with AIDS/ARC. Read before 2nd Intl Conference on AIDS, Paris, France, June 1986.
7. Mantell JE, Belmont MF, Spivak H, et al. Women with AIDS: a comparison of sex differences. Read before 2nd Intl Conference on AIDS, Paris, France, June 1986.
8. Chiodo F, Ricchi E, Costigliola P, et al. Vertical transmission of HTLV-III. *Lancet* 1986;1:739.
9. Wofsy CB, Cohen JB, Hauer LB, et al. Isolation of AIDS-associated retrovirus from genital secretions of women with antibodies to the virus. *Lancet* 1986;1:527.
10. CDC. Summary: recommendations for preventing transmission of infection with human T-lymphotropic virus type III/lymphadenopathy-associated virus in the workplace. *MMWR* 1985;34:681.
11. CDC. Recommendations for assisting in the prevention of perinatal transmission of human T-lymphotropic virus type III/lymphadenopathy-associated virus and acquired immunodeficiency syndrome. *MMWR* 1985;34:721.
12. CDC. *Weekly Surveillance Report—AIDS, AIDS Program*. Center for Infectious Diseases, Atlanta, Ga, Aug 25, 1986.

AIDS COUNSELLING STRATEGIES FOR THE
SUBSTANCE ABUSE CLIENT

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In Press

AIDS COUNSELLING STRATEGIES
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TABLE OF CONTENTS

INTRODUCTION	1
SECTION ONE: CONSELLING PLANS	4
Content and Objectives	4
Group 1: The "Worried Well"	6
Group 2: "Sero-Positives"	8
Group 3: Clients With AIDS Related Condition	10
Group 4: Clients With a Diagnosis of AIDS	13
Medication Agreement	16
Group 5: Clients Who Are Gay or Bisexual	17
Group 6: Family Members of Clients	20
COUNSELLING PLAN CHECKLISTS	22
Group 1: The "Worried Well"	22
Group 2: "Sero-Positive"	23
Group 3: Clients With AIDS Related Condition	24
Group 4: Clients With a Diagnosis of AIDS	25
Group 5: Clients Who are Gay are Bisexual	26
Group 6: Family Members of Clients	27
SECTION TWO: EDUCATION PLAN FOR IV DRUG USERS	28
Quick Guide for Minimizing the Risk of AIDS	31
SECTION THREE: SUPPORT GROUPS FOR PEOPLE WITH AIDS RELATED PROBLEMS	32

AIDS COUNSELLING STRATEGIES FOR THE SUBSTANCE ABUSE CLIENT

Introduction

The rapid spread of AIDS has presented enormous challenges for counselors who work with clients "at risk" for contracting the disease. Working with key issues, such as sexual behavior, health practices, intimacy, family relations, and death, are difficult to deal with when addressed individually. In the shadow of AIDS, all of them must be faced simultaneously along with the prospects of shortened lifetimes, medical uncertainty, and public fear and hostility.

These challenges are perhaps nowhere greater felt than among counselors, like yourself, who work with "substance abusers." Here, all of the issues normally faced by counselors of AIDS patients or risk groups are present. But the situation is further complicated in this instance by at least three major aspects of the substance abuse problem:

1. THE NATURE OF DRUG ABUSE ITSELF
2. THE POSITION OF DRUG ABUSERS IN SOCIETY
3. UNDERLYING HEALTH ISSUES

Complications

1. THE NATURE OF DRUG ABUSE ITSELF

When your client is a substance abuser, many of your most effective tools are blunted by the nature of the client's problem. For example:

- Substance abusers are already operating well outside the bounds of sound medical advice; they may be unwilling to trust or believe your warnings concerning AIDS.
- Substance abuse, for many, is already a form of gradual suicide; self interest and the will to live are less effective as personal motivators.
- Substance abusers are typically well experienced in the art of denial; their apparent concern for the threat posed by AIDS may be minimal.
- The value systems of substance abusers are often built upon a fatalistic outlook; AIDS can be more easily accepted, and ignored, from that perspective.

2. THE DRUG ABUSER'S POSITION IN SOCIETY

Because of their status as "outlaws" within society, most drug abuser clients are not well served by the community groups which provide help to those in other risks groups. Even where such groups exists to serve them, substance abusers are less likely to be aware of them and less likely to trust them. Unlike other risk groups, such as homosexuals, there is little sense of community among substance abusers.

Similarly, substance abusers are often cut off from many of society's basic institutions. Substance abusers are:

- unlikely to have medical insurance and are thus served primarily by public hospitals and clinics, which are often heavily burdened with AIDS patients in other risk groups;
- low on the priorities of publicly funded physicians, therapists, support groups, and educational campaigns due to historically poor recovery rates;
- usually unemployed and have fewer financial resources to draw on;
- often cut off from common forms of family and social support.

Without many of the basic institutions to draw on, substance abusers are at a distinct disadvantage both in learning how to avoid AIDS and in coping with it when it occurs.

3. UNDERLYING HEALTH ISSUES

The substance abuser's underlying health is likely to be a strong contributor to the problem. The list of suspected "co-factors" to the development of AIDS reads like an inventory of the personal practices of many substance abusers:

- poor nutritional and sanitary practices
- use of immune suppressing drugs, such as marijuana, alcohol, speed, and poppers
- repeated bouts of infection and illness
- high stress and the absence of basic life satisfactions

Drug abuse in any form poses a direct threat to the body's immune system, so when the client encounters the AIDS virus, it is with an already compromised immune system. Thus the course of the disease for the drug abuser is often more rapid and more devastating.

Results

This series of complications for the drug abuser is already beginning to show its effect in the annual AIDS statistics. While AIDS has publicly most often been associated with homosexuals, current trends in some major cities show that that may be changing. In the major New York/New Jersey metropolitan area, for example, the growth rate of AIDS among homosexuals appears to be stabilizing. Instead, the groups there at greatest (and growing) risk are the drug abusing members of ethnic minorities and the lower economic classes. The percentage of drug abusers in the caseload total for these areas is on a steady incline.

The problems posed by AIDS for drug abusers concern and affect all of society. It is in everyone's best interests to take the steps necessary to slow the transmission of this disease among drug abuse clients. Your role in that process is a key one, however difficult and challenging it may be.

Counseling, Education, and Support

The instructional materials which follow are divided into three sections:

SECTION ONE: AIDS COUNSELLING PLAN FOR
SUBSTANCE ABUSE CLIENTS

SECTION TWO: EDUCATION PLAN FOR IV
(INTRAVENOUS) DRUG USERS

SECTION THREE: GUIDELINES FOR CONDUCTING
SUPPORT GROUPS

Preceding each section is a brief description of its content, objectives, and a definition of key terms. No attempt is made, however, to define every aspect of AIDS. You are encouraged to build your knowledge of this subject through your reading of related materials elsewhere in this handbook.

The task you face will not be an easy one. Many of your clients have already formed attitudes regarding their response to AIDS, while others may choose to remain blissfully ignorant. The sad result and greatest challenge is that many, particularly those most in need, may not want to hear what you have to say or simply won't let it sink in. Getting through with your critically important message will take

PERSONAL CREDIBILITY AND KNOWLEDGE
SINCERE CONCERN AND CONSISTENT SUPPORT
A WILLINGNESS TO CONFRONT DEEP DENIAL.

The payoff, however, is great, both for the client and for society at large.

AIDS COUNSELLING PLAN FOR SUBSTANCE ABUSE CLIENTS

Content and Objectives

The AIDS COUNSELLING PLAN FOR SUBSTANCE ABUSE CLIENTS which follows is designed to give you practical tools for meeting the AIDS awareness and coping needs of drug abusers. It addresses the needs of six key groups of clients you may work with:

- GROUP 1: The "WORRIED WELL"
(Clients without symptoms of AIDS or ARC who have either tested negative to the AIDS/HTLV III anti-body test or who haven't been tested).
- GROUP 2: "SERO-POSITIVES"
(Clients with a positive AIDS/HTLV III anti-body test without an AIDS or ARC diagnosis).
- GROUP 3: CLIENTS WITH AIDS RELATED CONDITION (ARC)
(Clients with some clinical symptoms diagnosed as being AIDS-related but who as yet do not show the formal indicators of AIDS as defined by Federal government agencies).
- GROUP 4: CLIENTS WITH A DIAGNOSIS OF AIDS
(Clients who are diagnosed as having the formal symptoms of AIDS).
- GROUP 5: CLIENTS WHO ARE ALSO GAY OR BISEXUAL
(Drug abuse clients who also acknowledge either a homosexual or bisexual preference).
- GROUP 6: FAMILY MEMBERS of clients with AIDS, ARC, or SERO-POSITIVES

A counselling plan is presented for each group which concludes with a step-by-step guide for conducting your initial intervention with the client(s). Some elements of the plans are common to all of the groups, while others are uniquely directed to the special needs of each type of client. Each COUNSELLING PLAN includes:

- I. THE NEED GROUP'S KEY CONCERNS
- II. DESIRED OUTCOME OF THE COUNSELLING PROCESS
- III. SUGGESTED INITIAL INTERVENTION STRATEGY
- IV. CLIENT CARE CHECKLIST

The last item, the CLIENT CARE CHECKLIST, is a shortened summary of the INITIAL INTERVENTION STRATEGY. It can be used as a record keeping device to track your interactions with individual clients. When applied, it serves as a road map of the steps which have been achieved and those which require additional action. You are encouraged to make file copies of it for each client you work with. The necessary steps, in some cases, are quite numerous and neither mental record keeping nor file summaries may be adequate in tracking progress.

Common to all intervention strategies is continued attention to the underlying drug abuse problem. Despite high degrees of denial, concern over the impact of AIDS on themselves, their offspring, and their friends or loved ones may serve to motivate clients to seek treatment for their drug habits. Unlike drug abuse, where the consequences often accumulate slowly, the impact of AIDS is clear, devastating, and irreversible. It may help some clients keep their commitments to dependency treatment programs or move others to join such programs NOW, rather than in the "near future" which so easily eludes them.

GROUP 1: The "WORRIED WELL"

(Counselling clients who do not show symptoms of AIDS or ARC and who have either tested negative to the AIDS/HTLV III anti-body test or who haven't been tested at all).

I. KEY CONCERNS

- A. AIDS awareness/education
- B. Health maintenance & AIDS avoidance
- C. Resource/referral awareness
- D. Dealing with emotions generated by the need for change.

II. DESIRED OUTCOMES

- A. Changes in behavior, initiated by the client, which reduce the risk of contracting AIDS or ARC.
- B. Emotional support provided by the counselor to encourage and support behavioral changes.
- C. Increased awareness and knowledge of AIDS issues and available resources.

III. INITIAL INTERVENTION STRATEGY

- A. Assess the level of understanding of basic Aids information & formulate an education plan based on client needs (see other enclosed materials and the "EDUCATION PLAN FOR IV DRUG USERS, page 8).
- B. Confront denial or lack of commitment to minimize risky behavior.
- C. Offer hope for continued health through prevention measures (see recommendations elsewhere in this manual).
- D. Assess the need & depth of motivation for referral to chemical dependency or alcohol treatment programs.
- E. Encourage continuing commitment to the recovery process in treatment for chemical/alcohol dependency (if already in such a program).
- F. Assess the apparent need & refer for medical follow-up, emotional or sexual counselling, or to support groups and other self-help programs.

- G. Help the client verbalize feelings of anger, grief, and loss generated by the need for change in sexual & drug use behavior or by possible delay in child bearing.
 - H. Involve family & support persons in the assessment & treatment approach chosen.
-

GROUP 2: "SERO-POSITIVES"

(Counselling clients with a positive AIDS anti-body test without an AIDS or ARC diagnosis).

I. KEY CONCERNS

- A. AIDS awareness/education, particularly focusing on the meaning(s) of "Sero-Positive"
- B. Health maintenance & AIDS avoidance
- C. Resource/referral awareness
- D. Dealing with emotions generated by the positive test results, uncertainty, and the need for change.

II. DESIRED OUTCOMES

- A. Client will make changes which reduce the risk of contracting AIDS or ARC.
- B. Emotional support will be provided by the counselor to encourage and support behavioral changes.
- C. Client will be able to cope with uncertainty of future medical problems.
- D. Client will have increased awareness and knowledge of AIDS issues and available resources.

III. INITIAL INTERVENTION STRATEGY:

- A. Check the level of understanding of basic AIDS information & develop an education plan based on client needs (see other enclosed materials and the "EDUCATION PLAN FOR IV DRUG USERS, page 8). Review client's understanding of what a positive results does and does not mean.
- B. Confront denial or lack of commitment to minimize risk behavior.
- C. Offer hope for continued health through prevention measures (see recommendations elsewhere in this manual).
- D. Check the need & depth of motivation for referral to chemical dependency or alcohol treatment programs.
- E. Encourage continuing commitment to the recovery process in treatment for chemical/alcohol dependency (if already in such a program).

- F. Check the apparent need & refer for medical follow-up, emotional or sexual counselling, or to support groups and other self-help programs.
 - G. Help the client verbalize feelings of anger, grief, and loss generated by the need for change in sexual & drug use behavior or by possible delay in child bearing.
 - H. Reinforce the fact that taking action now may help prevent occurrence of AIDS in the future.
 - I. Discuss "contagion" issues with client & family members to allay fears of spread by casual contact
 - J. Encourage & support client verbalization of such feelings as:
 - 1. Fear of contracting AIDS
 - 2. Fear of having exposed others to AIDS or doing so through continued risk behavior
 - 3. Feelings of guilt over risk behavior in the past
 - 4. Feelings of loss over necessary behavior changes and possible postponement of child-bearing
 - 5. Fear of what others will think or do or of being isolated and/or rejected
 - K. Involve family & support persons in the assessment & treatment approach chosen.
-

GROUP 3: CLIENTS WITH AN AIDS RELATED CONDITION (ARC)

[Clients with some clinical symptoms diagnosed as being AIDS-related but who as yet do not show the formal indicators of AIDS as defined by Federal government agencies].

I. KEY CONCERNS

- A. AIDS awareness/education, particularly focusing on the meaning of "ARC" and the outlook for progression to AIDS
- B. Health maintenance & avoiding further disease progression
- C. Resource/referral awareness
- D. Dealing with emotions generated by the ARC diagnosis, uncertainty of medical outlook, and the need for changes in behavior to prevent progression or transmission of disease.

II. DESIRED OUTCOMES

- A. Client will make changes which reduce the risk of progressing to AIDS or transmitting AIDS or ARC.
- B. Emotional support will be provided by the counselor to encourage and support behavioral changes.
- C. Client will be able to cope with uncertainty of future medical problems.
- D. Client will be able to utilize appropriate community social service, medical, chemical dependency & alcoholism treatment, mental health, vocation, and legal resources.

III. INITIAL INTERVENTION STRATEGY:

- A. Check the level of understanding of basic AIDS information & develop an education plan based on client needs (see other enclosed materials and the "EDUCATION PLAN FOR IV DRUG USERS, page 8). Review client's understanding of what ARC means and does not mean.
- B. Confront denial or lack of commitment to minimize risk behavior.
- C. Offer hope for continued health through prevention measures (see recommendations elsewhere in this manual).

- D. Check the need & depth of motivation for referral to chemical dependency or alcohol treatment programs.
- E. Encourage continuing commitment to the recovery process in treatment for chemical/alcohol dependency (if already in such a program).
- F. Check the apparent need & refer for medical follow-up, emotional or sexual counselling, or to support groups and other self-help programs.
- G. Help the client verbalize feelings of anger, grief, and loss generated by the diagnosis, the need for change in sexual & drug use behavior or by possible delay in child bearing.
- H. Reinforce the fact that taking action now may help prevent occurrence of full-blown AIDS in the future.
- I. Discuss "contagion" issues with client & family members to allay fears of spread by casual contact.
- J. Encourage & support client verbalization of such feelings as:
 - 1. Fear of contracting AIDS
 - 2. Fear of having exposed others to AIDS or doing so through continued risk behavior
 - 3. Feelings of guilt over risk behavior in the past
 - 4. Feelings of loss over necessary behavior changes and possible postponement of child-bearing
 - 5. Fear of what others will think or do or of being isolated and/or rejected
- K. Compile and distribute a list of community resources to serve people with AIDS concerns or AIDS/ARC diagnosis (such as the one in Table 1 on page 8, compiled by UCSF AIDS Health Project for AIDS anti-body test recipients).
- L. Encourage use of tools learned in recovering from chemical dependency & alcoholism in coping with this life crisis.
- N. Continue to confront the drug abuse as you would with other clients not diagnosed with ARC.
- O. Emphasize positive things the client can do to maximize health and minimize the likelihood of progression to full-blown AIDS.

GROUP 4: CLIENTS WITH A DIAGNOSIS OF AIDS

(Counselling clients who are diagnosed as having the formal symptoms of AIDS).

I. KEY CONCERNS

- A. AIDS awareness/education, particularly focusing contagion, quality of life issues, and possible treatment options;
- B. Health maintenance & avoiding further disease progression;
- C. Resource/referral awareness;
- D. Dealing with emotions generated by the diagnosis, uncertainty, and the need for changes in behavior to extend life, improve the quality of life, and prevent transmission of the disease.

II. DESIRED OUTCOMES

- A. Client will minimize risk behavior and avoid relapse.
- B. Emotional support will be provided by the counselor to encourage and support behavioral changes.
- C. Client will be able to utilize appropriate community social services, medical, chemical dependency & alcoholism treatment, mental health, vocation, and legal resources.
- D. Client will be motivated to continue to benefit from participation in treatment for dependency.

III. INITIAL INTERVENTION STRATEGY:

- A. Check the level of understanding of basic AIDS information & develop an education plan based on client needs (see other enclosed materials and the "EDUCATION PLAN FOR IV DRUG USERS, page 8).
- B. Confront denial or lack of commitment to minimize risk behavior.
- C. Offer hope for stabilization of health through positive health care measures (see recommendations elsewhere in this manual).

- D. Check the need & depth of motivation for referral to chemical dependency or alcohol treatment programs.
- E. Encourage joining or continuing commitment to the recovery process in treatment for chemical/alcohol dependency.
- F. Check the apparent need and refer for medical follow-up, emotional or sexual counselling, or to support groups and other self-help programs.
- G. Help the client verbalize feelings of anger, grief, and loss generated by the diagnosis, the need for change in sexual & drug use behavior or by possible delay in child bearing.
- H. Reinforce the fact that taking action now may help stabilize the client's health and slow further deterioration.
- I. Discuss "contagion" issues with client & family members to allay fears of spread by casual contact
- J. Encourage & support client verbalization of such feelings as:
 - 1. Fear of dying from AIDS
 - 2. Fear of having exposed others to AIDS or doing so through continued risk behavior
 - 3. Feelings of guilt over risk behavior in the past
 - 4. Feelings of loss over necessary behavior changes and possible postponement of child-bearing
 - 5. Fear of what others will think or do or of being isolated and/or rejected
- K. Compile and distribute a list of community resources to serve people with AIDS concerns or AIDS/ARC diagnosis (such as the one in Table 1, compiled by UCSF AIDS Health Project for AIDS anti-body test recipients).
- L. Encourage the use of tools learned in recovering from chemical dependency & alcoholism in coping with this life crisis.
- M. Continue to confront the drug abuse as you would with other clients not diagnosed with AIDS.
- N. Emphasize positive things the client can do to maximize health.
- O. Extend hope that with continued attention to health matters that the client can live longer, possibly extending life until more effective treatments become available.

- P. Emphasize what control the client does have over the quality of life for as long as he/she lives.
 - Q. Encourage client planning for care of family members and for financial/legal matters.
 - R. Consult with physicians about any possible program modifications to help client stay in continued treatment.
 - S. Set realistic expectations for yourself as a counselor and for the client.
 - T. Consult with physicians and other care-givers on medication issues in order to maximize benefits without abuse of prescription drugs. See MEDICATION CONTRACT, page 4, if abuse is likely to remain a problem.
-

AIDS HEALTH PROJECT

Administrative Offices

333 Valencia Street
San Francisco, CA 94103
(415) 626-6637

- AIDS Mental Health Program
- AIDS Prevention Program
- Youth & AIDS Prevention Program
- AIDS Health Professional Training Program
- AIDS & Substance Abuse Program
- HTLV-III Counseling Program

MEDICATION AGREEMENT

I, _____, REALIZE THE FOLLOWING
PROBLEMS WITH MY CURRENT USE OF MEDICATION:

[Check if applicable]

1. Feeling Tired or having a clouded mental state. _____
2. Feeling "hyperactive" or nervous. _____
3. Anticipating my next dose ahead of time. _____
4. Wishing for a higher dose or stronger medication. _____
5. Supplementing medication with alcohol or drugs. _____
6. Thinking of asking more than one doctor for medication. _____
7. Other _____

I AGREE THAT THESE PROBLEMS INTERFERE WITH MY
TREATMENT AND I COMMIT TO THE FOLLOWING
AGREEMENTS:

1. Not to exceed the daily dose of medication prescribed. _____
2. To discuss any medication problems with my primary
Health Care Worker. _____
3. Not to obtain medication from other sources. _____
4. Not to self-medicate with alcohol or drugs. _____
5. Other _____

MEDICATION

<u>NAME</u>	<u>DOSE</u>	<u>FREQUENCY</u>
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

Patient Signature

MD/Health Care Worker

Date

A project concerned
with AIDS Prevention
and Health Promotion
University of California
SF and Department of
Public Health

GROUP 5: CLIENTS WHO ARE ALSO GAY OR BISEXUAL

(Specific counselling needs of gay and bisexual men with ARC/AIDS or who positive to the AIDS anti-body).

I. KEY CONCERNS

- A. All issues relevant clients with AIDS, ARC, or positive anti-body test results (see GROUPS 2,3,4 above).
- B. Increased attention to Gay/Lesbian concerns
- C. Role of lover or closest friend in the treatment process.

II. DESIRED OUTCOME

- A. Client will minimize risk behavior and avoid relapse
- B. Emotional support will be provided by the counselor to encourage and support behavioral changes.
- C. Client will be able to utilize appropriate community social service, medical, chemical dependency & alcoholism treatment, mental health, vocation, and legal resources.
- D. Client will be motivated to continue to benefit from participation in treatment for dependency.
- E. Enhanced staff sensitivity to gay/bisexual lifestyles.
- F. Client will make better use of appropriate resources in the gay/bisexual community.

III. INITIAL INTERVENTION STRATEGY

- A. Check the level of understanding of basic AIDS information & develop an education plan based on client needs (see other enclosed materials and the "EDUCATION PLAN FOR IV DRUG USERS, page 8).
- B. Confront denial or lack of commitment to minimize risk behavior.
- C. Offer hope for stabilization of health through positive health care measures (see recommendations elsewhere in this manual).

- D. Check the need and depth of motivation for referral to chemical dependency or alcohol treatment programs.
- E. Encourage joining or continuing commitment to the recovery process in treatment for chemical/alcohol dependency.
- F. Check the apparent need and refer for medical follow-up, emotional or sexual counselling, or to support groups and other self-help programs.
- G. Help the client verbalize feelings of anger, grief, and loss generated by the diagnosis, the need for change in sexual & drug use behavior.
- H. Reinforce to client that taking responsibility for one's health now may prevent AIDS in the future, may help prevent the progression of AIDS to ARC, or may help stabilize the client's health and slow further deterioration.
- I. Discuss "contagion" issues with client & "significant others" to allay fears of spread by casual contact
- J. Encourage and support client verbalization of such feelings as:
 - 1. Fear of dying from AIDS
 - 2. Fear of having exposed others to AIDS or doing so through continued risk behavior
 - 3. Feelings of guilt over risk behavior in the past
 - 4. Feelings of loss over the need to make behavior changes.
 - 5. Fear of what others will think or do or of being isolated and/or rejected
 - 6. Concerns about forced "coming out" as a result of a possible AIDS diagnosis
 - 7. Internalized anti-gay feeling stirred up by a possible diagnosis
 - 8. The difficulties in making changes in sexual and drug use behavior.
- K. Compile and distribute a list of community resources to serve people with AIDS concerns or AIDS/ARC diagnosis (such as the one in Table 1, page 8 compiled by UCSF AIDS Health Project for AIDS anti-body test recipients).
- L. Encourage use of tools learned in recovering from chemical dependency & alcoholism in coping with this life crisis.
- M. Continue to confront the drug abuse as you would with other clients.

- N. Emphasize positive things the client can do to maximize health and prevent progression to an AIDS diagnosis.
 - O. Set realistic expectations for yourself as a counselor and for the client.
 - P. Arrange staff participation in training programs to increase sensitivity to Gay/Lesbian concerns, such as:
 - 1. Fear of rejection
 - 2. Need for accurate knowledge of gay lifestyle
 - 3. Resources available within the gay community
 - 4. Ability of staff to discuss sexual issues
 - 5. Internalized homophobia (self hatred, anti-gay feelings)
 - Q. Include client's lover or closest friend in treatment process as a family member. Be prepared to support that role with other family members.
 - S. Consult COUNSELLING PLAN for Groups 1 - 4 as appropriate.
-

GROUP 6: FAMILY MEMBERS OF CLIENTS

(Counselling needs of family members of people with AIDS/ARC or sero-positive).

I. KEY CONCERNS

- A. Outlook for health of family member
- B. Fear of contagion, if any, presented by family member who is ill
- C. Coping with feelings over the diagnosis or positive test results
- D. How the family can help - providing support instead of passing judgment.

II. DESIRED OUTCOMES

- A. Changes will be made in behavior by family members and sexual or needle-sharing partners which can help reduce risk to the affected person.
- B. Emotional support will be provided by the counselor to encourage and support behavioral changes.
- C. Family member(s) will develop an improved ability to cope with uncertainty over future medical problems.
- D. Family member(s) will learn to utilize appropriate community social service, medical, mental health, substance abuse, vocational and legal resources.

III. INITIAL INTERVENTION STRATEGY

- A. Check the level of anxiety, concern, anger, grief, etc. felt around the AIDS-related diagnosis of the affected person.
- B. Allow for comfortable verbalization of feelings
- C. Check level of understanding of basic AIDS information & develop an education plan based family members' needs (see other sections of text).
- D. Offer hope for avoiding further progression of the disease and for possible improved quality of life.
- E. For family members of people with AIDS, stress the importance of a drug free lifestyle.

- F. Stress hope for the development of a treatment for AIDS.
- G. Check the apparent need and refer for medical follow-up, emotional or sexual counselling, or to support groups and other self-help groups.
- H. Reinforce appropriate steps as described in Sections I-IV, Initial Interventions.

COUNSELLING PLAN CHECKLIST

GROUP 1 - "THE WORRIED WELL"

- ☐ A. Check understanding of AIDS & develop an education plan.
- ☐ B. Confront denial or lack of commitment to minimize risk behavior.
- ☐ C. Offer hope for continued health
- ☐ D. Check the need & motivation for referral to dependency treatment programs.
- ☐ E. Encourage continuing commitment to treatment programs.
- ☐ F. Check need, refer to medical/support resources for follow-up.
- ☐ G. Help client verbalize feelings generated by the need for change.
- ☐ H. Involve family & support persons in the assessment & treatment.

COUNSELLING PLAN CHECKLIST

GROUP 2 - SERO-POSITIVE CLIENTS

- ☐ A. Check understanding of AIDS & develop an education plan.
- ☐ B. Confront denial or lack of commitment to minimize risk behavior.
- ☐ C. Offer hope for continued health
- ☐ D. Check the need & motivation for referral to dependency treatment programs.
- ☐ E. Encourage continuing commitment to treatment.
- ☐ F. Check need, refer to medical/support resources for follow-up.
- ☐ G. Help client verbalize feelings generated by the need for change.
- ☐ H. Reinforce taking action now to prevent AIDS in the future.
- ☐ I. Discuss "contagion" issues with client & family members.
- ☐ J. Encourage & support client verbalization of feelings:
 - ☐ 1. Fear of contracting AIDS
 - ☐ 2. Fear of exposing/having exposed others
 - ☐ 3. Feelings of guilt over past risk behavior
 - ☐ 4. Feelings of loss over behavior changes and possible postponement of child-bearing
 - ☐ 5. Fear of isolation/rejection
- ☐ K. Involve family & support persons.

COUNSELLING PLAN CHECKLIST

GROUP 3 - CLIENTS WITH "ARC"

- ☐ A. Check understanding of AIDS & develop an education plan.
- ☐ B. Confront denial or lack of commitment to minimize risk behavior.
- ☐ C. Offer hope for continued health.
- ☐ D. Check the need & motivation for referral to dependency treatment programs.
- ☐ E. Encourage continuing commitment to treatment.
- ☐ F. Check need, refer to medical/support resources for follow-up.
- ☐ G. Help client verbalize feelings generated by the the need for change.
- ☐ H. Reinforce taking action now to help prevent progression to AIDS in the future.
- ☐ I. Discuss "contagion" issues with client & family members.
- ☐ J. Encourage & support client verbalization of feelings
 - ☐ 1. Fear of contracting AIDS
 - ☐ 2. Fear of exposing/having exposed others
 - ☐ 3. Feelings of guilt over past risk behavior
 - ☐ 4. Feelings of loss over behavior changes and possible postponement of child-bearing
 - ☐ 5. Fear of isolation/rejection
- ☐ K. Compile & distribute list of community resources.
- ☐ L. Encourage use of tools learned in recovering from chemical dependency.
- ☐ M. Continue to confront the drug abuse.
- ☐ N. Emphasize things client can do to maximize health, prevent further progression.

COUNSELLING PLAN CHECKLIST

GROUP 4 - CLIENTS WITH A DIAGNOSIS OF AIDS

- ☐ A. Check understanding of AIDS & develop an education plan.
- ☐ B. Confront denial or lack of commitment to minimize risk behavior.
- ☐ C. Offer hope for stabilization of health.
- ☐ D. Check the need & motivation for referral to dependency treatment programs.
- ☐ E. Encourage continuing commitment to treatment.
- ☐ F. Check need, refer to medical/support resources for follow-up.
- ☐ G. Help client verbalize feelings generated by the diagnosis itself and the need for change.
- ☐ H. Reinforce taking action now to help stabilize health and slow further deterioration.
- ☐ I. Discuss "contagion" issues with client & family members.
- ☐ J. Encourage & support client verbalization of feelings:
 - ☐ 1. Fear of contracting AIDS
 - ☐ 2. Fear of exposing/having exposed others
 - ☐ 3. Feelings of guilt over past risk behavior
 - ☐ 4. Feelings of loss over behavior changes and possible postponement of child-bearing
 - ☐ 5. Fear of isolation/rejection
- ☐ K. Compile and distribute a list of community resources.
- ☐ L. Encourage use of tools learned in recovering from dependency.
- ☐ M. Continue to confront the drug abuse.
- ☐ N. Emphasize positive things the client can do to maximize health, slow further degeneration.
- ☐ O. Extend hope that the client can live longer.
- ☐ P. Emphasize client control over the quality of life.
- ☐ Q. Encourage planning for care of family members and financial arrangements.
- ☐ R. Consult with physicians about program modifications to help client stay in treatment.
- ☐ S. Set realistic expectations for yourself and for client.
- ☐ T. Consult medication issues to maximize medication benefit without abuse of prescription drugs (use medication contract?)

COUNSELLING PLAN CHECKLIST**GROUP 5 - CLIENTS WHO ARE ALSO GAY/BISEXUAL**

- ___ A. Check understanding of AIDS & develop an education plan.
- ___ B. Confront denial to minimize risk behavior.
- ___ C. Offer hope for stabilization of health.
- ___ D. Check need for referral to dependency treatment programs.
- ___ E. Encourage continuing commitment to treatment.
- ___ F. Check need & refer to additional resources for follow-up.
- ___ G. Help client verbalize feelings generated by the need for change.
- ___ H. Reinforce taking action now to help stabilize health and slow further deterioration.
- ___ I. Discuss "contagion" issues with client & family members.
- ___ J. Encourage & support client verbalization of feelings:
 - ___ 1. Fear of contracting AIDS
 - ___ 2. Fear of exposing/having exposed others
 - ___ 3. Feelings of guilt over past risk behavior
 - ___ 4. Feelings of loss over behavior changes and possible postponement of child-bearing
 - ___ 5. Fear of isolation/rejection
- ___ K. Compile and distribute a list of community resources.
- ___ L. Encourage use of tools learned in recovering from dependency.
- ___ M. Continue to confront the drug abuse.
- ___ N. Emphasize positive things the client can do to maximize health, prevent progression to AIDS.
- ___ O. Set realistic expectations for yourself and for client.
- ___ P. Arrange staff participation in training programs to increase sensitivity to Gay/Lesbian concerns.
- ___ Q. Include lover or closest friend as a family member.
- ___ S. Consult Counselling Plan for Groups 1 - 4 as appropriate.

COUNSELLING PLAN CHECKLIST

GROUP 6 - FAMILY MEMBERS OF CLIENTS

- A. Check the level of anxiety, concern, anger, grief, etc. felt around the AIDS-related diagnosis of the affected person.
- B. Allow for comfortable verbalization of feelings
- C. Check understanding of AIDS information & develop an education plan based on family members' needs.
- D. Offer hope for prevention of further progression of the disease or at least improved quality of life.
- E. For family members of people with AIDS, stress the importance of a drug free lifestyle
- F. Stress hope for the development of a treatment.
- G. Check the apparent need and refer for medical follow-up, emotional or sexual counselling, or to support groups and other self-help groups.
- H. Reinforce appropriate interventions as described in Sections I-IV to family members.

SECTION TWO: EDUCATION PLAN FOR IV DRUG USERS
BASIC AIDS INFORMATION SPECIFIC TO IV DRUG USERS

Introduction

Users of intravenously injected drugs are at the greatest risk for contracting and transmitting AIDS. In addition to the AIDS-related dangers inherent in any serious drug use, the use of the needle poses threats of its own and allows a direct path for the virus to enter or leave the body. The most powerful step the IV drug user can take to avoid contracting or spreading AIDS is clearly to forsake the use of the needle, even if this is accomplished simply by changing the manner in which drugs are taken. Unfortunately, the use of intravenous drugs has a powerful lure of its own which won't be easily overcome.

At the very least, you must take special efforts to alert and persuade IV drug users of the seriousness of the dangers they face. When you can't convince them to give up the needle, you must share important information about how to minimize risks in spite of it. This is in way meant to accept the use of intravenous drugs, but instead simply recognizes the on-going reality of the needle. While you may not be able to eliminate their use, you can certainly cause the user to reconsider the casual and sloppy ways in which they are utilized.

The following outline lists key points which should be made clear to every needle user.

I. RISK BEHAVIORS & FACTORS

(The ways in which IV drug users are exposed to AIDS or can transmit it).

- A. DIRECT TRANSMISSION BY SHARED NEEDLES & SYRINGES
(permits blood-to-blood contact, the surest way to transmit the virus)
- B. TRANSMISSION TO SEXUAL PARTNERS
(permits body-fluid to body-fluid contact, body fluid to blood contact, and possible blood to blood contact).
- C. TRANSMISSION TO AN UNBORN CHILD DURING PREGNANCY ("neo-natal" transmission, direct blood contact).
- D. POSSIBLE SUPPRESSION OF THE BODY'S IMMUNE SYSTEM
(caused by alcohol and most drugs).
- E. IMPAIRED JUDGMENT WHILE "UNDER THE INFLUENCE"
(very often leads to increased risk taking in drug and sexual behavior, opening the client to any of the methods of virus transmission listed above).

II. PREVENTION INFORMATION

A. ELIMINATING RISK FROM SHARING NEEDLES AND SYRINGES

AIDS PREVENTION MEASURES:

Needle/syringe use:

1. Don't share needles/syringes - "works"
2. Clean needles & "works" vigorously with bleach or alcohol and thoroughly rinse with water. DO NOT add bleach or alcohol to your mix - this won't kill the AIDS virus but might kill you.
3. Boil needles and "works" for 15 minutes
4. Remember that people who "look" healthy can still carry the virus.

B. ELIMINATION OF RISK FROM SEXUAL TRANSMISSION

AIDS PREVENTION MEASURES

SAFE SEX GUIDELINES

(or see SAFE SEX GUIDELINES elsewhere in this manual)

CONSIDERED SAFE	CONSIDERED POSSIBLY SAFE	CONSIDERED NOT SAFE
Massage, Hugging	French kissing (wet)	Semen or urine in mouth
Mutual masturbation	Anal intercourse with condom	Blood contact
Social kissing (dry)	Vaginal intercourse w/condom	Sharing sex toys or needles
Body to body rubbing	Sucking, stop before climax	Rimming, Fisting
Voyeurism, exhibitionism	Cunnilingus	Anal intercourse, no condom
Fantasy	Watersports, external only	Vaginal intercourse, no condom
	Use of spermicidal foam (with Non-Oxynol 9)	

C. MINIMIZING RISK FOR NEONATAL TRANSMISSION OF AIDS (transmission to the fetus during pregnancy)

AIDS PREVENTION MEASURES

1. Take AIDS anti-body test to check for exposure to the virus
2. If negative, wait six months while avoiding unsafe sex, alcohol and drugs, and shared needles.
3. Both partners take anti-body test again. If results is still negative for both, partners can resume usual sexual practices as long as:
 - a. both partners avoid sharing share needles, or
 - b. both avoid all unsafe sex with other persons in high risk groups.

4. If one or both partners is positive on the test, encourage them to delay child bearing until treatment for exposure to the virus is available.

D. HEALTH MAINTENANCE MEASURES

1. Decrease use of all immunosuppressive drugs (marijuana, "speed" or amphetamines, "poppers" cocaine, alcohol).
2. Remind clients that "being under the influence" can easily lead to unsafe sexual and drug-use behavior, thereby increase risk of exposure to the AIDS virus.
3. Maintain an adequate diet
4. Reduce stress - stay in chemical dependency/alcoholism treatment and maintain a drug free lifestyle.
5. Get regular medical and dental care.
6. Get adequate rest and exercise.
7. Have fun! [Yes, it's still possible].

QUICK GUIDE FOR MINIMIZING THE RISK OF AIDS

(Source UCSF AIDS Health Project - AIDS Substance Abuse Program)

1. THE BEST WAY IS TO QUIT SHOOTING DRUGS
 - You can get help to stop
2. IF YOU MUST SHOOT UP:
 - Don't share needles
 - You can get AIDS by sharing a needle or syringe.
 - Remember: people can look healthy yet still carry the virus
3. CLEAN YOUR WORKS:
 - Flush needle & syringe with Clorox (bleach). Rinse well with water
 - Or, boil for at least 15 minutes
4. USE OF OTHER DRUGS:
 - Remember: alcohol, marijuana, speed, cocaine, and "poppers" can lower your resistance.
5. REDUCE YOUR RISK OF GETTING AIDS SEXUALLY:
 - Use condoms
 - Avoid contact with semen (cum) or blood
 - Follow SAFE SEX guidelines: it can still be fun
 - Remember: people who look health can still carry the virus.
 - Sex while "high" can increase possibility of taking sexual risks due to impaired judgment.
6. IF YOU WANT TO HAVE CHILDREN, GET MEDICAL ADVICE IF YOU:
 - have shared needles;
 - are/have been a sexual partner of someone who used needles.
7. KEEP IN GOOD HEALTH:
 - Eat well.
 - Get rest and exercise.
 - Keep stress low.
 - Avoid drugs which can lower your resistance to disease.
 - Get a check-up and dental care regularly.
8. WANT MORE INFORMATION? (Insert local phone numbers)
 - AIDS HOTLINE () - - - - -
 - or (800) F O R - A I D S
 - DRUG HOTLINE () - - - - -
 - OTHER _____

SUPPORT GROUPS FOR PEOPLE WITH AIDS RELATED PROBLEMS

The Need:

The prospect of developing AIDS, fear of an AIDS or ARC diagnosis, or even the uncertainty of testing positive on the AIDS anti-body test can all be frightening experiences. Each can generate a significant life crisis. One widely used method for helping people cope is the use of SUPPORT GROUPS. SUPPORT GROUPS, when facilitated by a counselor, provide a safe, supportive setting in which people in similar situations can share their concerns, fears, and solutions.

Although each individual experiences an AIDS-related crisis in a personal way, groups of people with the most similar interests are easily identified. These commonly include:

- GROUP 1: The "WORRIED WELL"
[Clients without symptoms of AIDS or ARC who have either tested negative to the AIDS anti-body test or who haven't been tested].
- GROUP 2: "SERO-POSITIVES"
[Clients with a positive AIDS anti-body test without an AIDS or ARC diagnosis].
- GROUP 3: CLIENTS WITH AIDS RELATED CONDITION (ARC)
[Clients with some clinical symptoms diagnosed as being AIDS-related but who as yet do not show the formal indicators of AIDS as defined by Federal government agencies].
- GROUP 4: CLIENTS WITH A DIAGNOSIS OF AIDS
[Clients who are diagnosed as having the formal symptoms of AIDS].
- GROUP 5: CLIENTS WHO ARE ALSO GAY OR BISEXUAL
[Drug abuse clients who also acknowledge either a homosexual or bisexual preference].

SUPPORT GROUPS work best when the clients are placed together within these categories. The priorities of various issues vary substantially from one group to the next.

Joining such a group may not be easy for all of your clients. Many will express initial reluctance. When the purpose and function of the group is

well understood, however, much of this reluctance can be overcome. Joining such a group, of course, is best when it's a voluntary act.

A good method for encouraging people in need to join is to allow them to talk with others who have been active in such groups. The benefits to clients can often be best explained by someone with direct knowledge. They include:

- realization that many feelings, anxieties, and problems are not unique and have been faced successfully by others
- greatly increased knowledge of AIDS-related topics
- new solutions to familiar problems
- new information about medical options
- reinforcement of positive approaches, instead of the negativity and fatalism often found on the street
- meeting new friends who share their concerns and desire to solve the problems

Outreach

Potential group members can be sought in or through:

SOCIAL SERVICES AGENCIES

DRUG PROGRAMS

ALCOHOL PROGRAMS

FRIENDS AND ACQUAINTANCES OF CURRENT GROUP MEMBERS

Group Format

While the issues of greatest importance will vary depending on which of the five general categories the group falls into, the basic format of the SUPPORT GROUP should have several consistent elements:

1. There is a strong focus on drug and alcoholism treatment issues, such as relapse prevention and the use of AA and NA.
2. An "Introduction to the Group" is read each week.
3. Each group meeting begins with a 5 - 10 minute "check-in" by members to help focus the conversation.
4. Two facilitators are suggested for each group of 8 - 10 clients.
5. Counselors and the group work together to maintain a safe and supportive atmosphere with room for self-disclosure.

6. An effort is made to "reframe" hopelessness into a more positive view of the situation. Practical, problem-solving approaches are used to generate new choices for coping with the situation.
7. Groups typically meet once per week, though other arrangements are also possible.

Themes and Clinical Issues

The common elements of the format described above are supplemented by focus on the themes and clinical issues of special importance to the each group category.

GROUP 1: The "WORRIED WELL"

(Clients without symptoms of AIDS or ARC who have either tested negative to the AIDS anti-body test or who haven't been tested). Special group focus:

- support in staying clean and sober
- support in making behavior changes to minimize the chances of contracting AIDS
- sharing sense of guilt over past behavior; providing a safe, supportive place for airing personal feelings of guilt.
- fear of intimacy and sexual expression; impact of AIDS on sexuality
- knowledge of AIDS, its causes, effects, and treatment options (if any)

GROUP 2: "SERO-POSITIVES"

(Clients with a positive AIDS anti-body test without an AIDS or ARC diagnosis). Special group focus:

- group support concerning positive anti-body test result
- what positive results DO and DO NOT mean
- support in staying clean and sober through the anxiety period caused by the test result
- support in making behavior changes to maximize the chances of stopping further progression toward AIDS
- guilt and internalized homophobia ("I caused this by - using drugs, or being gay, or being promiscuous.")
- sharing sense of guilt over past behavior; providing a safe, supportive place for airing personal feelings of guilt.

GROUP 3: CLIENTS WITH AIDS RELATED CONDITION (ARC)

(Clients with some clinical symptoms diagnosed as being AIDS-related but who as yet do not show the formal indicators of AIDS as defined by Federal government agencies). These clients can have a very wide range of symptoms, ranging from mild to severe and disabling. Special group focus is on:

- lack of a clear-cut diagnosis (being in "limbo")
- Intimacy (Should I tell people? If so, how? How close is it safe to get?)
- uncertainty, anxiety over outcome
- fear of death
- thoughts of suicide
- guilt and internalized homophobia ("I caused this by - using drugs, or being gay, or being promiscuous.")
- social support problems, lack of services for ARC patients ("Can I trust you, the group leaders? Where do I go for help?")
- dealing with people (friends, lovers, employers, family): rejection by friends; difficulty in discussing diagnosis with everyone; fear of sexual isolation and rejection
- dealing with medical aspects of the illness (frequent physician visits, treatment options, fatigue)
- reasons for absences which occur within the group (are they due to illness or resistance to discussing emotional difficulties)

GROUP 4: CLIENTS WITH A DIAGNOSIS OF AIDS

(Clients who are diagnosed as having the formal symptoms of AIDS). These clients will also demonstrate a wide range of symptoms, again ranging from mild to severe and disabling. Special group focus on:

- need for dealing with death and dying
- staying clean and sober to maximize life and its quality
- intimacy issues, guilt over past behavior
- resource availability; medical options

GROUP 5: CLIENTS WHO ARE ALSO GAY OR BISEXUAL

(Drug abuse clients who also acknowledge either a homosexual or bisexual preference). These clients may be part of other groups, according to situation, or a special group of their own. In special groups of their own, focus is on:

- all issues listed for groups above, according to the medical situation of the clients
- internalized "homophobia" - self-hatred many gay people have learned from generally repressive attitudes toward homosexuality in society and religion
- guilt over past sexual practices
- sexual "addiction" which sometimes accompanies the drug addiction (if suggested by group members)
- resources available within the gay community
- coping with forced "coming out" caused by the disease

Group Leader Techniques

Within any SUPPORT GROUP, the role of the group leaders are critical to success. Leaders must take an active role in facilitating discussion in order to protect the rights of individual expression. Clients in a group setting will vary widely in their ability to speak out. If the group is to truly provide SUPPORT, the leader may often have to model it and sometimes set standards to avoid dominance by the most outspoken group members. SUPPORT can be modeled or demonstrated in several ways:

- protecting everyone's right to free expression as long as it doesn't harm others
- drawing out incomplete or unclear comments by group members
- keeping the discussion track by providing (or supporting) a particular focus for each meeting
- when discussion is stifled, asking questions to generate interest
- inviting the group as a whole to respond to overly aggressive or destructive behavior
- constructively directing the conversation to avoid clashes and overly heated disagreements
- constructively cutting off rambling or unfocused contributors for the good the group as whole
- occasionally summarizing the points of view which have been expressed.
- avoiding the temptation to play "expert" within the group or take too active a role in discussions

A complete set of guidelines for conducting SUPPORT GROUPS would require a manual of its own. Attention to these few basic points should make it possible to conduct useful SUPPORT GROUPS for any of the client categories described. In doing so, you'll learn a great deal and may help clients accept things they might have rejected had they come solely from the counselor.

RECOMMENDATIONS FOR AIDS-AWARE HEALTH CARE PROVIDERS

Staff Education

- * An AIDS-educated staff can be developed and supported by in-service presentations and trainings. A variety of resources, including the Women and AIDS Clinical Resource Guide, can be used in conjunction with these trainings. Education and materials should address: risk assessment and reduction for women, psychosocial issues for clients and staff, infection control, perinatal transmission, legal and ethical issues, drug use, teenage services, and other relevant topics. Your local AIDS agency or the San Francisco AIDS Foundation can provide consultation and resource guides to help develop these trainings.
- * It is important for staff to address their fears and other feelings regarding AIDS, death and dying, before working with clients at risk, so that these feelings are not projected onto clients. The health worker should also be able to talk about sex and the use of condoms in specific terms, in a comfortable, non-judgemental manner. Information regarding I.V. drug use should be offered in the same manner. It may be helpful to have an ongoing support structure within the work setting, in addition to personal support networks, to continue to address these issues.
- * Since many women at risk of contracting AIDS are members of stigmatized populations, health workers need to identify their assumptions and/or biases about these groups. Relevant groups include I.V. drug users, members of ethnic groups other than the provider's own, non-monogamous women, and lesbians.

Client Education

- * AIDS Educational literature in language(s) accessible to your clients should be provided in the waiting room. Posters and other AIDS educational graphics can be displayed on the wall.
- * Medical intake and history forms should include questions which specifically address risk factors for women, including:

- I.V. drug use;
 - Multiple sex partners who may be at risk, particularly gay or bisexual men, I.V. drug users, and hemophiliacs;
 - Blood product recipients.

Intake forms can also be used to determine a client's level of AIDS awareness and knowledge about preventative measures.

- * Transmission and prevention information should be provided for clients in the context of family planning education and in discussion of general health maintenance regarding drugs, sex or pregnancy.

* Information on the AIDS antibody test should be available to all women, and especially to those who are considering pregnancy and may be at risk of infection with the virus.

Confidentiality

* Agencies working with clients at risk for AIDS will need charting protocols that ensure the confidentiality of clients' AIDS antibody test results. In California, state law requires such procedures, in order to protect clients' employment and insurance status. The protocol should include a system which will protect client confidentiality both within the clinic or office, and when the record is transferred to another setting, such as a hospital.

Infection Control

* If staff members have contact with clients' blood, urine, or vaginal secretions, infection control guidelines should be established which are both appropriate to the agency and sensitive to clients' needs. Specific infection control measures can be as simple as use of disposable rubber gloves, standard procedures to avoid needle sticks, and proper handling and cleaning of soiled laundry and other materials. Refer to the chapter on Infection Control for more detailed instructions.

Referrals

* Current lists of referrals for health, mental health, social service and drug recovery programs which are AIDS-sensitive should be available to both staff and clients. These lists, which can be maintained in a looseleaf binder, should be updated on a regular basis. Handouts listing anonymous AIDS antibody test locations should also be available for distribution to clients. The toll-free AIDS Hotline numbers (415-863-AIDS in San Francisco, 800-FOR-AIDS toll-free in Northern California) should be conspicuously posted.

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Disabled-accessible
Sign language
interpretation
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SERVICES NEEDED	PROVIDED HERE?	REFERRAL (Address, Phone)
General Assistance _____		
Food Stamps_____		
AIDS/ARC Food Bank _____		
Social Security_____ State Disability_____		
VA Benefits _____ Other_____		
C. AIDS/ARC Housing Programs for women _____		
D. Legal Information and Advocacy_____		
E. Spiritual Services _____		

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