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Women AIDS Issue

DRAFT-NOT FOR DISTRIBUTION 10/14/93

To: **Patsy Fleming**
Special Assistant to the Secretary

From: **Art Lawrence, PhD**
Acting Deputy Director, NAPO

Date: **October 15, 1993**

Re: **Responses to Gay/Lesbian/Bisexual Health Care Concerns**

The following are the responses to the issues raised at the meeting with representatives of the Gay/Lesbian/Bisexual Community held during the March on Washington Weekend, April 23, 24 & 25, 1993:

1. **Because the total FY94 NIH budget request was not larger, concern that funding for AIDS services will be tapped to add to NIH (non-AIDS).**

   The HHS AIDS Appropriations for FY94 are as follows, showing an overall increase of 25% over FY93 in the aggregate (amounts in parenthesis signify percentage increase over FY93):

Overall increase:	$490 Million (25%)
Ryan White	$230 (65%)(Title I $140 (76%), Title II $69 (59%))
Research	$227 (21%)
Prevention	$45 (9%)
TB Elimination	$112

   Full funding appropriations ($156 million) were also allocated to the Department of Housing and Urban Development for the Housing Opportunities for PWAs and other AIDS Housing Projects.

2. **List of PHS AIDS Personnel for outside groups, who to call for which issues. (see attached list)**

3. **Health Care Reform: Burden of Proof in discrimination issues should be on the provider, not the individual.**

   The Health Care Reform plan is intended to guarantee health care coverage for all Americans, especially those individuals that have been subjected to discrimination in obtaining health care. Research indicates that persons living with HIV/AIDS have been subjected to discrimination, as have persons that are or are perceived to be gay/lesbian/bisexual.

The Health Care Reform plan will include provisions to allow for redress of individuals that are discriminated against. In the case of persons living with HIV/AIDS, the Office of National AIDS Policy (ONAP) is working with members of the HIV/AIDS community to identify those issues that are critical to persons living with HIV/AIDS. The question of necessary redress was raised at one of the community meetings. ONAP is working with Health Care Reform staff to find ways of making the process more accessible to individuals.

4. Need linkages between primary care and substance abuse programs.

SAMHSA

We agree that linkages between primary care and substance abuse are very much needed. The Substance Abuse and Mental Health Services Administration (SAMHSA) and the Health Resources and Services Administration (HRSA) have worked actively on developing and encouraging effective methods of linkage. The Substance Abuse Linkage Initiative (SALI) stimulated much discussion about how to develop such linkages and also explored barriers to the development of effective linkages.

For several years HRSA and the Center for Substance Abuse Treatment (CSAT) at SAMHSA have supported a demonstration grant program specifically encouraging substance abuse and primary care linkage. A new request for applications (RFA) is now open. A copy of this RFA is available for review. It addresses the primary care substance abuse linkage and AIDS.

Furthermore, SAMHSA and HRSA have been actively exploring ways to collaborate in relation to the substance abuse and mental health services that are and can be supported by the Ryan White CARE Act (Ryan White). SAMHSA participates in all of the Federal activities that support collaboration between the Centers for Disease Control and Prevention (CDC), HRSA and SAMHSA. In addition, several bilateral collaborations exist. Please note that the linkage programs, the development of counselling guidelines, the work on accessing Ryan White for substance abuse and mental health services, some training efforts, the tuberculosis information exchange are representative of ongoing efforts. In addition, SAMHSA is working with the Agency for Health Care Policy Research (AHCPR) on its ACSUS II program.

HRSA

- **Status of the Primary Care Substance Abuse Linkage Demonstration**

The Primary Care and Substance Abuse Linkage Demonstration Program that began in 1989 is in its fourth and final year. Currently, HRSA is collaborating with SAMHSA to begin a new demonstration project. This project will be an enhanced linkage initiative, in that it will encompass Primary Health centers, HIV/AIDS, Substance Abuse Treatment, and Mental Health services. In this new Linkage, mental health services will be a required component, unlike the former Linkage program. HRSA and SAMHSA will manage the program jointly over the 5-year demonstration period.

Grant applications for the Linkage Demonstration were due July 13. Peer Review of grant applications was held August 16-20.

5. Tattooing as a transmission route. Removed from CDC's list. What is the status? Why was it removed?

Since 1985 CDC has recommended that workers whose personal services (such as tattooing, ear piercing, and acupuncture) require needles or other instruments that penetrate the skin should follow the same precautions indicated for health-care workers. Therefore, tattooing is a practice where "Universal Precautions" should be applied.

No evidence clearly establishes that tattooing has been a transmission route for HIV. CDC has received no reports of HIV transmission through the use of personal service instruments for ear piercing, tattooing, or barbering. In theory, HIV transmission could occur if blood from a cut sustained by an infected customer were introduced to the open tissue of another customer via an instrument. However, the likelihood for these events to occur in this manner is extremely low if universal precautions are followed.

In addition, the transmission of the hepatitis B virus (HBV), another blood borne virus which is much more easily transmitted than HIV because of the huge concentrations of virus particles involved, has been documented only rarely in acupuncture, ear piercing, and tattoo establishments. This would suggest that any risk for HIV transmission in personal-service settings must be even lower than that for transmission of HBV.

6. What additional types of female controlled barrier devices are being developed?

FDA

The REALITY Female Condom was approved by FDA earlier this year. There are other female "condoms" under development for protection of sexually transmitted diseases.

NIH

The NIH does not currently sponsor any programs specifically focusing on the development and evaluation of physical barriers to prevent HIV transmission among lesbians. The National Institute on Child Health and Human Development (NICHD) supports research to evaluate barrier methods of preventing HIV infection through heterosexual transmission. A workshop in 1988 assembled experts on the epidemiology and the clinical research of STDs and contraceptive technology and evaluation. In addition, a standing advisory committee was established to review potential projects and recommend research concerning barrier methods as a means of stopping the spread of the epidemic.

Epidemiologic studies would offer the most direct evidence for a protective effect of barrier contraceptives for the prevention of HIV infection. In 1989, the NICHD completed a major laboratory program at UCLA to evaluate the suitability of using condoms and condoms plus spermicides in preventing HIV transmission. The results indicated that condoms available in the United States are of high quality and should provide a substantial degree of protection from HIV infection and other STDs. Additional studies supported the findings that spermicides plus condoms might offer additional protection against HIV infection. The possibility that spermicides decrease the risk of STDs is derived from both in vitro and in vivo studies. As part of the NICHD project described above, laboratory experiments also were conducted on six spermicides to determine their inhibitory concentrations against nine STDs including HIV. The findings showed that all spermicides tested inactivated HIV.

Although all available spermicides inactivate cell-free HIV in vitro and clinical trials have documented the efficacy of these agents for the prevention of some STDS, the efficacy of spermicides for the prevention of HIV infection in clinical practice needs to be documented.

The NICHD has also developed a statistical model to project the effect of condoms on the AIDS epidemic in America. The results provided assurance that condoms can be recommended as protection from HIV infection for those at low risk even in the absence of quantitative data about condom efficacy. However, for those individuals at high risk of HIV infection, e.g., those with partners known to be infected, the uncertainty about the exact efficacy of condoms makes their use problematic. Findings indicate that avoidance of high-risk sexual activity by these individuals is the only way to assure protection from the disease. NICHD and the OAR sponsored a conference on "Research on the Role of Condoms in Reproductive Health" in May to determine ways to use recent condom research data to design

better intervention programs.

The NICHD sponsors research for the development of a disposable diaphragm. The objective of this project is to develop a spermicide-releasing, disposable diaphragm with increased potential for high efficacy and acceptability. The development of this product may allow women to protect themselves against the transmission of the HIV, particularly in situations where male condom use is not culturally acceptable.

7. Discuss the need for programs designed for HIV positive women in prison.

Women account for 5 to 10 percent of the prison population, but their numbers are growing more rapidly than men. Women in this population have been found in numerous surveys to have a higher rate of HIV antibody seroprevalence than male inmates. A survey at ten geographically diverse correctional facilities revealed seropositive rates of 0.21 percent to 7.6 percent for males and 2.5 percent to 14.7 percent for females. In nine of the ten facilities, the rate was higher for women than for men.

Over 11 percent of all reported AIDS cases are among women. The number of female inmates is increasing, and prison health systems need to pay particular attention to women's specialized health care needs, including gynecologic and obstetric services.

Historically, the amount of funding appropriated for female correctional facilities, and for health-care services in these institutions, has been inadequate. This shortcoming has resulted in gaps in needed services. Although some studies have been done on HIV/AIDS and women in prison, additional seroprevalence data would be useful to support planning and funding for specialized health-care needs of HIV-infected women.

The Public Health Service (PHS) has no jurisdictional authority over correctional facilities. PHS does provide health-care staff to the Federal Bureau of Prisons, an agency of the Department of Justice that has jurisdiction over Federal facilities. State and local prisons and jails are administered through state or local correctional authorities.

We are not aware of any funds that have been appropriated for the development of guidelines or plans to address the full range of correctional health-care issues, including HIV infection and AIDS. Currently no comprehensive Federal plans exist to meet the unique health-care needs of incarcerated women and youth. However, to respond more fully to a 1991 House of Representatives Appropriations Committee request, PHS and the Bureau of Prisons formed a work group to address issues of HIV prevention and care

of inmates and parolees. Work group recommendations, including specific prevention and care issues of incarcerated women, are expected to be made in late 1993. (Attachment 1)

8. Discuss the need for programs and educational materials designed especially for lesbians.

CDC

Although several reports in the medical literature indicate possible female-to-female sexual transmission of HIV, information obtained from AIDS cases reported among lesbian and bisexual women indicates that they have been exposed to HIV primarily through injecting drug use. CDC has conducted studies specifically designed to examine behavioral risk factors among HIV-infected women. Data collected from AIDS case surveillance indicate that women with AIDS who report sexual contact only with other women represent a very small proportion of the total number of women with AIDS in the United States. However, nearly all of these women also have histories of injecting drug use or receipt of blood or blood products, which we know are efficient routes of HIV transmission.

Studies examining data from HIV serosurveys among women attending STD clinics and women's health clinics further suggest that HIV infection in lesbian and bisexual women is primarily linked to injecting drug use and to sex with men who are at increased risk for HIV infection. Additionally, a large population study involving nearly one million female potential blood donors identified no infected women who reported having sex exclusively with other women. Although these data do not exclude the possibility of female-to-female sexual transmission of HIV, they do indicate that it is extremely rare.

Like all women, women who have sexual contact with other women need to be aware of the potential for exposure to HIV, including the risk behaviors of their sex partners. Like any group at potential risk, lesbian and bisexual women could benefit from prevention materials that clearly describe practices which may result in the transfer of infectious fluids and that suggest safer alternatives.

HRSA

The HIV Health Services Planning Council in the New York City Title I Eligible Metropolitan Area (EMA) has established several priority objectives that provide health care and support services to women and in some cases specifically target the lesbian population. These objectives include:

- mental health services to lesbians, especially women of color;
- support services for lesbians (case management, peer counseling, and support groups);
- case management for prisoners and parolees (with lesbians specifically identified under this objective); and
- a specific objective targeting case management to women.

Five or more contracts have been awarded to HIV service providers in Harlem, including Harlem Hospital, Washington Heights Health Center, and Harlem Interfaith Counseling. All of these providers service both men and women who are HIV+.

9. Discuss the need for:

a. Safer sex materials for lesbians.

Little epidemiologic research has been done to indicate which female-to-female sexual practices may be implicated in HIV transmission. However, practices that involve exposures to body fluids such as blood or vaginal secretions would need to be carefully considered. Possible transmission vectors may include fingers, dildos, and other inserted objects that may transmit HIV or hepatitis B-infected fluids from one woman to her partner. In addition, consideration would need to be given to the risk of using semen from untested donors for artificial insemination purposes. Like any group at potential risk, lesbian and bisexual women could benefit from prevention materials that clearly describe practices which may result in the transfer of infectious fluids and that suggest safer alternatives.

b. Does the NIH sponsor natural history and epidemiology studies involving HIV infection among the lesbian community?

Natural history and epidemiology studies have demonstrated the changing demographics of HIV infection and AIDS from an illness initially afflicting homosexual and bisexual men to the current pandemic afflicting women, children, adolescents, minority populations, and injection drug users (IDUs). As the number of HIV-infected women has increased, the NIH has expanded its efforts and programs to address the special needs and requirements of HIV-infected women in biomedical research and clinical trials. All of the NIH sponsored natural history and epidemiology studies that are focusing on women and HIV infection are open to participation by lesbians. None of these studies, however, are designed to investigate HIV infection/transmission exclusively among the lesbian community.

In 1990, the NIH collaborated with other PHS agencies in sponsoring the first National Conference on Women and HIV Infection. This Conference developed a series of recommendations addressing many of the biomedical, psychosocial, and behavioral needs of HIV-infected women. The recommendations emphasized the collection and analysis of existing clinical trials data, and supported plans to initiate a collaborative study between the NIH, CDC and other PHS agencies, utilizing existing capabilities to conduct a large-scale natural history study using information from existing studies as a base. Other recommendations included the need for: developing primary care and ancillary services related to research; linking clinical trials site funding to performance relative to enrollment of women and minorities; developing studies on opportunistic infections (OIs) and malignancies frequently observed in women; and increasing behavioral research relative to women.

In 1991, the Institute of Medicine (IOM) issued a report on the AIDS Research Program of the National Institutes of Health that addressed NIH's programs for natural history studies and clinical trials. The IOM recommended that a high priority be placed on the enrollment of HIV-infected women and minorities in studies developed by these programs. Many of the plans proposed in these recommendations were implemented by the NIH prior to the publication of the IOM report.

Several issues presented in the recommendations of these two groups were included in the agenda of the NIH AIDS Program Advisory Committee (APAC) at their April 1991 meeting. The APAC, which provides guidance and direction to the NIH Director, has strongly supported increasing the number of women and other underrepresented populations in AIDS-related natural history and clinical trials programs.

Natural history and epidemiology studies provide crucial information concerning heterosexual transmission of HIV and transmission of HIV from infected mothers to their children. In addition, these studies provide important baseline data that can be used in determining the efficacy of potential therapies and vaccines for the treatment of HIV and its sequelae.

Several NIH-sponsored activities in this area include:

The National Institute of Allergy and Infectious Disease (NIAID)-sponsored Heterosexual HIV Transmission Study (HATS), which is a prospective study of HIV-infected women, excluding IDUs, who are sexual partners of men at high risk for HIV infection. This study strives to identify biological and behavioral factors associated with acquisition of or protection from HIV infection. A component of the program includes a study of discordant couples

to identify factors associated with heterosexual HIV transmission.

The National Cancer Institute's (NCI's) Hemophilia Cohort, a large multicenter study, evaluating the natural history of AIDS and cancer in female spouses and sexual partners of men with hemophilia.

The NIAID/NICHD Women and Infants Transmission Study (WITS), a collaborative, multicenter study that includes the natural history of HIV infection in nonpregnant women and those who have recently delivered babies.

The NICHD/NCI cosponsored Mother-Infant Transmission Cohort Study (MITS), a multicenter natural history study of the vertical transmission of HIV from mother to child. The identification in this study of a potential protective role for maternal anti-gp120 antibody may be a significant factor in the development of a vaccine to prevent maternal-fetal transmission.

The NICHD-sponsored seroepidemiologic study of the prevalence of HIV infection in child-bearing women in the northeastern and Mid-Atlantic United States. This research supported the development of the technology necessary to detect antibody directed against HIV in routinely collected samples of newborn blood, a technique widely acknowledged to be the most important innovation in pediatric AIDS epidemiologic research to date.

Additional NIH-sponsored natural history studies include:

NCI-sponsored studies that have shown women are particularly susceptible to HTLV-1 infection, which is associated with adult T-cell leukemia/lymphoma (ATL). A high prevalence of ATL has been observed in Hawaii and the southeastern United States.

An ongoing series of NCI-sponsored longitudinal studies defining the incidence of human papilloma virus (HPV) associated cervical cancer in HIV-infected women. Approximately 60 percent of HIV-infected women have cervical dysplasia, which suggests that HIV and HPV act synergistically. Studies are investigating the role of human herpes virus-6 (HHV-6) and herpes simplex virus (HSV)-2 that may amplify HPV and HIV expression and thereby facilitate the initiation and/or progression of cervical dysplasia to cervical cancer. These studies will provide significant insight into neoplasia associated with HIV infection.

A National Institute of Mental Health (NIMH)-supported behavioral epidemiological study of AIDS-related risk behaviors, knowledge, beliefs, and HIV serostatus that include a large number of minority women between the ages of 18 and 25. This research has

implications for the development of public health approaches to preventing the spread of HIV infection.

The NIAID-sponsored Preparation for AIDS Vaccine Evaluation (PAVE) program studies of various aspects of HIV infection and its sequelae in cohorts of high-risk women and men in eight countries.

A NIAID and Pan American Health Organization (PAHO) collaborative study of heterosexual transmission in three countries.

A National Center for Nursing Research (NCNR) study that examines the development of gender differences in the adaptation of young people to HIV infection, the influence of psychosocial variables in influencing high-risk behavior, and the impact of psychoeducational intervention.

A National Heart, Lung, and Blood Institute (NHLBI) investigation of factors important in the sexual transmission of HIV from men to women in a group of HIV-infected hemophiliacs. This study aims to determine the relationship of specific immune markers to disease progression in women and to determine the natural history of heterosexually transmitted HIV infection in women without other risk factors.

A series of National Institute of Neurological Disorders and Stroke (NINDS) programs supporting research on the natural history of HIV infection and its predilection for and damage to the central nervous system.

The National Institute for Dental Research (NIDR) study entitled "Oral Manifestations of the Acquired Immunodeficiency Syndrome (AWARE)" that is examining the oral manifestations of HIV infection. In addition, the NIDR Partner's Study is examining heterosexual transmission of HIV.

The NIDR-sponsored studies on the oral manifestations of HIV in different risk populations, the relationship between HIV infection and oral manifestations of the disease, and the identification of HIV inhibitory salivary factors.

The NHLBI-supported study on the cardiac complications of HIV infection in women that will determine whether the natural history of HIV-related cardiac disease differs in women.

NCI-sponsored studies on maternal-fetal transmission of HIV which have recently demonstrated that 62 percent of the newborn infants born to HIV-infected women exhibited T-cell immunity directed against HIV envelope antigens and did not subsequently develop HIV infection. Infants lacking such T-cell immunity were

found to be HIV-infected. This suggests that helper T-cells that target HIV envelope antigens may confer protective immunity. Additional studies on maternal-fetal transmission involving vaginally-delivered, multiple-birth cohorts in HIV-infected women have shown an increased incidence of HIV transmission in the first-born infant that occurs at the time of delivery in the cervix or vagina. Based on these findings, it has been suggested that administering local antiviral therapy prior to or concomitant with delivery might decrease the risk for perinatal transmission.

An NIDCD-sponsored study on the role of AIDS-associated immunosuppression on the rate and severity of congenital cytomegalovirus (CMV) infection. Fetal CMV infection is becoming a public health problem, with post-natal consequences ranging from severe generalized illness to more subtle neurological defects, including deafness and other communication disorders. Maternal immunity appears to play a protective role in reducing the virulence of fetal infection. Compromised maternal immunity would be expected to increase the frequency and severity of congenital infection.

The NCRR-sponsored Regional Primate Research Centers (RPRC) program has developed a model of maternal-fetal transmission of simian immunodeficiency virus in macaques. This system will provide a better understanding of maternal-fetal transmission and permit the evaluation of potential therapeutic agents to block HIV infection.

The NCRR-sponsored research in the areas of heterosexual, post-transfusion, and vertical and horizonal transmission risks for HIV infection.

An NIMH intramural study utilizing a macaque model to identify risk factors related to HIV infection in both mothers and infants, determine how HIV infection expresses itself in women and children, understand why some infants become infected and others do not, and discover how current therapies for HIV infection affect the CNS in infants and children.

Planned NIH-sponsored natural history studies will:

- continue research on defining the full spectrum of diseases affecting HIV-infected women;

- determine the factors related to transmission and progression of HIV-related disease in affected populations, with special emphasis on women, children, adolescents, IDUs, minorities, and hemophiliacs;

- examine factors that influence the infectivity of individuals in various stages of the disease and their susceptibility to infection, such as HIV shedding in semen;

- determine the role of sexually transmitted diseases (STDs) and genital lesions;

- ascertain the effects of antiviral therapies on transmission;

- evaluate the effects of barrier methods and oral contraceptives;

- further define the full spectrum of complications associated with HIV infection;

- identify specific markers of disease activity and the effects of therapy on these markers;

- define specific risk factors associated with the development of various disease complications; and

- further define the spectrum of diseases affecting HIV--infected women.

Several of the initiatives scheduled for expansion and implementation are listed below:

- An NHLBI Study on Pulmonary and Cardiac Complications of HIV Infection has been implemented to monitor women during the course of their pregnancy by serology and culture techniques for Epstein-Barr virus, cytomegalovirus, and HIV, as well as T-cell subsets (CD3, CD4+, CD8)

- A Request for Application (RFA) was issued in FY 1993 for the Women's Interagency Health Study (WIHS). This study will be sponsored by NIAID, NICHD, NCI, NIDR, as well as CDC and other PHS agencies. The major objectives of the study are to: describe the spectrum and course of clinical manifestations of HIV-infection in women; describe the pattern of immune markers in HIV-infected women; investigate the factors that may delay or accelerate HIV-induced immune dysfunction and specific HIV-related conditions; and study the length of survival and quality of life of women living with HIV infection. Approximately five awards were made in late FY 1993.

- The WITS II study was initiated in FY 1993 to further refine methods for the early diagnosis of HIV infection in perinatally-infected infants and provide baseline data

needed for developing vaccine trials in pregnant women.

- The National Institute on Aging (NIA), in collaboration with NICHD, NCNR, and the U.S. Agency for International Development, will support an international behavioral research program. The goals of this program are to support basic research that will provide information concerning high-risk behaviors and behavioral changes relating to the transmission of HIV throughout the life course, and to strengthen developing country capabilities to design and implement behavioral research and prevention programs to reduce HIV transmission.

c. The inclusion of lesbians in all meetings regarding women and HIV.

CDC

CDC attempts to assemble a cross-section of persons who represent the affected population in HIV meetings. In many cases, this includes women who are heterosexual or who identify themselves as bisexual or lesbian. The importance of input from affected persons is recognized, and the involvement of lesbians will be sought when a public meeting agenda indicates that it is appropriate.

FDA

Over the past few years FDA has held a series of meeting with groups concerned about particular diseases. The meetings have been favorably received by these groups and have proven very helpful to the FDA in improving our understanding of issues and our responsiveness to concerns. In many cases they have served as the starting point for effective long term interaction between FDA and various constituencies.

To continue this exchange, FDA held a one day meeting with women's AIDS advocacy groups. The meeting was held on Monday August 9. Representatives from 45 organizations dealing with issues related to women and AIDS were invited, including organizations representing lesbians.

SAMHSA

All SAMHSA Council meetings are open meetings and therefore anyone can attend. The SAMHSA AIDS coordinators meetings are working meetings. If any group wished to attend they could certainly do so by contacting Dr. Belfer. In addition, SAMHSA has been working with NORA on the development of its Strategic Plan. This linkage was developed specifically to provide as

broad input from constituency groups as possible. It was presumed that the interests of the Gay and Lesbian communities would be represented in NORA. It was evident that the concerns of the Gay community were well represented.

NIH

Individuals serving on NIH advisory groups and committees are not asked as to their sexual orientation. They are selected to serve in these advisory roles based on their biomedical or other relevant expertise. community constituency group participation on NIH-wide as well as individual Institute, Center, and Division AIDS advisory committees reflects the value and importance the NIH places on contributions from members of the AIDS advocacy groups. **All** of the NIAID AIDS Clinical Trials Group (ACTG) and Community Programs for Clinical Research on AIDS (CPCRA) committees include AIDS community constituency group participants.

d. Suicide prevention programs for lesbians (How are gay men and lesbians included in suicide prevention programs)?

In September 1992 CDC published "Youth Suicide Prevention Programs: A Resource Guide." The review found that most programs are designed to reduce youth suicide and are aimed at high school-aged youth. It also found that the effectiveness of these programs in reducing youth suicide has not been adequately evaluated. In addition, the extent to which programs address the unique needs of gay men or lesbians is not defined.

Better data on the prevalence of suicide among gay men and lesbians and their unique needs would be required for communities to tailor their suicide prevention programs.

e. To what extent are lesbians participating in NIH-sponsored clinical trials?

The enrollment of an individual in NIH-sponsored clinical trials is based on meeting specific eligibility criteria which varies based on the nature of the clinical trial. Enrollment and participation in NIH clinical trials are not based on sexual orientation. Study participants are not requested to identify their sexual orientation in order to enroll in NIH-sponsored clinical trials. The NIH/SAMHSA policy concerning inclusion of women in study populations is described in the *NIH* Guide 19 (31), August 1990.

The NIH has placed a high priority on the evaluation of therapeutic regimens for the treatment and control of HIV infection and its sequelae in HIV-infected women. Three

Institutes of the NIH have the primary responsibility for the clinical trials programs: NIAID, NICHD, and NCI. As of December 1992, there were 3,412 women enrolled in NIH-sponsored clinical studies. Women represent approximately 19 percent of the total number of individuals in NIH-sponsored clinical trials.

The NIAID program includes a nationwide AIDS clinical trials network, identified as the AIDS Clinical Trials Group (ACTG), which consists of 55 units (ACTUs) located at major medical centers. In addition, the NIAID sponsors the Terry Beirn Community Programs for the Clinical Research on AIDS (CPCRA), which involve 17 sites; the AIDS and HIV-Related Research Intramural program; and the Division of AIDS Treatment Research Initiative (DATRI), which has over 50 approved sites.

The NICHD has established 28 centers nationwide to test potential therapeutic agents in HIV-infected women, children, and adolescents. The NCI has developed an Adult and a Pediatrics AIDS Intramural Unit located at the NIH Warren Grant Magnuson Clinical Center that has conducted pioneering studies of several novel anti-HIV agents and new antimycobacterial agents.

The NCRR provides the infrastructure for many of the ACTUs through either its General Clinical Research Centers (GCRCs) or the Research Centers in Minority Institutions (RCMI) programs. The GCRCs are uniquely positioned to collaborate and contribute to AIDS clinical trial research, with 47 of the 74 GCRCs involved in this research effort. Women are enrolled in clinical trials at 35 of these GCRCS. The RCMI Program provides infrastructure support for clinical trials research at some institutions with large numbers of underrepresented individuals.

NCI and NIAID are collaborating to foster basic and clinical research on AIDS-associated malignancies including Kaposi's sarcoma, HPV-associated anogenital malignancies, and AIDS-related lymphomas. Administrative supplements were provided in FY 1992 by NIAID, Office of AIDS Research (OAR), and the Office of Research on Women's Health (ORWH) to nine NCIsponsored Cancer Centers to promote further collaborations and establish tissue repositories between these facilities and ACTUs located at the same institutions. In addition, joint strategic planning initiated in FY 1992 between NCI and NIAID has resulted in the implementation of AIDS-related cancer clinical trials.

Accomplishments/Developments of Clinical Trials

The consolidation of the NICHD and NIAID clinical trials units has been accomplished. This clinical trials system conducts and supports therapeutic research in HIV-infected pregnant women, mothers, and children and permits women at all sites to have

access to ACTG protocols.

NIAID-sponsored CPCRA program has successfully enrolled targeted underrepresented populations. As of February 1993, 19 percent of the participants were women, 57 percent were minorities, and 38 percent were IDUs.

NICHD has expanded the maternal/pediatric clinical trials network to extend the opportunity for participation of HIV-infected women and children in NIH-sponsored clinical trials at 28 sites.

NIAID provided supplements ($5.3 million) in FY 1990 to the ACTUs to increase outreach activities toward these populations. This permits the availability of increased obstetrical care for women and other ancillary services so that women can more easily participate in clinical trials.

NCI, through its intramural programs, has developed a comprehensive care program for families infected with or affected by HIV that coordinates health care for all family members and reduces enrollment impediments for HIV-infected women.

NCI and NIAID jointly develop AIDS-related cancer clinical trials.

NIAID recompeted the adult units of the ACTG in FY 1992. All applicants were required to include a plan addressing the enrollment of individuals representative of the demographics of the population served by the applicant institution.

NIAID has implemented an annual systematic evaluation of each ACTU as part of a performance assessment program which looks at the enrollment of underrepresented populations. These evaluations are utilized to make funding adjustments for each ACTU, resulting in a strong association between individual ACTU performance and the resources made available to it.

NIAID awarded funds in FY 1992 to nine new pediatric sites that established linkages with other local and federal health care organizations in order to offer comprehensive health care to families, particularly women and children, and to facilitate access to clinical protocols. The expansion of the ACTG permits cooperation with perinatal centers serving women in high-risk populations.

ACTG and CPCRA programs have established a Women's Health Committee and the Women's Caucus respectively within their organizations to address the unique issues associated with women and HIV. The major goals of these committees are:

- to enhance participation of women in ACTG clinical trials and review entry criteria to ensure that they do not exclude women;

- to ensure that clinical trials contain gynecologic recommendations to meet the medical needs of HIV-infected women;

- to participate in the design and development of clinical trials studying treatments for HIV-associated conditions that specifically affect non-pregnant and pregnant women; and,

- to participate in the development and design of clinical trials to interrupt maternal-fetal HIV transmission.

NIAID is collaborating with the National Institute for Drug Abuse (NIDA) to increase participation of HIV-infected female and male IDUs in ACTG clinical trials.

NIAID is collaborating with HRSA to provide ancillary care services to HIV-infected pediatric patients and their families under Ryan White.

NIAID has implemented the DATRI program with the capacity of performing a maximum of.10 phase I or phase I/II trials and 4 phase II trials annually at over 50 sites. This program will facilitate the rapid evaluation of potential therapeutic agents or innovative treatment approaches that may not be included in the immediate priorities of the ACTG and CPCRA.

National Eye Institute (NEI) Studies of the ocular Complications of AIDS (SOCA) program has recently completed its first clinical trial in collaboration with the NIAID ACTG. Approximately 8 percent of the patients enrolled in the foscarnet-ganciclovir clinical trial were women. Several of the significant advances in the treatment of HIV infection and its associated OIs resulting from cross-NIHsponsored clinical trials include:

- The benefits of AZT for adults and children with early and asymptomatic infection have been demonstrated. Phase I clinical trials of ddI have shown that the drug can significantly prolong life. Actuarial 2-year survival is 80 percent, even in individuals with advanced stages of disease.

- The safety and efficacy of ddI have been demonstrated for HIV-infected adults and children and concomitantly approved for both groups.

- ddI has been made available through expanded access programs, and it has received expanded FDA approval for patients who have been on AZT for prolonged periods of time. Previously, it had been licensed for AZT intolerant patients with CD4 counts <200/MM3 as well as for patients who have failed AZT therapy and whose disease is progressive despite AZT therapy.

- Nimodipine has been identified for treatment of AIDS dementia complex.

- The therapeutic benefits of ddC plus AZT combination therapy have been demonstrated, and this combination has been approved by the FDA.

- Interferon-alpha has been shown to reduce Kaposi's sarcoma lesions and has demonstrated antiviral activity.

- d4T has been made available through the parallel track/expanded access mechanism. A clinical trial of d4T has been initiated.

- A clinical protocol has been developed to evaluate hyperimmune anti-HIV immunoglobulin (HIVIG) for the prevention of maternal-fetal transmission.

- Accomplishments in combatting HIV-associated OIs include demonstration of the efficacy of:

- atovaquone (566C80) for treatment of Pneumocystis carinii pneumonia (PCP) in patients seriously intolerant of trimethoprim-sulfamethoxazole (TMPSMX),

- aerosolized pentamidine for prophylaxis and treatment of PCP,

- TMP-SMX for prophylaxis of recurrent PCP,

- fluconazole for the treatment of cryptococcal meningitis,

- foscarnet for the treatment of CMV retinitis,

- combination of pyrimethamine and clindamycin for the treatment of toxoplasmic encephalitis, and

- itraconazole for disseminated histoplasmosis.

Itraconazole has been shown to be more effective and have fewer side effects than amphotericin B. Ongoing NIH-sponsored clinical trials related to women and AIDS include: a gender-specific OI

protocol studying the efficacy of fluconazole prophylaxis for mucosal Candida infections in HIV-infected women; an evaluation of the safety of AZT during the third trimester of pregnancy; a study of the safety, efficacy, and tolerance of oral AZT vs. - placebo in pregnant women and their infants; and a study of the safety of recombinant CD4-Immunoglobulin G in the last trimester of pregnancy.

NIH-sponsored clinical studies also are being conducted to identify effective regimens for preventing HIV transmission from mothers to infants. Current studies are evaluating: AZT treatment in the second and third trimester of pregnancy with treatment during the first 6 weeks of the infant's life; recombinant CD4; and CD4-IgG in a phase I study. An NHLBI/NICHD/NIAID collaborative phase III study has been designed to evaluate hyperimmune anti-HIV intravenous immunoglobulin (HIVIG) as a means of reducing vertical transmission. This study will be initiated once the agent is made available by the manufacturer.

Planned AIDS clinical trials sponsored by the NIH will investigate:

- combination drug therapies (e.g., the pharmacokinetics, safety, tolerance, and activity of ddC plus AZT);
- cytotoxic chemotherapy;
- the neurodevelopmental and neurological manifestations of HIV infection;
- the possible role of high-dose steroids for treating PCP;
- two dose regimens of dapsone for PCP prophylaxis;
- fluconazole for prophylaxis of oral candidiasis; and
- the rheumatic and cutaneous manifestations of HIV infection and AIDS.

To maximize the performance of clinical trials, the NCNR is sponsoring a study to identify the levels of self care and self management of symptoms across the varying levels of the disease. The goal of this study is to understand better the needs of HIV-infected women and their support networks.

An NIMH Workgroup on Psychosocial Aspects of Clinical (Vaccine) Trials develops strategies to maximize recruitment and retention of women in clinical trials.

NIH-sponsored drug discovery and development programs in the area of women and HIV include:

- A "Workshop on the Role of the Placenta in HIV Infection and Therapy" in 1990 provided the scientific framework for a basic research agenda to determine the role the placenta plays in HIV infection and maternalfetal transmission and the interactions of the placenta and anti-HIV drugs.

- A NIAID contract was awarded in FY 1991 as part of a program initiative concerned with the "Evaluation of Pharmacokinetics of AIDS Therapies in Non-Human Primates." Studies are being conducted in pregnant or infant macaques and in certain primate models of pediatric AIDS to test the efficacy and pharmacokinetics of potential AIDS therapies. The latter will be instrumental in the design of clinical trials in HIV-infected pregnant women or children. The nonhuman primate macaque models developed by the NCRR-sponsored RPRCs have been important in the evaluation of the pharmacokinetics of antiretroviral agents.

The National Institute of Environmental Health Sciences (NIEHS) supports studies investigating the toxic effects of HIV therapies using rodent models of both sexes. In addition, NIEHS studies ascertain the effects of potential therapeutic agents on pregnant rodents and their developing fetuses as a model applicable to pregnant women. In collaboration with NIAID, toxicity studies of HIV and OI combination therapies in pregnant mice and their developing fetus are in progress.

In collaboration with NIDA, NIEHS initiated reproductive and developmental toxicity studies of HIV therapies in rodents in combination with drugs of abuse. These studies are being performed in order to predict if sex differences exists for the dose levels at which toxic effects occur and to assess the safety of antiviral and drugs of abuse combinations in pregnant women. Preliminary findings indicate that hematologic toxicity of AZT and ddC is more pronounced in females than in males. Preliminary results of combination studies with AZT and methadone in mice indicate that methadone enhances the hematologic toxicity of AZT, especially in females. Methadone did not appear to have increased the reproductive and developmental toxicity of AZT.

10. Discrimination against gays and lesbians by health care providers.

HRSA

- **HIV Training in Community/Migrant Health Centers (C/MHC)**

The Bureau of Primary Health Care (BPHC) through its Clinical Support Funds (CSF) provides comprehensive training opportunities for clinicians working in Bureau-funded programs. It is expected that these educational activities enhance the ability of programs to better serve the health care needs of the underserved in their communities, and improve the quality and capacity of primary health care services. The Regional office staff have direct responsibility and accountability to utilize educational programs that enhance clinical excellence and leadership in providers and clinical managers. Utilizing CSF is one of the BPHC's - mechanisms for providing support through Regional offices.

The CSF activities focus on a multi-disciplinary target audience (including physicians, dentists, and nurses) and address health care provider training needs in all BPHC-supported programs: Community and Migrant Health Centers, Health Care for the Homeless Health Care in Public Housing, HIV, Hepatitis B, Substance Abuse/Primary Care, Enhanced Perinatal Care, etc. Each region must develop a Clinical Support Strategy which includes an educational/training needs assessment as a component. Each Region must collaborate with State/Regional Primary Care Associations, State Cooperative Agreements, Area Health Education Centers, HRSA Bureau of Health Professions AIDS Education and Training Centers, and other professional organizations.

Some training opportunities for FY 93 encompass:

- Mini-residencies

  - Region X has collaborated with the Northwest AIDS Educational Training Center based at the University of Washington in Seattle. This Center provides a didactic and clinical practicum for primary care providers and dentists. Over the past two to three months, two providers (a dentist and nurse practitioner) have received training.

- Conferences/Special meetings

  - Regions I and II are providing a HIV Management Update which will present recent developments in the diagnosis and management of HIV infection, revise Program Development issues in sites serving populations with a high incidence and prevalence of HIV, and train a cadre of "consultants" of primary care providers with expertise in the management of patients with HIV/AIDS.

  - Region VI has scheduled a HIV/AIDS Conference to discuss clinical updates on AIDS prevention, diagnosis, and treatment; to review the psychosocial impact of

HIV/AIDS; to learn innovative strategies in delivery of services; and to work with other providers serving HIV/AIDS patients.

- Region IV is presenting a conference entitled Treatment of HIV Positive Patients in the Primary Care Setting: An Interdisciplinary Team Training Approach. This conference is in collaboration with The Emory AIDS Training Network and the Morehouse AIDS Education and Training Network.

- **Must community and migrant health centers accept HIV patients?**

By statute, Section 329 migrant health canters and Section 330 community health centers are required to define the geographic area they are to serve and the area to be served must have an Medically Underserved Area (MUA) or Medically Underserved Population (MUP) designation. The statute also requires that the applicant must provide access to any resident of the area that seeks services. In addition, the applicant must provide a description of the need in the project's catchment area.

In addition, the C/MHC Program Expectations require health centers to describe their service area geographically and to detail the targeted populations within their service area. The individual needs of the service area must be integrated into the service delivery plan for the center. The service area must be updated annually or more frequently, if necessary.

Thus, centers must accept HIV patients if these patients reside in their defined service area. To ensure compliance with this and other requirements, a center's policies and practices are reviewed. If at the time of Federal grant renewal, a center is found not to be complying with this or the other requirements, the organization must make arrangements to correct the deficiency.

- **What also are BPHC programs doing to address the needs of HIV/AIDS patients?**

In addition to the 57 C/MHCs with Title IIIb HIV services grants, the BPHC makes grants to national Cooperative Agreements (CAs). The primary intent of the national CAs is to strengthen relationships between BPHC programs and state/local health departments. Within that overarching goal, these national organizations are evaluated according to their ability to address activities in one or more of the following areas: (1) enhanced access to primary care, especially for populations such as persons with HIV infection/AIDS; (2) retention and recruitment of

health care providers in medically underserved areas and to serve medically underserved populations; (3) health care services for minorities; and (4) management and enhanced financing for primary care services.

Through these activities, along with the ongoing operations of C/MHCs, the BPHC is attempting to address the primary health care needs of individuals with HIV/AIDS.

AIDS Education and Training Center (ETC) Activities

The AIDS ETCs are a national network of centers charged with the goal of increasing the number of health care providers who are effectively educated and motivated to counsel, diagnose, treat and manage individuals with HIV infection, and to assist in the prevention of high risk behaviors which may lead to infection.

Part of the spectrum of programs offered by the AIDS ETCs are specific training programs to change the attitudes of health care providers who are reluctant to treat people with HIV disease. These programs range from small peer group sessions led by an ETC faculty facilitator to multidisciplinary sessions using "trigger tapes" and role playing. These sessions, along with training programs on cultural factors and special populations are all designed to make health care providers more at ease and more willing to treat all patients with HIV disease. In 1992 the network of AIDS ETCs conducted 1,197 sessions on attitude changes, 840 sessions on cultural factors, and 985 sessions on special populations. These sessions reached an estimated 30,000 health care providers.

SAMHSA

SAMHSA and its Centers have made a point of emphasizing cultural sensitivity and cultural competence in all of its programs. Through specific guidance, review criteria, technical assistance, conferences, internal working groups and caucuses of specific cultural groups every effort has been and is being made to ensure sensitivity and inclusion of cultural awareness in our programming.

11. Discrimination in medical school admissions.

12. Need inclusion in existing programs.

SAMHSA

Gay and lesbians are included as underserved populations where

appropriate in the programs of SAMHSA. It must be remembered that the specific mandates of SAMHSA relate to substance abuse and mental health services and prevention. In many instances SAMHSA has been at the forefront of inclusion and in other areas much remains to be done. The issue of selfdisclosure sometimes makes it difficult to document efforts that have been made.

13. Gay Youth are isolated and ignored. This leads to high risk behaviors. No targetted prevention. Especially true among gay youth of color. Individuals with AIDS aged 20 to 27 were infected in adolescence.

The Office of National AIDS Policy, in collaboration with the office of public affairs at the Office of the Assistant Secretary for Health, are looking for ways of addressing the need for positive role models for gay and lesbian youth in the development of HIV/AIDS Prevention materials. Current efforts include discussions with the NIDA on its "Get High, Get Stupid, Get AIDS" Campaign and with public messages being developed for the public.

The Office of National AIDS Policy will also work with CDC in the development of programs that will address the needs of gay and lesbian youth. Principal among these is the work of National Minority Organizations (NMO) to provide technical assistance to community based organizations. Organizations serving primarily gay and bisexual men of color applied for funding under Announcement 305 and are waiting to hear the result of the application process.

14. Release the report on youth suicide.

15. Youth hotline funds were cut 70%.

CDC is unaware of any hotline, directly supported with CDC funds, that has received such a funding cut. Several states and local organizations operate youth-serving hotline services.

16. Violence against gay youth.

a. How are gay males and lesbians included in violence initiatives?

Gay males and lesbians are included in CDC violence prevention activities as part of CDC's overall effort to prevent violence. They have not been separated from the general population for special emphasis.

b. What about gay reporting of violence?

The magnitude of this problem is unknown because current reporting systems are inadequate to assess the extent of the problem. Certainly there are anecdotal examples of violence against gays because of their sexual orientation. However, the extent to which gays, as a group, are victimized more often than other groups has not been established.

17. Need a curriculum for drug treatment programs serving gays and lesbians.

18. Do NIH-funded sex surveys include lesbians?

As the NICHD sexual surveys focus on sexual activity, these would naturally include lesbian populations. However, this is not a sampling factor. Participation in an NIH-sponsored sexual survey is not restricted based on sexual orientation.

19. Excess morbidity and mortality from STDs. There is an interface between substance abuse, STDs and TB. Comprehensive care is needed. Need coordination between CDC, HRSA and SAMHSA.

CDC

A substantial proportion of STD, HIV, and HIV-related TB morbidity in the United States is associated with the use of alcohol and other drugs (AOD), especially IDU. In 1992, 33 percent of all AIDS cases reported to CDC were associated with IDU. In women and children, 70 percent of the AIDS cases were IDU associated.

IDU and AOD use are associated with the spread of STDs, HIV, and TB. When co-infection occurs, one disease can exacerbate the effects of the other. Many clients enrolled in AOD treatment programs have undiagnosed STDs, HIV infection, and/or TB.

Collaborative efforts among CDC, HRSA, and SAMHSA have been initiated in several areas. HRSA and SAMHSA have participated on the CDC-chaired Federal TB Task Force responsible for developing the National Action Plan to Combat Multidrug Resistant TB. SAMHSA and CDC have collaborated on confidentiality training, especially related to HIV/AIDS, TB, and STDs. Representatives have held roundtable discussions on HIV/AIDS, TB, STDs, and AOD prevention issues during meetings in New York State, New Jersey, Washington, D.C., and California.

Ongoing discussions between CDC and HRSA have focused on collaboration on TB activities such as (1) ensuring

identification and management of active TB cases, (2) routine screening of persons at high risk for developing active TB, and (3) providing TB preventive therapy to high risk individuals with latent TB infection.

The connections between STD, HIV, TB, and drug use indicate that publicly funded AOD prevention and treatment programs could beneficially be offered in collaboration with STD, HIV, and TB prevention and treatment services. CDC's Division of STD/HIV Prevention and SAMHSA/CSAT, working together to expand access to STD/HIV prevention services for IDUs, have recently collaborated on the following:

- CSAT's 1993 Legal Action Center state workshops on confidentiality.
- Joint AOD and public health site visits.
- Joint participation in CSAT program reviews, exit conferences, and state AOD roundtable discussions.
- Meetings with representatives from state AOD and STD/HIV/TB prevention programs in New York, New Jersey, Arkansas, Pennsylvania, California, Maryland, Washington, D.C., Florida, and Rhode Island.
- Planning the upcoming drug abuse summit conferences in New Orleans and New York City.

To be most effective it is important for CDC's STD/HIV programs to coordinate prevention activities with other agencies' drug treatment efforts. Collaboration between drug treatment programs and CDC's STD/HIV prevention programs has begun. Ongoing communication and feedback on successes, failures, and evolving issues are important to sustain a dynamic working relationship with other agencies.

20. Call on gay/lesbian health care professionals for technical assistance in setting up HHS programs.

21. Gay and lesbian participation in clinical trials.

NIH-sponsored clinical trial study protocols have specific eligibility requirements so that the agent(s) can be evaluated in a scientific manner. All clinical trials are open to individuals, regardless of their sexual orientation, who meet the study criteria.

22. Funding for G/L health centers. Need access and equity in Section 330 funding.

A CBO that provides HIV specific services may apply for Section 330 Community Health Canter grant funds. However, such a center must meet all the requirements specified in Section 330 statute and regulations. In particular, a potential center must provide, either directly or through firmly established arrangements with other providers, the basic health care services described in the statute and regulations, and those services must be provided throughout all five lifecycles. The required services include: primary care services; translation services; diagnostic laboratory and x-ray services and pharmacy services needed to complete treatment, patient case management; preventive health and preventive dental services; emergency services; and transportation arrangements for users who might otherwise lack access.

Since each C/MHC must design its clinical program to meet the primary care needs of the community it serves, the relative emphasis on HIV patients is expected to correspond to the needs of the community. A center must ensure full representation of the target service area population in its delivery of services. In addition, the population served may not be limited as to age or gander.

If a CBO is able to meet these requirements, it is encouraged to apply for Section 330 grant funds.

23. Title III funding to gay & lesbian identified health centers. (includes responses to questions 22 & 40).

Title III(b) of Ryan White supports outpatient HIV early intervention services for low-income medically underserved people in existing primary care systems. Half of the Title III program grants were awarded to C/MHCs; the other half were awarded to health care for the homeless programs, local health departments, family planning providers, comprehensive hemophilia diagnostic and treatment centers, and private nonprofit organizations. Presently, there are 136 grantees under Title IIIb. Of these 136 grantees four (4) of the eleven (11) members of the National Alliance of Gay and Lesbian Health Centers (NAGLHC) are Title IIIb grantees. A review of previous Title IIIb applicants indicates that every one of the members of the Alliance that have applied for Title IIIb funds have been successful in obtaining these funds. Attachment 3 identifies the current grantees and their funding.

24. Lesbian participation in the women's health initiative at NIH. (See answer to question 9.)

25. Requested a meeting with SAMHSA leadership.

26. Follow-up meeting with Peter Edelman re: gay youth.

27. Use the expertise of gay/lesbian health centers in developing policies related to those centers.

28. In addition, are NIH studies investigating the causes and consequences of violence against gay men and domestic violence against lesbians?

The NIMH is sponsoring a project to develop a theoretical model to explain the psychological consequences for lesbians and gay men who are victimized through hate crimes. Data will be gathered to describe: 1) the prevalence of victimization through various forms of anti-gay and anti-lesbian violence in Sacramento; 2) the demographic psychological, and social correlates of different types of such victimization; 3) the psychological consequences of such victimization; and 4) the effects of various coping and attributional strategies, beliefs about victimization, commitment to a gay/lesbian identity, and other variables on those consequences. A four-stage, 4-year project has been proposed.

29. What programs does the NIH sponsor in the area of behavioral change/modifications for gays and lesbians?

The NIMH HIV Center for Clinical and Behavioral Studies at Columbia University is conducting a study of HIV Risk and Coming-Out Among Gay and Lesbian Adolescents. Another study sponsored by NIMH will assess the contextual and psychological determinants of sexual risk behavior in HIV serodiscordant male couples. Information gained from this study will be used to develop studies and interventions for lesbian couples.

The NIMH, NICHD, NIDA and the National Institute on Alcohol Abuse and Alcoholism (NIAAA) sponsor behavior change initiatives that broadly apply to lesbians and gays.

NIMH is developing effective prevention programs that change high-risk behavior and maintain low-risk behavior among various populations. NIMH supports several AIDS research centers that focus on behavior change and prevention programs. Results emerging from ongoing research suggest that successful prevention strategies may depend on increasing the sense of personal vulnerability, enhancing feelings of self-mastery through cognitive and skill-based approaches, and changing

group/community norms regarding protective behaviors.

This research also suggests that psychological distress and poor mental health may adversely affect an individual's attempts to change risk patterns of behavior. In addition, NIMH is supporting a multi-site, multipopulation prevention clinical trial. Findings indicate that it is possible to change risk behavior levels in targeted communities by identifying "opinion leaders" and teaching them to communicate effective AIDS prevention messages to their friends and acquaintances. This study confirms the results of an earlier NIMH-supported study that suggested the effectiveness of this intervention approach, known as "diffusion of innovation." In the earlier study, initial surveys of approximately 2,000 homosexual men in 16 small United States cities indicated high rates of risk behavior.

In half of these cities, opinion leaders were identified and trained to serve as behavior change endorsers to their peers. In the community populations where the experimental program was conducted, there was a reduction of almost 50 percent in mean frequency of high-risk behaviors, and 25 percent of men who formerly reported high-risk sexual behaviors ceased practicing these behaviors. No changes were evident in the comparative city populations that had not received the intervention program. This study indicates that it is possible to discourage high-risk behaviors in entire communities by enlisting individuals already popular and trusted.

The NIMH HIV prevention research portfolio includes pre-intervention and intervention studies. Most of NIMH's primary prevention efforts have been focused at the individual level. With the development of new medical therapies and increased emphasis on early intervention, increasing numbers of HIV-infected individuals are living longer and more productive lives. Prevention research is also being expanded into secondary prevention efforts.

NIMH prevention programs provide support and funding for:

- A clinical trial to test the efficacy of an HIV prevention program in seven sites with multicultural populations that include African-American and Hispanic/Latina women.

- A collaborative effort with the AIDS Research Center in New York to develop prevention strategies for women, especially barrier-methods controlled by women.

- A program to develop culturally appropriate prevention efforts targeting minority women at the AIDS Research Center in San Francisco.

- Studies of preventive intervention programs, several of which target inner-city women. A study conducted with women in family planning clinics has been successful in reducing high-risk behavior. One of the studies is examining intensified case management as an effective approach with cocaine addicted pregnant women.

- A study of young inner-city African-American women who are at high risk for HIV infection. This study is evaluating whether increasing skills at negotiating difficult sexual situations and enhancing ability and motivation to implement safer sexual practices are more effective than knowledge-only interventions.

- A behavioral study of Haitian women living in Miami designed to understand their perception of sexually transmitted diseases and HIV infection. The data will be used to develop culturally appropriate techniques for effective HIV risk reduction.

- A longitudinal study of HIV serostatus disclosure involving women. This study is investigating the factors that motivate or act as barriers to disclosure to sexual partners, significant others, and associates (e.g., employers, medical providers, landlords). Several of the NIMH preintervention studies with homosexual and or bisexual men.

- A study of 100 Hispanic/Latino homosexual and bisexual men between the ages of 18-60 designed to investigate the sexual behavior patterns of these men including sexual identity issues, HIV risk, and the association of ethnic identity, race and acculturation.

- A study of sexually active, ethnically diverse homosexual and bisexual African-American men as well as heterosexual young adults. The objective is to identify possible psychological and interpersonal determinants of AIDS-related risk and risk reduction behaviors.

- A study of 1,000 African-American homosexual and bisexual men designed to identify past levels of sexual behavior, perception of risk for contracting AIDS, attitude and social risk-reduction factors, and ways to adopt further risk-reduction measures.

- A study of homosexual and bisexual men, injecting drug users, sex trade workers, and multiple-partner heterosexuals designed to apply attitude and behavioral change theory to understanding the way individuals use condoms.

- A study of 400 homosexual and bisexual men with the objective of providing information to HIV-infected individuals on support groups that help identify aspects that will lead to preventive behavior.

- A study of 1,000 homosexual men designed to investigate psychosocial factors associated with the AIDS pandemic.

NIMH intervention studies with homosexual and/or bisexual men:

- A study of 240 HIV-infected and uninfected homosexual men designed to investigate coping effectiveness training in a randomized clinical trial.

- A study of 400 African-American homosexual men focusing on AIDS risk reduction using culturally appropriate behavior change interventions.

- A study of young (18-25) homosexual men with the objective of establishing a system of peer outreach HIV-risk reduction workshops and a publicity campaign in order to influence behavior change.

- A study of homosexual men in small cities designed to test community intervention techniques as a method of AIDS risk reduction behavior.

- A study of adult men over 18 years of age who engage in sex with other men. The objective is to assess cognitive-behavioral group counseling conducted via the telephone as a method for reducing barriers to AIDS prevention.

- A study of 450 runaway and homosexual/bisexual youth investigating the reduction of HIV sexual risks following intensive intervention strategies.

The NICHD research program in behavior/prevention builds on a long standing program of research examining the choices individuals make regarding their sexual behavior and protection against adverse outcomes of those behaviors such as unwanted pregnancy or STDS. NICHD research focuses on conceptualizations of disease, particularly of diseases that are unlikely to be known to the individual through direct experience. The intervention research builds on previous family planning studies as well as proven interventions for smoking and other health-related behaviors.

The NICHD has undertaken a major program of research in an effort to understand the effect of HIV/AIDS and other STDs on choices regarding sexual and reproductive behavior. This research makes

use of a wide range of populations, including national probability samples, regional samples of minority adolescents, high school health clinics, teens in detention centers, clients in STD clinics, and male prostitutes. These studies use the Health Belief Model, the Subjective Expected Utility Model, and other theoretical frameworks to examine questions relating to how the risk for HIV infection and AIDS affects behavior. While NICHD studies do not focus on HIV infection among lesbians, participation in these studies is not restricted by sexual orientation. These studies are producing data that elucidate patterns of sexual behavior and protective behavior and its relationship to a variety of social and background variables.

Specifically, the NICHD sponsors projects on reducing the risk of sexually transmitted HIV infection; preventing HIV infection in sexually active adolescents; teaching youth social skills; evaluating AIDS prevention efforts; assessing social context for adolescent high-risk sexual behavior; understanding decision making processes in youths regarding AIDS risk behavior; and understanding the development of attitudes and knowledge about AIDS.

NICHD planned research activities include:

- a case-control study of reversible contraceptives;
- the development of new spermicidal products;
- a clinical trial of hormonal contraceptives in HIVinfected women; and
- a study of side effects of vaginal inserts that might increase susceptibility to HIV infection.

The NIDA supports a research program to develop a variety of effective, cost-efficient comprehensive programs. These programs offer a continuum of care designed to reduce the use of illicit drugs and related high-risk behaviors and thereby reduce the risk of HIV infection among drug abusing women. Research initiatives scheduled for implementation include: clinical studies focused on psychotherapy, behavior therapy, and other psychosocial interventions; treatment evaluations aimed at strategies to improve entry and retention in treatment and improve compliance with treatment regimens; and health services studies directed at understanding the impact of organization, structure, financing, management, and staffing patterns on the availability, accessibility, and utilization of therapeutic and preventive interventions.

NIDA sponsors a national media campaign to reach various segments

of the public with information about the relationship between drugs, sexual activity, and the risk of HIV infection. The first phase of the campaign, entitled "AIDS, Another Way Drugs Can Kill," is aimed at young teens. Phase two uses a unique cartoon format to reach young women and men (18-24) with messages about the HIV risks inherent in modern lifestyles, particularly those linking intoxication and sexual intercourse. The third phase of this campaign focuses specifically on young women with messages about reducing their risks for HIV exposure when in situations in which the use of alcohol or other drugs may lead to sexual activity. The National Institute on Alcohol Abuse and Alcoholism (NIAAA) sponsors research on alcohol use/abuse and unsafe sexual practices with the goal of understanding the salient decision making processes and developing socio-psychological prevention and interventions strategies to reduce the risk of alcohol-related HIV exposure. Studies of HIV-infected women focus on female partners of bisexual males, women alcoholics in treatment programs, and school-based prevention research programs for adolescent girls.

NIAAA sponsors several studies on drinking, sex and HIV risk among African American adolescents, the relationship among adolescents between alcohol use and risk for HIV-infection as a consequence of engaging in high-risk sexual behaviors, and risk factors for HIV transmission among alcoholics who also participate in needle sharing activities or drug use.

30. Discuss changes in CDC guidelines involving transmission from health care workers to patients.

a. Review

In July 1991 CDC published "Recommendations for Preventing Transmission of HIV and Hepatitis B Virus During Exposure-Prone Invasive Procedures." In summary, these recommendations stated that certain invasive surgical, dental, and obstetric procedures inherently carry risk of injury to the health-care worker (HCW) and subsequent exposure of the patient to the HCW's blood. The recommendations state that HCWs who perform such procedures should know their status for HIV and HBV and, if infected, should refrain from performing such procedures unless they have sought counsel from an expert review panel and have been advised under what circumstances, if any, they may continue to perform these procedures. The document also recommends that these exposure-prone procedures be specifically identified by medical, surgical, and dental organizations and by the institutions at which these procedures would be performed.

On October 28, 1991, President Bush signed into law the Treasury, Postal Service and General Government Appropriations Act, 1992.

This Act mandates that each state must certify within one year that guidelines issued by CDC or guidelines equivalent to those promulgated by CDC concerning recommendations for preventing the transmission of HIV and HBV during exposure-prone invasive procedures have been instituted in the state. In addition, the law requires that state guidelines shall (1) apply to health professionals practicing within the state, (2) be consistent with Federal law, (3) be the responsibility of the state public health official, and (4) describe what appropriate disciplinary or other actions shall be taken to ensure compliance. If such certification is not provided within the one-year period, the state shall be ineligible to receive assistance under the Public Service Act (42 U.S.C. 301 et seq.) until such certification is provided. However, the Secretary may extend the time period for a state, upon application of such state, that additional time is required for instituting such guidelines.

b. What is the status?

- All states, territories, and the District of Columbia submitted forms on or before the required deadline of October 28, 1992, certifying compliance or requesting an extension.

- Five states and three territories certified that they had instituted the guidelines published by CDC. They received a letter indicating that their certification was in compliance with the requirements of Public Law 102-141.

- Twenty-seven states certified that they have instituted guidelines equivalent to those published by CDC. They have received a letter indicating that their guidelines were determined to be in compliance with the requirements of Public Law 102-141.

- Eighteen states, five territories, and the District of Columbia requested an extension of time. They were granted an extension of time up to October 28, 1993, to comply with the requirements of Public Law 102-141.

When CDC has determined that a state's certification complies with Section 633 of Public Law 102-141, no further action is taken.

On May 7, 1993, CDC reported on the continuing investigations of patients who have been treated by HCWs infected with HIV. Ongoing investigations of nearly 20,000 patients have revealed no further evidence of HIV transmission from a HCW to a patient, beyond the six cases reported from the Florida cluster. CDC does not plan to modify the July 12, 1991, recommendations, since they

provide a sufficient basis for states to decide that exposure-prone invasive procedures may be determined on a case-by-case basis, taking into consideration the specific procedure as well as the skill, technique, and possible impairment of the infected health-care worker.

35. CDC should assess the extent of gay and lesbian health problems. What is the extent of CDC's awareness of this?

At the present time, none of the National databases that provide information on the health status of the population include questions on sexual orientation. Virtually all these surveys include personal identifiers. In light of recent concerns over issues of confidentiality and questions on sexual orientation in national databases, this issue would require further discussion with the lesbian and gay leadership. Additional concerns include the accuracy of responses to questions on sexual orientation, and whether persons identified by responses to such questions would be representative of the total lesbian and gay population.

36. Gay men of color.

a. Need more extensive prevention efforts.

Data obtained from studies of minority men who have sex with men indicate that these men do not always self-identify as homosexual or bisexual. As a result, CDC has focused prevention messages on risk behavior rather than on self-identified group membership.

However, CDC has an extensive HIV prevention effort directed toward gay men of color. These men are served both generally and specifically with HIV prevention programs funded by CDC through the following:

- Directly funded state and local health departments providing counseling, testing, referral, and partner notification; health education/risk reduction; minority initiatives; and public information.
- Directly funded minority and other community-based organizations (CBOs).
- Directly funded national and regional minority organizations (NMOs).
- Indirectly funded CBOs through cooperative agreements with state and local health departments.
- Indirectly funded CBOs through the United States Conference of Mayors (USCM).

CDC also supports HIV prevention programs that target specific racial/ethnic subpopulations. For examples:

- From 1989 to the present, 19 of the CDC directly funded CBOs directed a portion of their program efforts toward reaching gay/bisexual men of color.

- Of the 41 CBOs that were awarded FY 1992 funds, 12 served this group.

- From 1985 through 1991, USCM has provided funding and technical assistance to 15 organizations for HIV/AIDS prevention programs.

- Another four organizations received HIV Education and Service Coordination Grants through USCM for HIV counseling, case management and referral, health education, and support groups targeting the gay and bisexual minority community.

b. Assess the current effort - expand if needed.

Many CDC-supported CBOs implement HIV prevention programs that either include gay and bisexual men of color in their target audiences or have programs designed exclusively for that population. An example of such a program is the Minority AIDS Project (MAP) in Los Angeles that receives funding and technical assistance through the United States Conference of Mayors' Education Service and Coordination Grants. MAP is a comprehensive AIDS service organization targeting black and Hispanic communities with comprehensive client services, educational programs, and HIV-antibody counseling and testing. The majority of the clients are gay and bisexual men of color.

The National Task Force on AIDS Prevention, developed by the National Association of Black and White Men Together, targets gay/bisexual men in racial/ethnic minority communities. The mission of the Task Force is to increase the capacity of its 25 chapters through technical assistance, develop culturally appropriate HIV/AIDS prevention models, and recruit and train volunteers to serve as peer educators and workshop facilitators.

37. One third of teen suicides occur among gay and lesbian youth.

CDC does not have data confirming that one-third of teen suicides occur among gay and lesbian youth. Although better data would be needed to answer this question more accurately, current estimates of the prevalence of teen suicide and homosexuality suggest that this is an overestimate.

39. The federal government is more friendly than many state and local governments. Easier to get grant money.

40. Ryan White Title III(b) funds Needed

- **Can NHSC providers be placed in Title III(b) sites?**

Generally, NHSC providers can be placed in any site that (a) has been designated as a HPSA, (b) has applied for NHSC assistance, and (c) has provided the data necessary to score the site relative to all other potential NHSC sites. Those NHSC providers with scholarship and loan repayment obligations must be placed in sites that also (d) have been identified as being in a HPSA of greatest need (using a scoring system that compares all HPSAS), and (a) have been identified as a site of greatest need (using a scoring system that compares all applicant sites).

Title III(b) sites may apply for HPSA designation by providing appropriate data to BPHC's Division of Shortage Designation. The existing criteria for HPSA designation allow for designation of population groups with economic and/or other access barriers to the existing health care system even within urban areas having significant resources available to the general population. The data provided an a site's service area should include the approximate boundaries of the service area, a description of the population in need, a description of the barriers to access for that population, a count of the primary care providers serving that population, and a discussion of the availability and accessibility of providers in contiguous areas.

Title III(b) sites may apply for NHSC assistance by contacting the NHSC Regional Program Consultant in the appropriate PHS Regional Office, and/or by contacting the State Cooperative Agreement coordinator for their State.

- **Is HIV a criterion for placement of new centers?**

The Bureau of Primary Health Care (BPHC) makes grants to public and nonprofit private entities for the development and operation of community and migrant health centers (C/MHCs).

C/MHCs provide comprehensive primary health services for underserved populations throughout the united States and its territories. C/MHCs provide a broad array of medical and support services to individuals located in isolated rural areas and impoverished inner cities.

In many communities, these centers are the sole providers of care to a highly vulnerable, medically needy population. C/MHCs

tailor their services to meet the specific needs of the co=unity and its special populations that include the homeless, people infected with HIV/AIDS, the elderly and substance abusers. Centers are community administered and are under the direction of a governing board, whose membership includes the canter's consumers.

To ensure that community/migrant health center program resources are targeted to the areas of highest need, the BPHC has developed review guidance to identify those areas across the United States that are most needy. In addition, through State-based planning activities, communities with high unmet health care needs are identified and appropriate steps are taken to assist these identified communities. In particular, the Bureau works with State and Regional Primary Care Associations and State Cooperative Agreements to help these communities develop viable health care deliver systems.

In addition, the Bureau reviews its guidance for C/MHC funding decisions each year to ensure that the communities of highest need are given every opportunity to obtain funding. For FY 1993, the review criteria include service area data on the following "need" factors: poverty levels; percent minority populations; distance to primary care providers; physician to population ratios; and other community health issues. The data is then used to determine the level of "need" in a community.

As for HIV infection rates, many of the documented "need" factors listed above are directly correlated to the level of HIV infection in a community. In particular, the poverty rate level and the percent of minority populations have been well documented as being correlated with higher HIV infection rates. In addition, in an effort to better reflect the unique health issues in each community, the point total for the Community Health issues factor was expanded for FY 1993. As a result, communities are now able to more fully describe the health care needs in their proposed service areas.

Cited examples in the community health issues factor include: high uninsured rates; high growth rate of minority/special populations; high morbidity rates due to specific diseases; cultural/language barriers; etc). Within this category of need, applicants may document the level of HIV infection in their communities and address the need for specific primary health services to serve this vulnerable population.

In combination with a project's plan for addressing the identified health care needs in its community, these "need" factors serve as a basis for funding decisions concerning C/MHCs.

For FY 1993 , approximately $14 million will be made available to establish C/MHCs in now geographic areas and/or to expand the capacity of existing C/MHCS into now or existing geographic areas. of the funds available, approximately half will be directed to now service areas and half will go toward expanding capacity (i.e., increasing the number of now patients served) of existing C/MHCs within their current service areas. In addition, a limited number of planning grants for future CHCs will be awarded.

49. Vaccine Clinical Trials

The AIDS Vaccine Clinical Trials Network (AVCTN) has established five AIDS Vaccine Evaluation units designed to evaluate potential vaccines in phase I and II trials. Women make up 22 percent of the participants in these trials. To date, 19 phase I trials have been initiated using products based on HIV envelope proteins, gpl60 or gpl20 or recombinant products. Currently, there are eight vaccine candidates undergoing evaluation at these sites.

Significant progress has been made in the development of potential vaccines for the prevention of HIV infection. For example, all vaccine candidates tested to date in phase I trials have been shown to be safe and well tolerated. Phase I trials involving HIV seronegative individuals have shown that the majority of vaccine candidates produce binding antibodies. Tiers of neutralizing antibody directed toward homologous virus, however, were low. The vaccines in these trials also produced low or non-existent neutralization tiers against heterologous virus, and the duration of the response lasted only from weeks to months. More positive results have been observed in recent studies testing a recombinant vaccinia virus gpl60 vaccine candidate followed by a booster of a recombinant subunit vaccine candidate have produced functional CTLs capable of destroying HIV-infected cells.

NCI will initiate shortly clinical trials of a vaccine candidate in HIV-infected laboratory workers. In addition, NCI will collaborate with the Department of Defense (DoD) in an evaluation of a vaccine candidate in HIV-infected populations.

<u>Phase II Clinical Trials</u>

The NIH has initiated phase II trials with two gpl20 vaccine candidates in uninfected high-risk individuals. The NIH also has developed a study protocol and will initiate soon the first phase II trial of a vaccine candidate in HIV-infected individuals as well as a trial in HIV-infected pregnant women to study the possibility of preventing maternal-fetal transmission. In order

to characterize the types of responses obtained to different vaccine candidates, the NIAID will evaluate serum samples from these study participants using sophisticated techniques.

Infrastructure for Phase III Efficacy Trials

Clinical evaluation of vaccine candidates in phase III efficacy trials is being planned in several domestic and international areas with populations at high risk of HIV infection. Through the "Preparation for AIDS/HIV Vaccine Evaluations (PAVE)" initiative, eight awards were made in FY 1992 to assure that the necessary infrastructure required to conduct vaccine efficacy trials is developed and operational. These awards will facilitate a study of cohorts of women and men at high risk for HIV infection in order to determine the feasibility of conducting vaccine efficacy trials within these populations. These studies will evaluate seroincidence, risk factors, and risk reduction efforts. The sites funded through these awards also may be used for perinatal transmission prevention trials.

Planned activities will:

- implement the HIV Vaccine Efficacy Trials Network (HIVNET) designed to conduct prevention research and provide the capability to evaluate the efficacy of vaccine candidates for preventing HIV infection domestically and internationally; and

- conduct the Correlates of Immunity in HIV Vaccinees Study to characterize immune responses in selected HIV vaccinees in phase III/efficacy trials and determine the correlations between various immune responses and protection from infection and disease progression.

50. Substance Abuse among gay and lesbians is three times the general population. Need more funds for this and mental health services.

We can confirm from a number of studies that substance abuse, particularly alcohol abuse is in the range of 30% among Gay men. The citations are in the enclosed materials. Fifield in 1975 reported "31.4 % of the Los Angeles County gay and lesbian population show signs of alcoholism or heavy drinking." Saghir and Robins in 1973 reported that "among lesbians, 35% described their drinking behavior as excessive or alcohol dependent at some point in their lives."

53. Need more substance abuse prevention and treatment.

We are in complete agreement that more substance abuse treatment is needed. We are dependent on the advocacy of constituent groups and the administration for the support of additional services.
As yet, however, we are unable to confirm the data source for quoted figure of 80% of Gay men who are receiving primary care are substance abusers.

55. Communities and community-based organizations need funds for planning so that prevention funds will be better used. As it now stands, communities are not prepared to take on additional prevention funds.

CDC

CDC is supportive of a comprehensive community planning approach that addresses HIV prevention and care, sexually transmitted diseases, drug treatment, tuberculosis (TB), and reproductive health issues. Representative Nancy Pelosi has introduced a bill (The Comprehensive HIV Prevention Act of 1993) that establishes local planning councils to be responsible for determining HIV prevention priorities. The proposed membership of these local planning councils includes a broad range of community citizen representatives. CDC has formed an ad hoc working group to examine current HIV funding policies and consider approaches that incorporate community planning as an integral component of the process.

A meeting of governmental and non governmental consultants was held at CDC on September 17 to discuss a proposed approach to community planning. A larger public meeting is planned for October. A supplemental guidance has been developed to assist in the preparation of plans in FY 1994. Funds will be awarded through the HIV Prevention Cooperative Agreements on January 1, 1994.

SAMHSA

Communities and community-based organizations need funds for planning so that prevention funds will be better used. As it now stands, communities are not prepared to take on additional prevention funds.

Answer: At the October 13, 1992, HIV Leadership meeting the Assistant Secretary for Health instructed Agency Heads to assign senior staff to serve on a PHS Inter-Agency Planning and Coordination Work Group to do the following:

- Coordinate the PHS HIV-related strategic planning and implementation process among and with the agencies and

operational offices;
- Examine how specific activities within PHS agencies and OASH Staff Offices plans relate to each other;
- Examine and make recommendations on how PHS can promote community-based planning and implementation and assure that PHS activities are an integral part of such planning; and
- Examine and make recommendations to improve the coordination of HIV-related grant activities across agencies and offices.

NAPO convened a series of meetings with agency staff to address the four specific areas. The objective of the work group was to create a process which resulted in ease of application, reduction of duplication, support for community decision making, and promotion of a coordinated local system for health care. The group concurred that a major role for PHS will be to strengthen both State and local capacities to determine their health needs and to establish their own local objectives through community health planning. The group agreed that the objectives of such an undertaking should be the following: (1) assure that communities engage in broad-based health planning and take steps to guarantee that PHS-funded programs or activities are integrated at the local level; and (2) coordinate relevant agency funding streams and target PHS funding to communities which provide integrated plans.

The work group concluded that the communities at greatest risk for HIV were also at greatest risk for other health related problems i.e drug abuse, infant mortality, violence, accidents, homicides, STD'S, TB, poor access to health care, and low educational attainment. The resulting PHS document: *Promoting Planning and Program Integration for HIV-Related Programs at the Community Level,* recommended expanding and enhancing community planning for HIV-related programs such as: HIV prevention, Ryan White, substance abuse treatment and prevention, STDS, TB prevention and treatment programs, and other primary care treatment programs.

56. State surveillance data are not being transmitted to CBOs. This information is needed in order to apply for and award grants.

CDC

CDC receives statistical and demographic information on reported AIDS cases from state and local health departments after all personal identifiers have been removed. This information is collected under assurances of confidentiality within the states and CDC. CDC provides statistical data back to states on a quarterly basis and compiles data for public dissemination on a quarterly basis through the *HIV/AIDS Surveillance Report,* the CDC

voice information system (404-332-4570), and the AIDS Public Information Data Set (PIDS) (a public-use data set that allows for cross tabulations of data from the AIDS reporting system). Although many states provide monthly data upon request, trends in reported cases are more accurately represented through examination of quarterly data. Copies of the *HIV/AIDS Surveillance Report* are made available free to the general public through the CDC National AIDS Clearinghouse; individuals or organizations can also be added to the mailing list upon request. CBOs are encouraged to use this information in planning their HIV prevention programs.

The collection of demographic and other information (such as sex, age, race, and mode of exposure of the infected person), through both surveillance and epidemiologic studies, helps to direct prevention efforts and funding to areas and groups of persons at highest risk of infection.

CDC also compiles quarterly reports on information gathered by all state and local health departments on counseling and testing services provided through sites within their jurisdiction. Since the inception of HIV counseling and testing, CDC and states have been assessing self-reported risks of clients according to their race/ethnicity, age, gender, and the type of site at which they received services. This information is used to monitor trends in HIV counseling and testing.

Selected state and local health departments submit quarterly, computerized reports to CDC for the Client Record Database. This Database, which allows for detailed and programmatic analyses of counseling and testing services provided with CDC funds, was established in the fall of 1988 and currently has 36 of 65 project areas contributing data with an additional 6 areas piloting the system. The Summary Database for HIV counseling and testing, which was established in 1985, includes information on the self-reported risk factors listed above. It includes information about counseling and testing services such as self-reported risks, race/ethnicity, age, gender of clients, and site type. This information is very useful for planning, targeting, and evaluating coverage, and acceptance of these services. It is a "service delivery" database which provides descriptive trends and an opportunity to focus and target appropriate interventions at the individual site or clinic level.

State and local health department HIV surveillance programs have received strong encouragement from CDC to be responsive to total CBO needs for data that could be helpful in planning community HIV prevention and care programs.

SAMHSA

PHS will establish an electronic bulletin board which will contain relevant HIV surveillance data required for specific grant announcements. The announcement of availability of funds will contain information about the bulletin board and instructions as to its use.

DRAFT-NOT FOR DISTRIBUTION 10/14/93

Attachment 1

MATERIAL RELATING TO WOMEN'S ISSUES
CONTAINED IN HIV IN PREVENTION AND CARE
IN CORRECTIONAL FACILITIES -
A REPORT TO CONGRESS
ORIGINATING LEGISLATION
House Report 102-121

The issue of health care in the correctional system continues to be an issue of serious concern to the Committee. In a recent report issued by the National Commission on AIDS, the Commission recommended that the"U.S. Public Health Service;..develop guidelines for the prevention and treatment of HIV disease in all Federal, State, and local correctional facilities. Immediate steps should be taken to control the subsidiary epidemics of TB and sexually transmitted diseases. "Particular attention should be given to the specific needs of women and youth within all policies." Consistent with the Commission's findings, the Committee directs the Department to develop a plan for the implementation of programs that address these concerns, as well as the overall health care treatment and prevention needs of the correctional system. The Department should report its findings before the 1993 hearings.

There are currently no comprehensive Federal plans to meet the unique health care needs of incarcerated women and youth.

Recommendations in HIV in Correctional Facilities - A Report to Congress include:

11) All entering inmates and correctional staff, including probation and parole officers, should be required to attend education/risk reduction programs for TB, HIV and other STDs specifically designed for cultural competency and to meet the needs of drug users, men who have sex with men, **women,** and youth. Confidentiality should be specifically addressed as it relates to the correctional setting.

12) Education programs for **women** should include safer sex techniques, risks of STDs and HIV to the fetus and infant, risks of adverse pregnancy outcomes and strategies to gain control over sexual decision making. Prenatal care and counseling, and, if desired, abortion referrals should also be available to pregnant women.

23) Circumstances unique to incarcerated women and youth with HIV infection should be recognized and addressed using a case management approach. This will require effective collaborative arrangements with key agencies in the

community, such as drug treatment programs, family planning programs, and other community health care providers.

36) **Standards of care for women** need to be developed and disseminated. Research on "patterns of care" for women shows an increasing need to evaluate the types of HIV services being provided to women. This need for specialized HIV services for women in the general population is equally important for incarcerated females.

38) Consideration should be given to encouraging various medical specialty societies to become involved in formulating case management guidelines. For example, groups such as the **American College of Obstetrics and Gynecology should be involved in the creation of HIV treatment guidelines for incarcerated women.**

WOMEN INMATES

Although women account for only 5 to 10 percent of the prison population, their numbers are growing. According to the report on HIV in correctional facilities released by the National Commission on AIDS in March, 1991, in 1980, the number of women in correctional facilities was 13,000, in 1989 it was 49,000. In 1989, the female prison population grew 25 percent, nearly twice the rate of males. Women have been found to have a higher rate of HIV antibody seroprevalence than male inmates in numerous surveys (Michigan, Mississippi, Utah, Nevada, California, Hawaii, and Oregon).[1] A survey at 10 geographically diverse correctional facilities revealed seropositive rates of .21 percent to 7.6 percent for males and 2.5 percent to 14.7 percent for females. In nine of the ten facilities, the rate was higher for women that for men.[2] CDC reports that over 11 percent of all reported cases of AIDS are women. As the number of female inmates increases, prison health systems need to pay particular attention to their specialized health care needs, especially in relation to gynecology and pregnancy.

Historically, the amount of funding appropriated for female correctional facilities and consequently for health care services in these institutions has been inadequate. This has resulted in gaps in needed services. While some studies have been done on HIV/AIDS and women in prison, there is a need for additional seroprevalence data to support planning and funding

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[1] Ibid, P.1

[2] Vlahov, et al. JAMA, 265:1129-32, 1991

for specialized health care needs of infected women.

Medicaid is available, however, to those persons who leave correctional institutions on parole and those who live in community facilities, such as half-way houses, with fewer than 16 occupants. In all cases, the person must meet Medicaid eligibility criteria, such as being caretaker relatives of children in low-income families, being low-income pregnant **women**, infants, and children or being aged, blind, or disabled.

The number of **women** in state and federal prisons more than tripled between 1980 and 1990. About two thirds of these women are racial/ethnic minorities and three fourths have children. Special emphasis and priority should be placed on identifying and meeting the HIV prevention and case management needs of incarcerated, seropositive women. Issues of special relevance to HIV-infected women include contraceptive counseling, risk for perinatal HIV transmission, prenatal care, prevention and treatment of STDS, and strategies for negotiating condom use with male partners.

Volunteer programs facilitate bringing representatives from community-based services into contact with inmates to establish a link prior to release. New York City has a number of social service organizations providing pre-release support and planning to inmates with HIV/AIDS. The Alliance for Inmates with AIDS, is a coalition of over 20 voluntary organizations that provide a number of services to inmates and parolees with HIV/AIDS including prevention education, substance abuse treatment and emergency housing. Member groups include:

- ACE-OUT which provides education and support for women leaving the Bedford Hills facility;
- Women's Prison Association-Support, which provides emergency interim housing; and
- El Rio which provides intensive treatment for people who are substance abusers.

Special Treatment Programs address the special needs of inmates such as substance abuse or focus on specific groups such as women or youth. Whitman Walker Clinic in the District of Columbia (D.C.) and the DC Women's Council On AIDS target women in the D.C. area facilities with education, support groups and provides some pre-release linkage services.

Community Based Programs

The Office of Women's Health and the Office of Minority Health

within the Office of the Assistant Secretary for Health in collaboration with the Health Resources and Services Administration (HRSA), have funded a "Transitional Health Program with Incarcerated Females" in Los Angeles which trains an interdisciplinary team of health professionals to provide comprehensive health care to African-American and Hispanic women who have been incarcerated in youth facilities in South-Central Los Angeles.

DRAFT-NOT FOR DISTRIBUTION 10/14/93

ATTACHMENT 2

NIH/ADAMHA POLICY CONCERNING INCLUSION OF WOMEN IN STUDY POPULATIONS

P.T. 34, II; K.W. 1014002, 1014006

National Institutes of Health
Alcohol, Drug Abuse, and Mental Health Administration

Tha National Institutes of Health (NIH) and the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA) recognize that most researchers adequately and appropriately consider gender representation in clinical research design. Nevertheless, the following statement is published as a reiteration and further interpretation of the existing NIH/SAMHSA policy concerning inclusion of women in study populations. Clinical research findings should be of benefit to all persons at risk of the disease, regardless of gender. This policy was previously published in the NIH Guide for Grants and Contracts on October 24, 1986; January 23, 1987; March 27, 1987; January 15, 1988; and June 16, 1989. For the purpose of this policy, clinical research includes human studies of etiology, treatment, diagnosis, prevention, and epidemiology of disease, including but not limited to clinical trials. While this policy statement refers to inclusion of women, applicants are strongly reminded that a similar policy exists regarding the inclusion of minorities (NIH Guide for Grants and Contracts - September 25, 1987; January 15, 1988; and June 16, 1989). Both policies must be considered when preparing clinical research applications/proposals for submission to the NIH/ADAMHA.

Public concern requires that clinical studies include both genders in such a way that results are applicable to the general population; exceptions would be those diseases or conditions that occur only in one gender. Therefore, applications/proposals for NIH/ADAMHA support of clinical research should employ a study design with gender representation appropriate to the known incidence/prevalence of the disease or condition being studied. If inclusion of women is impossible or inappropriate with respect to the purpose of the research, the health of the subjects, or other reasons, or if in the only study population available there is a disproportionate representation of one gender, these reasons for excluding women or men must be well explained and justified by the applicant. Similar justification is required if women will not be included in numbers appropriate to the incidence/prevalence of the disease.

In conducting peer review for scientific and technical merit,

members of Initial Review Groups (IRGs)/Technical Evaluation Groups (TEGs) will be instructed to evaluate the proposed gender composition of the study population.

1) if there is an inadequate number of women in a study design AND this affects the potential to answer the scientific question(s) addressed, that will be considered a weakness or deficiency in the study design and should be reflected in the assigned score given to the application/proposal, and in the summary statement of the review.

2) If an applicant proposes that there is justification for conducting a study in men only, or in a study population in which the proportion of women does not reflect the gender prevalence of the disease or condition under study, a strong scientific rationale, an explanation of the need to protect the health of the subjects, or other well-supported justification must be provided. The IRG/TEG will be instructed to evaluate the merit of such justifications. Appropriate justification will not adversely affect the assigned score. The IK/SAMHSA will not fund such applications/proposals unless the justification provided is compelling.

3) If the gender composition of the study population is not described, BUT the study otherwise has the potential to answer the scientific question(s) posed and translate the findings to all persons at risk of the disease, the omission will be documented by the Executive Secretary of the IRG/TEG in an administrative note, and will not adversely affect the scientific assessment and the assigned score. If there is inadequate information on the study population to allow evaluation of the scientific question(s), the review may be deferred. The NIH/ADAMHA funding components will not fund/award grants or contracts until the applicant provides sufficient information on the study population to assure compliance with the NIH/SAMHSA policy on inclusion of women in study populations.

Attachment 3

TITLE 111(b) FUNDS TO NATIONAL ALLIANCE MEMBERS

ALLIANCE MEMBER	IIIB	TITLE III SUBCONTRACTOR
Fenway Community Health Center Boston, Mass	$347,522	
Puerto Rico CONCRA San Juan, P.R.	$402,439	
Los Angeles Gay & Lesbian center Los Angeles, California	$429,384	
Whitman-Walker Clinic Washington, DC	$258,853	
Chase Braxton Clinic Baltimore, MD		X
Lyon-Martin Women's Health Services San Francisco, CA		X

- **Title III(b) HIV funding relative to need**

Approximately half of the FY1992 Title IIIB grant funds have been awarded to community based organizations in the highest incidence areas (Title I Cities). The fifty three grantees in these cities represent a broad range of HIV primary care service providers including community and Migrant Health Centers, Homeless Health Care Programs, Hemophilia Centers, Family Planning Programs, public and private not for profit hospital affiliated primary care centers, as well as gay and lesbian identified health canters. The following chart identifies Title IIIb grantees in the Title I cities and the gay identified Title III grantees in those cities:

- **FY 1992 TITLE IIIB GRANTEES LOCATED IN TITLE I CITIES**

TITLE I METROPOLITAN AREAS	TITLE IIIB	GAY IDTFD
BOSTON	3	1
NEWARK	4	
NEW YORK	19	
SAN JUAN	2	1
PHILADELPHIA	3	
BALTIMORE	2	
WASHINGTON, D.C.	2	1
ATLANTA	2	
MIAMI	3	
FT. LAUDERDALE	1	
CHICAGO	4	
HOUSTON	1	
DALLAS	1	
SAN FRANCISCO	1	
LOS ANGELES	3	2
SAN DIEGO	1	
TOTAL	53	5

RYAN WHITE TITLE IIIB GRANTEES IN TITLE I CITIES

REGION	TITLE I CITY	# OF GRANTEES	FY1993 LEVEL OF SUPPORT
I	BOSTON, MA	2	$610,032
II	SUB-TOTAL REGION II	29	$12,311,094
	JERSEY CITY	1	$449,232
	NASSAU-SUFFOLK	1	$145,500
	NEWARK	4	$1,675,023
	NEW YORK	18	$7,653,684
	SAN JUAN	4	$1,827,655
	PONCE	1	$560,000
III	SUBTOTALS FOR REGION III		$2,688,514
	BALTIMORE	3	$734,497
	PHILADELPHIA	3	$1,144,004
	WASHINGTON, D.C.	2	$810,013
IV	SUBTOTALS FOR REGION IV		$3,366,502
	ATLANTA	2	$742,047
	FORT LAUDERDALE (POMPANO)		$475,000
	MIAMI		$1,674,455
	TAMPA/ ST.PETERSBURG		$475,000
V	SUBTOTALS FOR REGION V		$2,099,010
	CHICAGO		$1,614,067
	DETROIT		$484,943

VI	SUBTOTALS FOR REGION VI		$1,027,660
	DALLAS		$292,942
	HOUSTON	1	$423,468
	NEW ORLEANS		$311,250
VII	- - -		
VIII	-	-	
IX	SUBTOTALS FOR REGION IX	6	$1,846,168
	ANAHEIM	0	-
	LOS ANGELES	4	$1,239,918
	OAKLAND	0	-
	SAN DIEGO	1	$121,250
	SAN FRANCISCO	1	$485,000
X	SEATLE	2	$638,786
SUB-TOTALS		60	$24,587,766
	PROJECTED TITLE I CITIES FOR FY 1994		
IV	WEST PALM BEACH		$316,440
VIII	DENVER		$500,000
IX	RIVERSIDE - SAN BERNARDINO		-
II	BEGEN-PASSAIC, N.J		$141,301
SUB-TOTAL		6	$816,440
TOTALS		66	$25,404,206

AIDS/HIV and WOMEN
Remarks by Warren W. Buckingham III
before the Junior League of Washington
Washington, DC • September 15, 1993

I am both honored and humbled to be with you this evening. I'm honored to have the opportunity to accept your invitation to Kristine Gebbie, the nation's first "AIDS Czar", to speak to you about one of the most complex health, social, and human care dilemmas this nation has faced, and I'm humbled by the history of the Junior League in performing simple acts of mercy for the most fragile and forgotten members of the human family. Some Leagues across the country have just begun their response to HIV and AIDS, while others have been about it for several years. Wherever this League is, or wherever you may personally be on the journey of responding to AIDS, I salute your commitment and plead with you to do more.

I'm sorry for you that my boss wasn't able to accept your invitation, but I'm happy for me. I've been working with members of the Junior League, both in Dallas and at the national headquarters, for nearly fifteen years -- which I think will qualify me for Sustainer status soon. It's been too long a time since I visited a League event, so thank you for this opportunity to get reconnected.

Why are we here this evening? We're here because HIV and AIDS have long since ceased to be a man's disease -- specifically a gay man's disease; or a drug-addict's disease. It increasingly affects women -- young

women -- and it is a disease which can, and if we don't change both policies and behaviors, which <u>will</u> affect every human being on the face of the earth. Your League has put together a diverse panel

- to help you appreciate the personal impact of HIV and AIDS,

- to learn about behaviors which can minimize your risk for infection, and

- to hear about the impact of AIDS on women in the full scope of this pandemic, and some words about the future.

(That last bit is me, in case you'd wondered.) And I'd like to start by reminding you of the magnitude of the problem we're facing. When I started my career in AIDS work eight years ago, 541 women had been diagnosed with AIDS in the United States, and fewer than ten of them were residents of the D.C. area. As of June 30th of this year, 38,914 women have been diagnosed with AIDS. 12,372 of those women -- nearly one-third of the total over the last twelve <u>years</u> -- were diagnosed in the twelve **<u>months</u>** between July 1992 and June 1993. I remember as if it were yesterday the time when women represented less than one percent of AIDS cases, and now they're suddenly over ten percent.

And so you have the full picture, as of June 30th of this year 315,390 men, women and children have been diagnosed with AIDS -- and 194,334 of those brothers and sisters and children and parents of ours' have died.

With that sobering background, let me share my perspective on women in the HIV epidemic thus far -- and let me emphasize that they are my opinions and observations and do not necessarily represent those of Kristine Gebbie or the Administration.

So here's what I think: for too long women with HIV or AIDS have been placed in one of three categories: they have been viewed as **vectors**, as **vessels**, or as **victims**. The people who have laid out those roles for women have tended -- not surprisingly -- to be men; and a lot of them have been wearing white lab coats. And there's something very seriously wrong, and terribly limiting, about each of those ways of defining women. But first, what in the world do I mean by the terms **vectors**, **vessels**, and **victims**?

A **vector** is a pathologist's term -- it's an organism that carries pathogens from one host to another. In the context of AIDS and HIV, it's also a conveniently obtuse way of talking about the transmission problems associated with prostitution, or with trading sex for drugs. Or by any unprotected sexual intercourse, for that matter. By defining women in the HIV epidemic as vectors, many

people have limited their female-focus for the last twelve years to ***how can we get them to stop doing things that put men at risk for HIV infection***? And too many of those people haven't, it seems to me, paid much attention at all to how we can protect **women** from becoming infected in the first place. Thank goodness your League included someone who can help you acquire those skills on the panel this evening.

And what about women as **vessels**? What I mean here is that many of the people working in this epidemic have defined women solely as vehicles of reproduction; as incubators in which unborn children develop; as maternity machines. In this instance, all of the attention focuses on how we prevent perinatal transmission and protect babies from infected mothers. I am not arguing that unborn children should not be carefully protected from HIV infection; I do believe that with all my heart. But I am arguing that they should not be the elemental -- and often exclusive -- focus of health care workers who deal with pregnant women.

Too often, women's privacy is violated when their blood is tested for HIV antibodies without their knowledge or consent because an obstetrician is worried about a high risk pregnancy. Women who are HIV positive and pregnant should know all there is to know about the risk which pregnancy presents to them and to their unborn child; they must also be compassionately helped to plan for

the strong possibility that they will not be alive to raise their child to adulthood. Furthermore, over 29,000 of the 39,000 females diagnosed with AIDS in this country are from communities of color -- and it has been my experience that far too many of the people who provide their care are absolutely un-equipped to deal with the cultural and socio-economic factors which differentiate them from the mainstream.

And that leads me to the notion of women as **victims** in the HIV/AIDS pandemic. I must tell you right off that I have just used the most politically **un**-correct word in the AIDS lexicon, and would caution you against using it in everyday speech. Most adults with AIDS or HIV, and especially gay men, reject the notion of being victimized by this virus because -- among other reasons -- it seems to imply a defeatist attitude.

But having taken the risk of offense, I must press on. My dictionary defines a "victim" as ***one harmed by or made to suffer from an act, circumstance, agency, or condition.*** For most women I know with HIV or AIDS, the answer would be ***all of the above***. That answer would also hold for many, many men with AIDS -- but not quite so universally as it does for women.

Based on my observation, here's what it means to be victimized as women in this epidemic -- and why you want

to do everything in your power to be sure that you, and those you love, never fall victim to AIDS --

- you will have to deal with a clinical trials and research establishment that is nearly completely male-dominated, and which has only recently "noticed" that there was something fundamentally shortsighted about designing protocols which only included men. I couldn't get my hands on the precise statistics, but I'd bet real money that less than ten percent of the people in clinical trials are women; and it's probably less than five percent.

- you will have to cope with a culture that gave you few, if any, behavioral, social, or legal tools to protect yourself from infection -- but which expects you to assume <u>full</u> responsibility for preventing transmission of the virus to others.

- you will have to contend with a public health surveillance system that has had to re-define AIDS three times since the start of the epidemic -- with too much of the motivation for change a result of the un-noticed chilling -- and killing -- differences in the way the virus affects women. And those differences typically took far too long to notice, because women are so much an after-thought of the medical establishment.

- you will likely have to deal with the reality of deciding whether your own health, or the health of your child, is a higher priority. Maternal instincts and societal norms will make you lean toward putting the child first. But if his or her chances for survival are worse than your's, who will be there to support you in deciding to preserve your health for your own life's sake?

- as you pursue care for your multiple ailments -- financial, physical, emotional, or spiritual -- you will be entering "systems" that aren't exactly built around women's needs, much less sick women's needs, and even less around the needs of sick women with sick children.

So by all means -- protect yourself, protect your loved ones, and stay well. Listen carefully to the other speakers on this panel.

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But what does the future hold? I hold on to hope that there is a fourth "V" in this epidemic for all people infected or affected by HIV and AIDS -- and especially for women. My prayer is that we will all be **victors** in the struggle. And where do I get my hope?

- For starters, there's my boss. We finally have a President who isn't afraid of AIDS and was willing to make it a top domestic priority. And then he did himself one better because not only is his choice for our first National AIDS Policy Coordinator a woman, but she's a nurse -- and in my experience nurses have an outlook on life, and systems, and people in need that's more humane and radically different from the men in white lab coats (or the men in thousand dollar suits, for that matter).

- Where else? Well, a critical mass seems to have been reached of empowered women with HIV who are following the example of their activist brothers and demanding that the systems which care for them or which should be protecting them, are doing their jobs in a responsible and effective way the recognizes that we are in the midst of a public health **emergency**.

- I'm hopeful because the CDC AIDS case definition, and the Social Security Administration's definition of AIDS-related disability, are both finally much more responsive to and reflective of the experience of women with HIV and AIDS.

- I have hope because last summer both political parties brought people with AIDS to their podiums to educate themselves and the nation about this pandemic -- and because two of those speakers were women.

- I'm hopeful because of people like my own Mother, who became something of an AIDS activist in her sixties -- not just because of what her son was and was doing, but because she can't stand injustice anywhere she sees it. *And we have had far too much injustice in our response to AIDS.*

- And I'm hopeful because organizations like the Junior League of Washington are realizing that this epidemic is about them and about their members, and that they have a role to play in shaping a responsible and compassionate response to the epidemic.

I'm very sure that there those of you out there who still need to be in denial -- who need to believe that "this can't possibly affect me or my family." I am here tonight to remind you that the human family has AIDS. And that in my experience, the Junior League has always been about the business of lifting up the human family. My friends, <u>your</u> family has AIDS.

In closing, I would like to take a moment of personal indulgence to honor two people who guided and informed my work in AIDS during my years in Dallas, and whose memory comforts -- and confronts -- me every day.

First, my friend Lydia Allen. Lydia was a gifted nurse who worked at the pediatric AIDS demonstration

project in Dallas. She was also the loving mother of Matthew, and the mournful mother of Bryan -- probably the first infant to die of AIDS in the Dallas area, and the soul for whom Bryan's House, a comprehensive care center for children affected by HIV and AIDS, was named. And Lydia was living with AIDS. Lydia gave and gave and gave and gave. To her children, to the community, to other women living with AIDS, to her husband Scott who served on the National Commission on AIDS, and to dozens of children and moms served through the Dallas demonstration project.

Lydia died last year, but her legacy lives on in this room and across the country. When Bryan died, she wrote a book for Matthew (and, I think, for herself) to try to explain the feelings of loss. That book is entitled **I Miss my Baby Brother**. What I need to say this evening is that I miss the bright morningstar who was Lydia. She showed me that "Mother Courage" was more than the name of a play by Bertholt Brecht -- it was a definition.

The second person I need to honor is John Hannon. Some of you may wish I would tell you what you should do about AIDS and HIV and the government's response to it, but I'm an employee of the Executive Branch, and that means I'm subject to pretty stringent restrictions around advocacy. But my friend John wasn't a Fed, and since he died last Fall he can't get into any more trouble anyway. So here's what John thinks you should do.

His advice comes from several years ago when the National Commission on AIDS visited Dallas. Back in those days -- and sometimes still today -- you heard a fair amount of talk about who was innocent and who had gotten what they deserved when AIDS befell them. John Hannon was from the first waves of the epidemic -- he was white. He was gay. He was in recovery. And he was one of the most compassionate and open people I have ever been honored to know.

He came forward to give testimony to the Commission and spoke eloquently of the need to join forces in the biggest, most diverse, most colorful coalition ever to ensure **honest and explicit education to prevent transmission of HIV**, and **research to find effective treatments and a cure**, and **high quality health and supportive services** for every man, woman, and child suffering with AIDS. And he concluded his remarks with the following rebuttal to those who would divide this coalition -- would separate the wheat from the chaff -- and diminish its power. John said --

Like every human being on the face of the Earth
who is infected with HIV,
I am a child with AIDS, for . . .
I am a child of my parents, and
I am a child of God.

What John was suggesting -- no, insisting -- is that each person and organization engaged in AIDS/HIV education or service delivery must guard against the temptation to cast the competition for attention, or sympathy, or limited resources as one that takes place within the HIV community. Or as competition between women and men, between children and adults, between people of color and those who are white, or between organizations that started in the earliest days of the epidemic and those that are just coming to the table.

Rather, John would say, you must join forces with one another -- and with other people and organizations concerned about forgotten, and vulnerable, and hurting people -- to ensure that the pie is large enough so everyone can get what he or she truly needs.