12-17-1991

Hearing on AIDS in Ethnic Minority Communities II: A Reassessment

Senate Committee on Health and Human Services

CALIFORNIA LEGISLATURE

SENATE COMMITTEE ON
HEALTH & HUMAN SERVICES

SENATOR DIANE E. WATSON, CHAIRPERSON

Hearing on

AIDS IN ETHNIC MINORITY COMMUNITIES II: A REASSESSMENT

December 17, 1991
9:30 a.m. - 4:30 p.m.
Museum of Science and Industry
Kinsey Auditorium
Los Angeles, California

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TUESDAY, DECEMBER 17, 1991
9:30 A.M. - 4:30 P.M.
MUSEUM OF SCIENCE AND INDUSTRY
KINSEY AUDITORIUM
700 STATE DRIVE
LOS ANGELES, CA

AGENDA

COMMITTEE ADDRESS

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COMMITTEE SECRETARY

California Legislature

Senate Committee

on

Health and Human Services

A G E N D A

"FUNDING FOR AIDS IN ETHNIC MINORITY COMMUNITIES"

Tuesday, December 17, 1991
9:30 a.m. - 4:30 p.m.

MUSEUM OF SCIENCE AND INDUSTRY
KINSEY AUDITORIUM
700 STATE DRIVE
LOS ANGELES, CA

T E S T I M O N Y

THE FEDERAL, STATE, COUNTY AND CITY PERSPECTIVE

1. Wayne Sauseda, Chief, Office of AIDS, Department of Health Services

2. Jim Kooler Dr. P.H. Deputy Director, Prevention Division, Department of Alcohol and Drug Programs

   Eddie Yamamoto, Program Analyst II

   Askia Abdulmajeed, Deputy Director, Governor's Policy Counsel

3. Alan Harris, AIDS Regional Coordinator, U.S. Public Health Service

4. Bob Frangenberg, Director, AIDS Programs, Los Angeles County Health Department

5. Phil Wilson, AIDS Coordinator, City of Los Angeles

6. Galen Leung, Office of AIDS, City and County of San Francisco

Continued---

HOSPITALS, PHYSICIANS AND CLINICS

7. Reed Tuckson, M.D., President, Drew University of Medicine and Science

8. Wilbert Jordan, M.D., Director, AIDS Program, Martin Luther King Hospital

9. Cleante Stain, Director of the South Los Angeles AIDS Program, Watts Health Foundation

10. Germaine Maisonett, M.D. Director, AIDS Program, California Medical Facility at Vacaville

COMMUNITY-BASED ORGANIZATIONS

11. Rev. Carl Bean (Darryl Judd, Director of Fiscal Management; Barbara Draden, Director of Client Services; Paul Davis, Director of Education; Valarie Taylor, Director of In-Home Nursing Services), Minority AIDS Project

12. Elsie Go-Lu, Ph.D., Deputy Director, Department of Mental Health, Forensics, Los Angeles County

13. Elma Colbert, Women's Outreach Project Coordinator

14. Cynthia Davis, National Organization of Black County Officials

15. Suzie Rodriquez, Director of Drug Abuse Project, Alta Med Hospital

16. Calvin Williams, Health Services, Public Policy Specialist

17. Mario Solis-Marish, AIDS Project Los Angeles

18. Mike Neely, Director, Homeless Outreach Program, (Skidrow)

19. Kazue Shibata, Executive Director, Asian Pacific Health Care Ventures

20. Helen Fitzgerald, PROTOTYPES-WARN PROJECT

21. Joel Tan, Colors United Action Coalition of Los Angeles

22. Corinne Tanon, Health Educator, American Indian Free Clinic

23. Paula Starr, Assistant Executive Director, So. California

PUBLIC TESTIMONY

24. Cleo Manago - Black Men's Exchange

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PRESS RELEASE

SENATOR DIANE E. WATSON

STATE CAPITOL BUILDING / SACRAMENTO, CALIFORNIA 95814
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FOR IMMEDIATE RELEASE
PR-127 Sacto

NEWS RELEASE

AIDS IN ETHNIC-MINORITY COMMUNITIES II: A REASSESSMENT

The Senate Health and Human Services Committee will hold a public hearing on "AIDS in Ethnic-Minority Communities II: A Reassessment" on December 17, 1991, the Committee's Chair, Senator Diane E. Watson, Ph.D. has announced. The hearing scheduled from 9:30-4:30, will be held at the Museum of Science and Industry, Kinsey Auditorium, 700 State Drive.

For many years now, AIDS has been viewed primarily as a white, gay male, disease. Unlike this myth, AIDS has consistently been a disease which has disproportionately affected ethnic-minority communities. In fact, the rate of HIV/AIDS infection in people of color is approximately double the rate of the general population.

It is expected that the numbers of ethnic minorities with HIV/AIDS will continue to increase over the upcoming years. While the white gay community has been fairly well educated about the modes of transmission of the virus and the types of behavior which must be avoided; the same cannot be said about California's ethnic minorities.

According to the National Minority AIDS Council: "If allowed to continue unchecked, disease and death from AIDS in minority communities will continue to mount into the next century; the social and economic impact of this projected loss to minority communities is almost incalculable."

Continued---

The Senate Health and Human Services Committee will study the amount allocated for AIDS research, treatment, prevention, education and outreach; the manner in which funding is allocated on a federal, state and county level; how and why AIDS is spreading at such an alarming rate; and measures to improve the quality of life for HIV/AIDS victims, their families and our communities. The committee will hear testimony from AIDS experts, such as physicians, educators, health workers and various organizations about the recommended ways to increase the state's role in slowing or halting the transmission of the virus.

"We know that we must improve our outreach efforts to reach people with basic information about stopping the spread of HIV and AIDS," Senator Watson said. She recommended, Monogamous relationships, regular use of condoms, and refusal to share needles would dramatically reduce the incidence of AIDS. We as policymakers are taking a leading effort in letting people know about the prevention behaviors that people should adopt to put themselves at much lower risk of getting AIDS."

The hearing will be open to the public.

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RELATED LEGISLATION

HIV/AIDS BILLS THAT HAVE BEEN AUTHORED BY SENATOR DIANE E. WATSON 1989-1991

Measure Number	Topic
SB 99	Re-authorization of Proposition 99 Funds
SB 964	Alcohol and Drug Abuse: Pregnant Women
SB 174	Increase Reimbursement Rates: Hospital Care
SB 402	AIDS Program Contracts
SB 403	Information and Education in Family Planning Clinics
SB 404	Health Care: Hospice Programs
SB 1829	Needle Exchange Program
SB 2866	Alcohol and Drug Allocation Methodology Formula

OPENING STATEMENT

"AIDS IN ETHNIC MINORITY COMMUNITIES II: A REASSESSMENT"

TUESDAY, DECEMBER 17, 1991

9:30 A.M. -- 4:30 P.M.

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700 STATE DRIVE

LOS ANGELES, CA

OPENING STATEMENT

SENATOR DIANE E. WATSON

GOOD MORNING AND WELCOME TO OUR STATEWIDE INTERIM HEARING ENTITLED "AIDS IN ETHNIC MINORITY COMMUNITIES II: A REASSESSMENT." THIS HEARING IS SPONSORED BY THE SENATE HEALTH AND HUMAN SERVICES COMMITTEE. TODAY, WE ARE GOING TO HEAR TESTIMONY FROM MANY EXPERTS ON THE HUMAN IMMUNODEFICIENCY VIRUS (HIV) AND THE ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS), ON COMMUNITY OUTREACH TO PERSONS OF COLOR WHO HAVE BEEN EXPOSED TO AIDS OR WHO ARE AT RISK OF EXPOSURE, AND MOST IMPORTANTLY FUNDING FOR THIS DISEASE (FROM PREVENTION AND EDUCATION TO RESEARCH AND TREATMENT TO LONG-TERM CARE AND HOSPICE CARE).

CONTINUED---

IN 1987 (APPROXIMATELY 4 YEARS AGO), THE COMMITTEE SPONSORED A SIMILAR STATEWIDE HEARING IN WHICH WE HEARD TESTIMONY FROM EXPERTS ON THE MANY ISSUES THAT CONFRONT OUR COMMUNITIES. SINCE THAT TIME, OUR STATE HAS SEEN AN INCREASE IN THE NUMBER OF REPORTED AIDS CASES IN ETHNIC MINORITY COMMUNITIES. UNFORTUNATELY, THE RATE OF GROWTH IN THESE COMMUNITIES IS CAUSE FOR ALARM IN CALIFORNIA. FOR EXAMPLE, ALTHOUGH AFRICAN-AMERICANS REPRESENT 24% OF THOSE WHO HAVE BEEN DIAGNOSED WITH AIDS, AND HISPANICS REPRESENT 14%, THIS RATE IS GREATER THAN THEIR OVERALL PROPORTION IN THE COMMUNITY (12% AND 6% RESPECTIVELY). MOREOVER, AFRICAN-AMERICANS ARE THREE TIMES MORE LIKELY TO HAVE CONTRACTED AIDS THAN WHITES. THE STATE OFFICE OF AIDS AND OTHER AIDS ORGANIZATIONS, WILL PRESENT DATA ON THIS GROWTH DURING THEIR TESTIMONY.

OUR AGENDA IS ORGANIZED INTO SEVERAL SECTIONS, BEGINNING WITH STATE AND LOCAL GOVERNMENT PERSPECTIVES, TESTIMONY FROM HEALTH CARE PROVIDERS AND RESEARCHERS, FOLLOWED BY OBSERVATIONS FROM COMMUNITY-BASED AIDS AND ETHNIC MINORITY ORGANIZATIONS. IN ADDITION TO OUR OVERALL GOAL, WHICH IS TO LEARN MORE ABOUT THIS DISEASE

CONTINUED---

IN ORDER THAT WE MAY BETTER SERVE HUMANKIND, THE COMMITTEE AND PARTICULARLY MY OFFICE, ALONG WITH MEMBERS OF THE SENATE LEADERSHIP, AND OTHERS WILL BE DEVELOPING A MAJOR LEGISLATIVE PACKAGE (THAT WILL BE INTRODUCED NEXT SESSION)ON AIDS. THIS HEARING WILL SIGNIFICANTLY CONTRIBUTE TO THESE MEASURES.

IF TIME PERMITS, AFTER OUR EXTENSIVE AGENDA, WE MAY BE ABLE TO HEAR ADDITIONAL TESTIMONY FROM THOSE NOT ON THE AGENDA. IF WE RUN OUT OF TIME, WE WILL INCLUDE IN THE TRANSCRIPT ANY WRITTEN TESTIMONY THAT IS SENT TO US WITHIN THE NEXT TWO WEEKS.

AGAIN, WE APPRECIATE YOUR ATTENDANCE AT THIS HEARING, AND ANTICIPATE LEARNING MUCH MORE ABOUT THE EXTENT OF THE PROBLEMS AND ISSUES ASSOCIATED WITH HIV AND AIDS THAT CONFRONT ETHNIC MINORITY COMMUNITIES. LASTLY, MAY I TAKE THIS OPPORTUNITY TO WISH EACH OF YOU HERE TODAY AND YOUR LOVED ONES, HAPPY HOLIDAYS!

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TRANSCRIPT

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DR. LENORE TATE: We're going to go ahead and begin. Senator Watson and possibly other members of the committee should be coming in momentarily. But because we have such a long and extensive agenda, I think it would be best for us to begin.

Let me say that all your testimony will be recorded, and all the committee members of the Health and Human Services Committee of the Senate will review this recording, as well as all written testimony. But because our agenda is so extensive, Senator Watson has said we would like to start as an unofficial subcommittee. And so with that, let me just say that basically we're going to go in the order of the agenda. I think most of you have the agenda. If time permits, towards the end of our hearing, we will allow for testimony from other people in the audience.

So at this time, I would just like to begin with Mr. Wayne Sauseda who is the Director of the Office of AIDS for the State of California.

Mr. Sauseda. Is he here?

MR. WAYNE E. SAUSEDA: Yes, I'm here.

DR. TATE: Okay.

MR. SAUSEDA: Good morning. My name is Wayne Sauseda. I'm the Chief of the State Office of AIDS for the State of California.

Dr. Tate and members of the audience, on behalf of the Department of Health Services, thank you for the opportunity to discuss the state's AIDS program today. During my testimony, I'm going to overview the programs administered by the State Office of AIDS, to set in context the discussion of epidemiologic trends, and also discuss state funding for education and prevention, testing, care and treatment, and research.

You have my written testimony. I believe that there are three copies of it on the table there in a black binder. I'm going to, for purposes of brevity, as well as -- some of this information is somewhat dry in nature -- I'm going to abbreviate some of my comments. But certainly the written testimony there is provided for the record.

DR. TATE: Thank you.

MR. SAUSEDA: As an overview of the Office of AIDS, the objective of our office is to provide information and education, testing, epidemiological investigation and surveillance, research, and treatment to address the public health problems resulting from Acquired Immune Deficiency Syndrome.

The Office of AIDS provides a complete AIDS-case registry. It provides educational information for high-risk groups, health professionals and the public, and policy direction and development of pilot projects for the care of people with AIDS and early intervention of projects to provide services to HIV-infected persons.

Additionally, the office conducts surveillance activities to identify risk groups and patterns of transmission and epidemiology for selected cases. The office also administers a program which tests for the antibody to the AIDS virus at over 100 alternative test sites, which are free and anonymous. In addition to that, we provide a substantial amount of HIV testing and confidential test sites which number over 450 throughout the State of California.

Local assistance block grants are also provided to local agencies for AIDS, epidemiological investigation and surveillance.

I'd like to comment briefly on five significant legislative measures which were passed by the California State Legislature and signed by Governor Wilson. These measures reflect the Governor's commitment to prevention, patients' rights, integration of services, and expanded access to health care.

To begin with, AB 11, authored by Assemblywoman Hughes, which is AIDS In-School Education, beginning with the 1992-93 school year, instruction for the prevention of AIDS will be provided by trained teachers to students in grades 7-12, at least once in junior high or middle school, and once in high school.

AB 11 fits into the current California Department of Education Healthy Kids/Healthy California Project which is funded by the Office of AIDS to provide training to teachers and school administrators on providing instruction on HIV transmission to students in the 7th and 8th grades as well as high schools.

Studies on youth have shown increases in drug use and sexually transmitted diseases, which are major co-factors for HIV infection. Surveys on youth out of mainstream schools indicate that nearly all of their health and HIV- and AIDS-related knowledge and information was obtained from their school experiences.

SB 1070 was authored by Senator Thompson, known as the Patient Protection Act of 1991. This is a measure that deals with HIV-infected health care workers. It requires the Department of Health Services to develop written guidelines and regulations as necessary to minimize the risk of transmission of blood-borne infectious diseases from health care worker to patient, from patient to patient, and from patient to health care worker. SB 1070 reinforces the Department of Health Services' leadership role in establishing consensus-based recommendations for the prevention of transmission of HIV and Hepatitis B virus between health care workers and patients.

There are three other bills I'll briefly describe. One is AB 305 authored by Assemblyman Friedman. It redefines the term chronic, life-threatening illness to mean HIV disease or AIDS. It also provides that the Department of Health Services may provide supplemental funding to residential AIDS shelters and to residential care facilities.

AB 1281 authored by Assemblymember Filante updates current law prohibiting the use of HIV antibody blood tests as a prerequisite for determining eligibility for health insurance.

AB 1287 authored by Assemblymember and Chairman of the Assembly Ways and Means Committee, John Vasconcellos, with respect to HIV test disclosure, ensures that those individuals who are involved with HIV -- or AIDS -- vaccine clinical trials as a volunteer who test HIV antibody positive or negative as a result of their participation in those clinical trials -- will not be denied health care, disability, welfare, or life insurance coverage.

One other item I'd like to highlight for you is this last November, the Office of AIDS, in keeping with its theme of prevention, secondary and tertiary prevention, also was successful in expanding the AIDS drug program Formulary. Previously, the AIDS drug program consisted of two drugs only. We added an additional 11 drugs, and we also are now the largest state AIDS drug program in the United States.

California's contribution in state funds is $9.1 million which also is the largest state contribution of any other state in the United States.

I'm going to briefly go to epidemiology. To place my testimony into perspective, I'd like to give some information about the scope and course of the AIDS epidemic in the state and Los Angeles County. As indicated, I'm going to abbreviate some of my comments in this section particularly.

As of November 30, 1991, 38,660 cumulative cases of AIDS and 26,369 AIDS-related deaths have been reported in California. As of this date, Los Angeles County has reported 13,672 cases of AIDS; and deaths totaled 9,576. Statewide, during the most recent 12-month period, 7,683 new cases were diagnosed; and 6,036 deaths were reported. An average of 640 new AIDS cases were diagnosed and 503 AIDS-related deaths reported each month.

There are an estimated 12,500 Californians living with AIDS at the end of 1990. At the end of 1993, two short years from now, there will be an estimated 16,200 people alive with an AIDS diagnosis.

The incidence of AIDS continues to increase in all ethnic and racial groups within the state. Of the cumulative total AIDS cases reported in California through this past June 1991, whites have accounted for 71 percent of the total;

African Americans, 13 percent; Latinos, 14 percent; and Asian/Pacific Islanders, 2 percent. In contrast to statewide racial and ethnic distributions, 62 percent of AIDS cases reported in Los Angeles County -- again, that's compared to a statewide total of 71 percent in Los Angeles County -- 62 percent have been among whites, 16 percent among African Americans, 19 percent among Latinos, and 1 percent among Asian/Pacific Islanders.

Between 1986 and 1991, you can see a very dramatic shift in the proportion of AIDS cases reported among whites in California decreased from 77 percent to 65 percent. Conversely, among African Americans, the percentage of new cases increased from 10 percent in 1986 to 14 percent in 1991. Latinos accounted for 11 percent of new cases reported in 1986 and now represent 18 percent in 1991. The percentage of new cases reported among Asian/Pacific Islanders also increased from 1 percent in 1986 to 2 percent in 1991.

The proportion of new AIDS cases among different transmission categories, however, has remained relatively stable over time. The majority of new AIDS cases continue to be reported among gay and bisexual males. Approximately 83 percent of California AIDS cases diagnosed in 1991 were among this group. Cumulatively, nearly nine out of every ten California AIDS cases have been diagnosed among gay and bisexual men.

The number of cases attributable to heterosexual injection drug use continues to increase. Nearly 1,250, over half, of the 2,211 cases in this transmission category, that of heterosexual injection drug use, have been reported in just the last two years. Notably, African Americans account for 12 percent cumulatively of all AIDS cases in California, but 40 percent of all cases among injection drug users.

The number of new cases attributable to heterosexual contact with an infected person also continues to increase. As of November 30, a total of 702 AIDS cases have been reported among persons who cite heterosexual contact as their primary risk for infection. More than half of the reported cases have been diagnosed in the past two years. To date, 204 cases of AIDS have diagnosed among hemophiliacs; 802 cases have been diagnosed among transfusion recipients.

Children, 258 AIDS cases diagnosed among children in California being evenly distributed among white, 34 percent of those cases; African American, 29 percent; and Hispanic, 33 percent. Because of under-reporting and mis-diagnosis, the actual number of children with AIDS may be as much as 50 percent higher.

We estimate that there are currently 146,000 Californians living with HIV infection in California in 1990. An estimated 83 percent of the people are gay or bisexual men; 9 percent are heterosexual injection drug usuers; 2 percent are women

infected through heterosexual transmission; and 6 percent transfusion recipients, hemophiliacs, men infected through heterosexual transmission, or infants infected perinatally or vertical transmission.

The National Centers for Disease Control estimate that at least 40,000 new HIV infections occur each year nationally. This could imply that as many as 8,000 new HIV infections occur each year in California. An estimated 100-150 new infections occurred annually in newborns as a result of perinatal HIV transmission in 1988 and in 1989.

We estimate that AIDS cases will continue to increase through 1993, 9,700 in 1993. And by 1993, the cumulative number of AIDS cases diagnosed in California -- recall that currently we have an AIDS case of a cumulative total of 38,000, that by the end of 1993, without any changes in the CDC definition of the AIDS cases, that there will be as many as 68,000 individuals in California with an AIDS diagnosis or have -- excuse me. I should say that there will be as many as 68,000 cumulative AIDS cases reported in California.

I'd like to move quickly now -- yes.

DR. TATE: Yes. Cumulative. So are you saying from the time that the state started collecting data, the numbers -- so from what? 1981 or...

MR. SAUSEDA: From 1981 till now, there have been a diagnose and reported 38,000 cases of AIDS in California. By the end of 1993, what we've seen in the first ten years we will see again within two years; and we'll reach, we're estimating, 69,000 cases of AIDS...

DR. TATE: And then out of -- so that's basically almost double?

MR. SAUSEDA: Almost double within the next two years.

DR. TATE: Has your office at all looked at what types of people will be acquiring the disease though? Will it still look similar to the way it is now?

MR. SAUSEDA: The epidemic is changing. We're seeing -- although I've indicated in my testimony previously, we're seeing the cumulative number of cases being relatively stable among different transmission categories. We are, however -- and that's because of the sheer volume of numbers early on in the epidemic -- we are seeing the increased numbers being reported among heterosexual injection drug users and also heterosexual, either through heterosexual injection drug -- excuse me -- injection drug use or heterosexual contact as a means of transmission. That increase is particularly increasing in communities of color.

DR. TATE: Thank you.

MR. SAUSEDA: With respect to state AIDS funding, the funding for AIDS programs administered by the state -- and I should qualify that by saying that there is direct funding that's provided to certain localities within the State of

California, including the major metropolitan areas of San Diego, San Francisco, and Los Angeles. But of the funds that are administered through the state, that totals $124.6 million for 1991-92, the current fiscal year. Of this amount, $76.6 million represents state funds, and $48 million are federal funds. And there are some attachments that provide some graphic representation of that.

Funding for education and prevention projects began during fiscal year 1983-84. At that time, $450,000 was available. Since then, the education and prevention budget has grown to $16 million for 1991-92. While the specific numbers of clients served are unavailable at the moment, the numbers of education and prevention contractors increased from 15 in 1983-84 to 137 in fiscal year 1991-92.

The Office of AIDS began distinguishing between education and prevention services to minorities and other groups during fiscal year 1988-89. During that fiscal year, the total education prevention budget was $16 million, as it is today, of which 38 percent was targeted for minority projects. In fiscal year 1991-92, the amount available again is $16 million. Of the 137 contractors funded, 52 percent are from minority-owned and/or serve more than 50 percent minority populations.

State-funded HIV antibody testing is provided through various sources in the state. Free and anonymous testing is provided through the alternative test site, also known as the Anonymous Test Site program. Additionally, confidential HIV testing is provided through various county primary care clinics and other free-standing community primary care clinics, such as family planning clinics, rural and community health clinics, and the State Department of Alcohol and Drug program administered testing sites.

Of all testing and counseling services provided during January-December 1990, that is, calendar year 1990, 25 percent of the services were received by Latinos; and 13 percent were received by African Americans.

The testing program is also conducting an outreach campaign to provide information on testing and the services available to the public. Of the $300,000 earmarked for this campaign, one-third is being used in the Latino community, and one-third is being used in the African American community.

I might comment briefly that this past year, as part of our campaign for testing, we ran, in certain parts of the states, including Los Angeles, a testing campaign. As a result of that, and we recognized that there was a substantial increase in testing, we were able to measure it before the campaign started with testing activity at testing sites in those locations of the testing campaign. And as early as October, we noticed a tremendous increase in testing. Since that time, of course, the disclosure by Earvin Magic Johnson has further driven up demand for

HIV testing services. I believe in Los Angeles County, I understand that what was a two-week waiting period at one time instantly turned into a two-month waiting time for HIV-tested services. Many testing sites were faced with the prospect of running out of funds for testing, turning away people who sought to find out their HIV status, people who might not otherwise have presented for a test.

We have gained the support of Dr. Coye, the Director of the Department of Health Services, and Mr. Russ Gould, the Secretary for Health and Welfare Agency, to push forward for increased funding for the testing program to ensure that people who are interested and who have examined their behaviors and believe that they have a reason to test are provided the opportunity to find out their HIV test status.

The Early Intervention Program provides behavior change interventions, psychosocial support, health education, case management services, and early medical assessment and treatment to HIV-infected persons. The goal of the program is to prolong the healthy and productive lives of those infected with HIV. Statewide, 22 percent of the EIP, or Early Intervention Program, clients are Latino; and 11 percent are African American. These percentages are even higher at some locations, such as the Early Intervention Program in San Francisco where 52 percent of the clients are Latino and South/South-Central Los Angeles where 49 percent are African American. The total funding for the Early Intervention Program is $2.6 million.

Pilot care and home and community-based care projects began in 1985-86. At the time, the budget was $1.6 million. Since then, the budget is now $6.6 million. The Pilot Care Prject Program has officially targeted 25 percent of their funds for services to minorities; however, the actual percentage has been over 35 percent since fiscal year 1988-89.

There are a number of projects throughout the state which our office funds addressing ethnic minority groups, including Latinos, African Americans, Asian/Pacific Islanders, and American Indians. All minority-based projects provide education and materials in the target groups' native language with a special emphasis on cultural values. Some examples -- I'll pass over this -- identified in my testimony -- certain examples of AIDS-funded minority projects, including the Minority AIDS Project, or MAP, in Los Angeles, as well as others in Los Angeles and other parts of the state.

I'd like to comment briefly on other Office of AIDS' efforts. The Office of AIDS began working last fall to develop a comprehensive plan in response to the Ryan White Comprehensive AIDS Resources Emergency -- or CARE -- Act of 1990. As a result of that, we sought to include a very representative working group to advise the state on the appropriate allocation of resources. Fifty percent of that working group, representing a very geographic distribution, was represented by

communities of color on that working group. Also, as part of the development of the formula, we identified eight factors that would impact how the formula would actually translate into services in a local community. In recognition of the impact that HIV and AIDS has taken into communities of color, one of the factors, weighted at 20 percent of the total, was a non-white index factor.

The Minority AIDS Resource Center is a program funded by the Office of AIDS providing information, training, and technical assistance to our education and prevention contractors. It includes a library, a computer database, bulk literature, and a resource guide.

The Office of AIDS also provided funding to Multicultural Training Resource Center in sponsoring multicultural AIDS consensus and collaboration workshops. The participants are Office of AIDS contractors currently providing direct education and prevention client services.

The purpose of the workshops is to discuss barriers and find solutions to providing quality and education and prevention services to minority communities. Workshops focus on barriers as they pertain to rural, urban, communited-based organizations, and health department issues.

The Office of AIDS also provided funding for a statewide "People of Color" conference this past summer of 1991 with the goal of improving the survivability, a very real issue, for service providers in minority-based communities and focusing on strategies to improve outreach and prevention activities to ethnic minority populations. At the conference, the group elected representatives to serve on the newly formed Office of AIDS Multicultural Liaison Board. This elected group, which is composed of 12 members, 3 each from the major ethnic racial minority groups -- African American, Latino, Asian/Pacific Islander, and Native American -- will serve as an effective and important liaison between the Office of AIDS and multicultural providers and community.

Before I conclude with my remarks, I'd like to comment on another issue which impacts on the issue of survivability of service providers. The Department of Health Services this past year, because of budget reductions, reduced over 500 positions in its department. It would equate roughly to about one of every five positions that are state funded. The Office of AIDS took a commensurate cut. One of every five positions state funded were reduced from the budget.

In order to try to continue to provide funding in a geographically balanced way, the contractors were reduced also in local assistance because of the trigger reduction, because of the state budget crisis.

The problem has occurred, however, that because of the department's cuts, because of the threat of potential layoffs, the department is also, as many

positions that are unfunded in the Office of AIDS alone, we see after our budget cuts, we still have a 40 percent vacancy rate overall which is having a very dramatic impact on those contractors and providers in the community we work with.

From a department-wide perspective, it also means that contracts are slowing down, that payments to providers are slow, slower than is reasonably to be expected. And that threatens very seriously the survivability of community-based organizations, many of whom do not have the financial resources to float the money necessary to provide periods of service, sometimes long periods of service, without reimbursement. Dr. Coye has convened eight of her top managers who have experience in both programmatic issues, as well as very expert knowledge of administrative practices, both at department level, as well as control agency levels. I'm fortunate enough, in representing the Office of AIDS, to be one of those eight individuals selected by Dr. Coye.

The purpose of this -- the objective of this group is to try to streamline the contractive process, to try to expedite the invoice processing, and reimburse our providers in the community who, without whose support, without that infrastructure out there, the services to communities simply would not take place.

We have a commitment to our providers. We are going through a difficult period of time because of the state budget process. Dr. Coy and our office, as well as other offices in the Department of Health Services, are very committed to correcting what we believe to be currently an intolerable situation.

In closing, the Office of AIDS is committed to stopping the AIDS epidemic in all parts of California, particularly in communities of color. We recognize that this must be done, not in isolation, but in concert with a comprehensive approach to addressing overall health care issues and needs.

I'd like to thank you for this opportunity to appear before you today. I'm available to answer questions from the audience.

CHAIRPERSON DIANE E. WATSON: I want to thank you, Mr. Sauseda, for coming here and giving us this comprehensive update on what the Office of AIDS is doing. I want to apologize to the office for being tardy, but we were on another issue as epidemic as AIDS is, and that was breast cancer; and we had to be out at UCLA for that.

I think that you probably have addressed many of the concerns that I have, but I'd like to fine-tune some of them. First, I'm concerned about the amount of dollars that has been targeted into minority communities. You did give us the exact amount. I'd like to know what the department can do in terms of limited funds to address the growing need, particularly among African Americans and Latinos, of AIDS. The Minority AIDS Project sits in my district, and we've been

working closely with them for several years now.

There is some lack of immediate response to the pain of their claims. Since Magic Johnson made his announcement, they were getting thousands of calls per week asking for testing. Now because it is a community-based organization that grew out of the grass roots, the expertise to fill out the forms, the way the Department of Health would require them, and the ongoing expertise to be able to handle the paperwork within your framework is sometime, most oftentimes, very difficult. But these are serving the people and they're serving the need.

Can you respond to what the Office of AIDS can do, and I know 500 positions have been cut. But can you respond to what they can do to get the funds to them in a timely fashion, to keep those doors open, in spite of the paperwork, and what kind of commitment will be made in the year '93, or 92-93, to MAP and other organizations like it. It's not the only one suffering from lack of funding, but they all have the high-risk community of major concern. How can you help?

MR. SAUSEDA: I agree with, Senator, agree with you completely. Even before the budget reductions, I think that the contracting process and the invoice, or reimbursement process, was slow. Minority organizations and other small community-based organizations don't have the resources to effectively front the money for services that are being contracted in good faith by those organizations on behalf of the state.

In our office, one of the things that we've done just recently, because it did reach an intolerable perspective, proportions, although we could not recruit individuals into our office because of the threat of overall layoff, we did provide additional resources to the department's accounting office directly, devoted exclusively for our contractors. Now that doesn't solve the problem for other contractors outside of AIDS contractors. It did for us, and that was our commitment to our contractors. And I do have a chronology of what occurred in the invoicing process or the contract process for the Minority AIDS Project. But it is a very prime example of what was occurring. We've now made the resources available to both our contact management section of the Department of Health Services, as well as the county section, to expedite our claims, our contracts, to ensure that we can now work for the State Controller's Office who are also a key, a player in the process, to get the funds out to community organizations.

An overall issue that the department is addressing currently is that of categorical programs. We have a tremendous number of vertical programs within the state. One contractor may have several contracts with the state and subject to many different rules and regulations and payment timetables. What we're looking at is some way of being able to minimize administrative burden that places on

contractors, to try to remove, to truly try to identify those things we need to have to be accountable as a public steward of funds and those things that we really don't need to have that only serve as barriers to providers who have spent an inordinate amount of time on administrative paperwork instead of delivering the services. So we're taking a very hard look at that. I hope to draw from the, benefit from the expertise of those providers in reworking our RFP process -- let me digress for a moment.

This last year, it's still not perfect, but our RFP process, or Request For Proposal process, for education and prevention projects was tremendously streamlined. It's going to get better next year -- excuse me. Next year, we're not going to -- in fact, next year -- it got better already. We didn't do one. In years out, we have established an education and prevention evaluation group who's looking at the relative success of education prevention efforts but who is also looking at different ways of getting money out to the community, ways that are less cumbersome, ways that are less time consuming, and ways that do not just impose or interject barriers to the provision of service.

CHAIRPERSON WATSON: I appreciate that response, and I have a lot more faith and confidence in the Department of Health Services now that Dr. Molly Coye is at the head; and we've worked together on other projects, and we will work together in the near future.

I'm pleased to know that you're looking at the obstacles in the way. I think there's too much bureaucracy. I think the need is documented over and over again, and I would hope that we would find some way to provide contractors with resources without all the paperwork because of the need. If these community-based, grassroots projects have to close down, who's going to serve those in need? County hospitals can't do it; public health can't do it. Those programs that you've listed here, and I do appreciate your summary, are those that are fashioned to serve that particular clientele; and we've got to give them the support. I've got to call all the time to help MAP and other programs to get their funding. And they're having to turn people away. There are people dying in their homes without the kind of care that they can give them through some of these programs. So whatever you can do to strengthen that effort, we would appreciate it.

Let me go and backtrack over some of the things that you had mentioned. I'm concerned about what the department is doing on promoting information about safe behavior for our youngsters. Now we have battled in the legislature, as you know, over the years trying to implant in the educational system a program that would follow the child through primary, elementary, the middle, and the senior high school, somewhat to very little avail, because of the resistance we get on the

outside. But how are you planning to promote a safe sexual behavior and about the way to ensure protection against the HIV virus, and how it's transmitted? What are you going to do as a department?

MR. SAUSEDA: Let me first, and in responding to that question, indicate that this, of course, is a tremendous issue of need. In the past legislative measures that would discuss HIV and AIDS within the public education system failed. They were -- they didn't failed passage in the Legislature. They failed signature. This year...

CHAIRPERSON WATSON: Let me just interject this here --

MR. SAUSEDA: Certainly.

CHAIRPERSON WATSON: -- because we're talking about strategy now because I know where the policies are made. So I want to talk with you about how we do it.

Would you be willing through the department, your unit, the department, Molly Coye, to sit down with the Governor and talk about the need to train our youngsters? I don't think any sex is safe. We talk about abstinence -- is that realistic? But we ought to have a strategy worked out from the Office of AIDS, the Department of Health Services, to the executive branch. We in the legislative branch will do our role and play our part, me in particular. That's how we're holding the hearing. But I think more effective and putting more clout and force behind it would be for your department, your unit, working with the administrative executive branch, saying we've got to do it. There's no reason why youth should be contracting AIDS. They understand the risks they're under. We need help because you know where it's been blocked. So I think that approach, if you feel, could be feasible.

MR. SAUSEDA: Let me just say that there's no question as to the willingness of the department to do that. Dr. Coye this last year, let's say, cycle, talked to the Governor personally on four measures.

One of those measures was Assembly Bill 11 authored by Assemblywoman Hughes, that provides for education in schools for HIV. She strongly supported that with the Governor. We worked with the Department of Education, shepherd the bill through, joining not only the executive branch, of course, but the superintendent of education. We joined forces together in helping to secure passage of that bill. Dr. Coye is very committed to that; we are committed to that in the Office of AIDS. We recently negotiated a memorandum of understanding between our office and department and the State Department of Education to ensure in fact that students in school and teachers who are very critical to this process are trained in HIV and AIDS effectively to educate our students in school at an early age.

It's very clear from the information that we've seen and the number of

individuals who are diagnosed with AIDS who incur their infection as a teenager, particularly those people who are homeless -- excuse me -- I should say the homeless youth or out-of-mainstream youth, those who are runaways, or also some are considered throwaways -- that most of these individuals receive their health education in school before the eighth grade. So that very clearly points out the fact that if this particularly at-risk population of young people are going to get the message, it has to occur at an early stage.

CHAIRPERSON WATSON: Right. Let me respond to a strategic point. You went to the Governor on a specific piece of legislation. What happens there is that you've got provisions in that piece of legislation upon which the Governor can respond to, well, I don't like this provision or there's not abstinence at the top of the list and so on. What I'm talking about is a philosophy and a strategy attached to that philosophy, going to him and saying, look, let's come out with a position for the State of California as to how we approach AIDS education, outreach, and so on; and then let's go find members to carry legislation. So what we want to do is try to build the attitude in the executive branch, that we've got to do something -- we've got to start early. Why deprive youngsters from the knowledge about their own safety, about sexual practices, about their own biology? Why keep youngsters away from that information? That's the kind of approach that I think might work with Governor Wilson. I do believe he is committed to prevention; he is committed to services for children; and I think if you approach him, not on a particular piece of legislation but on overall philosophy for the state, it might hold some promise.

Let me move on because I don't want to keep you on the hot seat too long. We have other witnesses here.

I'd like to know a little more about the type of set-asides for the ethnic minority providers in terms of outreach. I think what we experience is that the four major ethnic communities -- Latinos, African Americans, Asians, American Indians, and others -- what we find each one of those ethnic categories respond differently, understand the problem differently, or lack the understanding of the problem.

What are you doing in terms of setting aside resources to meet the outreach, the education, the treatment, and so on? Can you briefly...

MR. SAUSEDA: Certainly. This last year, in developing the request for proposals for education prevention and efforts, we for the very first time, and it's hard to imagine but I've got to say that for the first time, the Office of AIDS combined epidemiologic information and targeted those to where we were seen the trends of HIV infection in AIDS-case diagnosis. And our epidemiologic information suggested that there are three primary groups of emphasis, and those

being women of childbearing age, particularly among women in communities of color, those homosexual, bisexual men who are closeted, or not necessarily gay-identified men, and then also adolescent youth. So for the 1991-92 fiscal year, last year, and we developed our RFP, we specifically targeted those three groups of emphasis so that contractors who would be competing for funds and who are on a competitive basis would tailor their proposals very specifically to these three groups of emphasis with specific risk behaviors.

CHAIRPERSON WATSON: How's the RFP drafted to catch the attention of these categorical groups that might come after those funds?

MR. SAUSEDA: It's broadly distributed to existing contractors, as well as through other publications we have through the minority-trained resource center and also through our contract monitors working in different parts of the state. There was also some public notice regarding those, and also within the California AIDS information network. So I believe that there was a substantial distribution of that.

I'd like to further indicate that we very clearly acknowledge that there are barriers to successful education-prevention programs in communities, particularly communities of color.

CHAIRPERSON WATSON: Yeah, let me just interject these things because your explanations are in depth and I appreciate those.

The contract monitors, I don't sense enough real community work. I don't sense that grassroots people understand the risks. In fact, I know they don't. And what really concerns me is how we get into the community by people who reflect the ethnicity of their community, the language patterns, and behavior patterns. That is something I just want to put on your mind if there's a gap. And I know you're trying to do the right things, but it's still coming from a bureaucratic level of how it should be done.

We've got to probably recruit people off the streets, like we do drug addicts and we give them treatment and then we train them to go back and be workers in the community. We've got to get people that live day by day, that experience, and try to get them to talk to like kind.

Look at this room, practically, empty. Everybody in here is an expert. We're talking to each other. What we're saying, we already know. This room ought to be packed. We still haven't found yet the way to reach that particular level.

Dr. Jordan was just in here, but I was appalled when we had a hearing with him. And there was a woman who had three children, was HIV positive, and was HIV positive by diagnosis before she even had the first one. So somewhere we are missing out. And the people who he brought in to talk to us had no clue as to how

they contract this, regardless of what we do on television and the paper and what you do. So I just share these things with you.

We have a serious problem, and I'd like you to get out on the streets; and if you haven't visited these programs, do so. I know I took a bit of Dr. Coye's time when she was trying to spend a day out here in the streets. And I commend that, but you've got to do more of it. And I know we're short-handed. We're all working together to try to solve this problem.

One last question, and you can be very brief, we're hearing, now that there's an increasing number of people acquiring HIV from tattooing and ear piercing, particularly among teenagers and other various youth groups. Can you comment on that? Do you have any evidence of that?

MR. SAUSEDA: In the interest of being brief, I'm going to have to say that we are aware -- we have anecdotal information indicating that needle sharing, not just the injection of drug use, but needle sharing does carry the risk of transmitting HIV.

CHAIRPERSON WATSON: When they use that same needle to do the tattooing, is that what you mean by needle sharing?

MR. SAUSEDA: That's correct; yes, that's correct.

CHAIRPERSON WATSON: Yeah, we better be real clear on that because needle sharing means you're injecting something as we formally have used -- you're injecting something into your veins?

MR. SAUSEDA: Injection.

CHAIRPERSON WATSON: But when we talk about needle sharing, I think you've got to be real specific, saying that needle that they use over and over. They sterilize it, in quotes, but they use it over and over again? That's the needle you're talking about?

MR. SAUSEDA: Right, right.

CHAIRPERSON WATSON: Okay.

MR. SAUSEDA: And that's occuring not only on the street; it's occurring in detention and correctional facilities as well. It's very important that as we communicate needle use, that we don't just stop with, as you've pointed out, injection and drug use, but all needle, or needle-sharing behaviors, including tattooing and ear piercing.

CHAIRPERSON WATSON: Can you do something out of the Office of AIDS that will clarify what we mean by needle use or sharp-instrument use on the skin, of penetrating the skin or in the veins and so on? I think we need to broaden that out.

MR. SAUSEDA: As we develop our material and review our existing material,

we'll keep that in mind.

CHAIRPERSON WATSON: Because I know in prisons, you know, that's the thing to do, and California Youth Authority, the thing to do is come out with all these tattoos meaning you belong to this set or that set or you've been through this experience and so on. Our kids really don't know what they're doing.

So if we can send something to the Department of Education that can at least get this out, whenever you puncture or scratch the skin with a sharp instrument, you're at risk. And particularly where fluids are being exchanged, I think something like that would be a beginning.

One last and final question, audience, to the current speaker, and what is the Office of AIDS' role in ensuring that, and the department's role, ensuring that experimental drugs, will be made available doing clinical trials to low-income persons who might be on Medi-Cal, Medicare, or those who don't have any health coverage at all? That's my final question.

MR. SAUSEDA: That's an area that we've not yet covered, I think, in terms of our efforts, and we're looking at doing that. I believe that one of your witnesses today is going to comment a little bit more specifically about the representation of ethnic and racial minorities in women and children in AIDS clinical trials. I believe Mr. Alan Harris will be covering that.

Let me just conclude my comment by saying that the Department of Health Services does have some research funds, the AIDS vaccine research and the Block Grant Fund, AIDS Vaccine Clinical Trials funding. This, last year, in awarding our contract to CYRON Corporation, for the clinical trials, we made as a stipulation in that contract that they have very aggressive outreach to women and ethnic and racial minority communities as participants in their clinical trials. We are now verified with them -- in fact, it is the role of individuals that they are in fact are aggressively recruiting individuals. It's a very important need, not just because of the vaccine perhaps that they're being studied for but because by and large these research groups gain access to a wider variety of health care, health care that they might not otherwise be able to access, very important resource to the communities.

CHAIRPERSON WATSON: Thank you so much, Mr. Sauseda. We appreciate your in-depth presentation this morning, and we'll be looking forward to the continued work with you and the Department of Health Services.

MR. SAUSEDA: Thank you very much.

CHAIRPERSON WATSON: You're welcome.

I'd like to ask for these three people to come up at the same time. Jim Kooler, Dr. Kooler, is the Deputy Director, Prevention Division, with the

Department of Alcohol and Drug Programs; and Eddie Yamamoto, Program Analyst II; and Askia Abdulmajeed -- is Askia here?

DR. JIM KOOLER: Askia is not with us today.

CHAIRPERSON WATSON: Okay. Fine. Thank you. Dr. Kooler.

DR. KOOLER: Thank you. Good morning. I'm Dr. Jim Kooler, Deputy Director for the Prevention Division for the Department of Alcohol and Drug Programs. And as you mentioned, Eddie Yamamoto is a Program Analyst working on our AIDS/HIV Counselor Program.

You have before you the written testimony. I would like to summarize some points of that for you, specifically around some of the principles by which our operation and our departments work, and that is, to provide a statewide effort, we must be focusing on a partnership of community governments, private and public agencies, and groups of individuals. And the cornerstone of our effort is the California Master Plan, one which you are very supportive of in that developmental process, that our emphasis reflects an awareness that effective policies have to come from local communities, and that we need to honor and respect local communities and counties in their ability to select the programs and policies that did best for them.

Currently, 55 counties have been participating in a Master Planning process, and Los Angeles is one of those counties in Phase VI; and their Master Plan is due to us in June of '92. Thirty-one counties are in Phase I and Phase II. And at this point, of those 31, almost a third of them have focused on HIV and IVDU, Intravenous Drug Use, as priority populations in their community.

In regards to the HIV/AIDS issues, the department formally addressed this first in 1986. And we did that with some emergency regulations which are still in place. The first of those is allowing programs to exceed their capacity by 10 percent when the need is documented. Secondly, upon our approval to waive the requirement that the clients document that they have at least two years of narcotic addiction. And finally, again with our approval, to waive that they must document two unsuccessful attempts of withdrawl and having return back to narcotic use.

By the next year, we started to use our ADMS, Alcohol and Drug (Abuse) and Mental Health Services, dollars specifically targeting again the IVDUs. This process brings money to the counties through the subvention process reflecting our relationship with the counties and the state. Our hope is to give maximum flexibility to the counties in determining the best way in which they can use those dollars while still meeting the federal regulations.

During 1987-88, a total of $5 million was allocated to the counties of which Los Angeles County received nearly $2 million of those.

Currently, 35 percent of the department's total Alcohol and Drug (Abuse) and Mental Health Services' Block Grant is dedicated to drug programs. Half of that is set aside specifically for the IVDU. Right now, the department has over $23 million available for this, a 360 percent increase from just four years prior. And of this, Los Angeles County receives over $8 million or a 300 percent increase since 1987.

In addition to those IVDU set-asides, there are several issues which may bring other funds, versus the AB 1903, the augmentation to the Budget Act of 1988. Currently, there are approximately $1.2 million allocated to counties of which Los Angeles received nearly $400,000. And this money is allocated to those counties which have the highest numbers of AIDS cases.

The next is our HIV/AIDS counselor program which is an inter-agency agreement with the Office of AIDS. We have approximately $1.8 million going to this program to do training for counselors, to do precounseling, to do the tests, and do the post-counseling, allowing clients to access services more readily. This program operates in 20 counties throughout California. Of those populations, approximately 12 percent of the clients are Black, 27 percent Hispanic, and the other 4 percent representing 43 percent of the clients in that program of people of color.

Statewide, we have an AIDS-training program for counselors and people working in the treatment programs to be trained to understand the HIV/AIDS issue. That operates on ADMS funds, approximately $100,000 a year. That program is in its third year, and we're currently doing an RFP to put that out to bid for another three years.

And finally, our Continuation Waiting List Reduction Program, the intent of this grant was to rapidly expand treatment capacity here in California, and that's consistent with the National Commission on AIDS Report earlier this year. Approximately $13 million of continuation funding is available through this program, of which $2 million must be targeted to IVDUs. For this year, Los Angeles received approximately $3.7 of that continuation funding, and $750,000 of that targeted towards IVDUs.

So in closing, the department funds approximately $28,000,000 in programs targeting IVDUs throughout the state, Los Angeles County receiving approximately $9 million of that. For California, that's a 460 percent increase; for Los Angeles, a 450 percent increase. Our department looks forward to continuing to focus on the issue, and I appreciate the questions that you brought up earlier around the youth.

There are some areas in which I think we as a department can participate in bringing information to young people. To those would be through our Club Live or Friday Night Live Program which are intermediate and High School Programs reaching

approximately 1 million high school students, another 750,000 intermediate school students, bringing to the coordinators who work in the 44 counties who provide that program, I think, that we can raise the issue around HIV and AIDS to our young people in ways that have not been done before.

CHAIRPERSON WATSON: Thank you very much. Have you discovered in the 58 counties programs that you feel are effective are doing the job; and if so, can you describe just very briefly what the elements are?

DR. KOOLER: For the elements for the prevention efforts or for the...

CHAIRPERSON WATSON: Yeah, prevention efforts, the outreach programs, those particular efforts reaching ethnic minorities. Do you know of some particularly effective programs throughout the 58 counties?

DR. KOOLER: Well, many of those would be here in Los Angeles, as you've already described. They're effective in working from the grassroots level. Our belief is consistent with yours, that before programs to be effective, they must be based in the community; and they must have people from that community providing those services. I believe that's consistent with our Master Planning process. I personally could not hold up a particular program other than to reinforce the philosophy by which we concur as to how best programs can operate in communities.

CHAIRPERSON WATSON: What do you see the difference between targeting programs, say, to the broad general white male gay community versus the ethnic minority social, lower socioeconomic communities? What's the difference there in approach? Have you been able to figure that out?

DR. KOOLER: The approach must reflect the participation of that community, that we've got to make sure that the people working in those programs are from that community, that they understand the issues there, that programs in different areas were developed to meet the needs of those different areas. So specifically the difference between a white gay male program and a program centered in the black community would have to reflect the differences in those areas. So I could not give you the programmatic differences that we would outline and develop a criteria by which...

CHAIRPERSON WATSON: They'd have to grow out of the efforts?

DR. KOOLER: Out of that community itself.

CHAIRPERSON WATSON: Your opinion now. I carried a bill last year that dealt with needle exchange and allowing a test pilot to do needle exchange. Your opinion as to: (A) Do you think it would go a distance to prevent contracting the spread of AIDS; (B) Is this an effective approach; (C) How do you sell it to the other communities? Opinion.

DR. KOOLER: Thank you. And we are also addressing and doing the research

within our department, along with the Office of AIDS, as to the feasibility of such an effort. The research, I think, is showing effectiveness in reducing the transmission of the disease. So the implementation of that type of program is in the interest of the public health slowing down the transmission of the HIV disease.

The political issue as to whether you are encouraging more drug use by making needles available will continue. The use and the selling of that kind of program to a community is a difficult issue. Some communities will view it as a moral issue and that the drug abuse is the issue that we want to address; and if you're providing needles, you're encouraging drug use. Other communities will say that if you provide the needles, you will slow down the transmission.

In my opinion, we have to fall back into a position of honoring communities' needs and listening to them. I think one of the things that we can look at as a state is getting out of the way of those communities who feel that it is most appropriate for that program to operate in their area. Right now, we don't have that opportunity because of statutes and the availability of needles.

CHAIRPERSON WATSON: I intend to reintroduce that particular bill again. I think even more so, because of the discussion I just had with Mr. Sauseda about sharp instruments scratching the skin, and I think that the -- we know how AIDS is contracted, and we know how it's spreading rapidly and why it's spreading rapidly. We know all that information, we who are enlightened, know it, and we're afraid to enlighten others and to provide a safer way. I guess it's like the condom whole thing.

DR. KOOLER: The condoms at high schools.

CHAIRPERSON WATSON: You're up against these archaic attitudes. I'd like you to start exploring ways of dealing with the community on that issue, also dealing with the Governor on that issue. I don't know if he's going to be a friend on this particular one. But I'd like your department, a preventitive sense, to get real of these people. You know, we've got to come and face reality as we find it on the streets.

I don't care -- you know, those of us on high who make the policy -- many of us don't have a clue. You've got to come down here and face what's going on. And AIDS among, particularly black women, heterosexual women, is epidemic. So...

DR. KOOLER: And listening also to our young people. We have the California Youth Council which is planning a conference. And one of the tracks that they chose themselves was HIV/AIDS. So we will open the doors...

CHAIRPERSON WATSON: You know, if we haven't gotten the word to Magic Johnson, then we're in deep, deep trouble. And I think that we're going to see funding from the athletic associations nationally; because if the thought is in their minds,

like it's in mine that AIDS can spread through their whole team -- and the industry of athletics in this country is like next to the entertainment industry -- they both can be lumped into the same category -- it's entertainment. And the threat of AIDS running through a team, I'm sure, will probably motivate them to share resources with those of us in the public sector. I'm hoping that that will be the case.

But I want to come back again, and I'm going to come back again and again until we can catch the attention of all those people that beat us up with the bible, beat us up with, you know, the morality and the ethics of all this. I'm dealing with science.

DR. KOOLER: From a public health perspective.

CHAIRPERSON WATSON: From a public health perspective. Thank you very much.

DR. KOOLER: Thank you.

CHAIRPERSON WATSON: Yes.

DR. TATE: I just have a very short question. With regards to Friday Night Live, I understand, I think you said, that it reaches over a million high school kids, maybe even more, but most of those kids are Anglo kids, middle-class Anglo kids. What is the department doing to outreach to kids of color or low-income kids for Friday Night Live and those sorts of outreach programs?

DR. KOOLER: A great deal. And the perspective that it's a white middle-class program is reflective of where the program began in 1984. I think, if we take a look at where we are today, there is much more going on in ethnic communities. Here in Los Angeles, just last month, there was an event here at the Palace in Hollywood where they bussed in 1,300 kids from all over Southern California; a tremendous mix of young people had a chance to see Boys to Men. It was Doritos' 25th Anniversery, a great event, mixing young people from all over. So we're doing some good...

DR. TATE: Is the State Department, though, doing any very specific outreach to ethnic minorities to that, you know, for them...

DR. KOOLER: One of the ways that we're doing that is, again, consistent with the Master Planning process, working with the 44 counties, to make them available and doing that kind of outreach because it's not a state-operated program but a locally operated program which we're a partner in. So part of budget language talks about any new programs going specifically into high-risk communities. So we're supportive in encouraging that we focus in those areas.

CHAIRPERSON WATSON: Thank you so much for your testimony. We appreciate it.

DR. KOOLER: Thank you.

CHAIRPERSON WATSON: I'm going to ask for the next four panelists to come up

as a block. First, I'm going to ask Alan Harris, AIDS Regional Coordinator, U.S. Public Health Services; Bob Frangenberg, Director of AIDS Program for for L.A. County Health Department; Phil Wilson, AIDS Coordinator, City of Los Angeles; and Galen Leung who will take the place of Sandra Hernandez, Director of Office of AIDS, City and County of San Francisco.

I'm going to ask that we indulge Mr. Leung because he must leave. So if that panel will come up now, and we'll lead off with Mr. Leung.

Would you repeat your name at the mike, please.

MR. GALEN LEUNG: Yes. My name is Galen Leung. Honorable Chairwoman Watson, Members of the Commmittee, Ladies and Gentlemen, and invited speakers. As I've said, my name is Galen Leung. I've come to testify on behalf of Dr. Sandra Hernandez who's Director of the San Francisco Department of Public Health AIDS Office. Dr. Hernandez sends her regrets but wanted to make the most of this opportunity.

Of all the HIV-related issues facing San Francisco, five stand out.

One. The funding trends for prevention and health-related services has not kept up with the epidemic. Chairwoman Watson, you have alluded to this already. What is of particular concern is the shift of prevention funds to health services thereby cutting funds for behavorial surveys and major prevalent surveys. This comes at a time when prevention efforts must be focused on the most difficult-to-reach populations -- communities of color, injection drug users, youth, men who have sex with men but do not self-identify as gay or bisexual, and last but not least, women.

So basically what I'm saying is that we have very little or no information to guide us as to what kinds of programs, educational messages, prevention messages, what sort of media, how to go about targeting many of the prevention messages that we would like to make, that we have services out there that we've been talking with the communities; but we don't have anything to strongly guide us as to which would be our top priority. We have a million priorities, and we have ten but it becomes problematic. This is of particular concern because of the cutbacks at the Centers for Disease Control.

As you are probably well aware, the Centers for Disease Control reduced funding to contracts through the Office of Minority Health for prevention messages to minority communities. And that had a direct impact in San Francisco and with the Black Coalition on AIDS and several other contracts similar to those. So we are trying to find the resources to make up for the loss of funds there.

Two. The needs of the communities of colors for culturally and linguistically appropriate AIDS services, both prevention and health services, will continue to

grow exponentially while resources remain limited on the national, state, and local levels. All three levels face deficits. And we don't -- we are not optimistic about increased levels of funding, as in the past, in terms of percentage increases, which means we then have to turn around and re-prioritize, re-evaluate; and we are spending as much time as we can possibly do on evaluating and re-evaluating our programs today.

As the epidemic shifts and more people of color are affected, resources will have to shift and providers will need to be trained to serve the HIV-infected individuals in their community. This is basically the focus that we are going toward, to train providers that are in the community, already existing in the community, on HIV, on issues of transmission, on issues of what is available in San Francisco related to early intervention, support services, issues related to death and dying, a whole gamut of issues.

We are fortunate in that many of the providers that have participated in the past are fairly up to date about the latest breaking news. However, this tends to be a little bit more on the technical, medical side as opposed to the let's provide the information and resources to the physicians and other providers as to what is out there in terms of social workers, case managers, support services, et cetera.

This is a stop-gap measure at this point. As the epidemic continues to grow, we will be straining our resources. There will be waiting lists. We are facing that right now. They come and go, and they are in different groups -- or in different communities, I should say. And right now, with the district health centers that the department runs, some of our district health centers do have waiting lists related to HIV-related care and others do not and in fact have some capacity to spare. So we are also looking at re-programming or shifting resources around and trying to accommodate where the demand is as opposed to where the resources are at this point.

DR. TATE: Let me ask you, is there a greater demand -- what communities have the greatest demand and the longest waiting list in San Francisco?

MR. LEUNG: Currently, the greatest demands are still at our district health center number one which serves the Castro/DuBois triangle area. The second greatest demand area is the area served by Western Edition, which is a -- in terms of the number of living cases of AIDS, it's the second highest neighborhood in San Francisco. We curently have about 500 there and we have about 500 -- I'm sorry -- 600 in the Castro/DuBois triangle.

In terms of our capacities, they are in, remarkably enough, in the Chinatown area and Potrero Hill, Bayview, Hunter's Point area. We are not sure if that has to do with marketing, a perception, in other words, that these clinics only provide

a certain kind of service as opposed to the full range of services or if there is possibly -- and I'll address this later -- a stigma attached to going to the local one or going away from your local area and your local provider to a place that is known as a place where HIV is treated and AIDS is addressed.

Three. The twin epidemics of substance abuse and AIDS may intertwine and come up over and over again. But the funding -- this is very important -- the funding must be unlinked in order to provide enough funds or resources for both epidemics.

In San Francisco, the Department of Public Health has drafted a comprehensive plan to prevent transmission of HIV among injection drug users. This plan calls for the involvement of community members, the expansion and enhancement of susbstance abuse treatment services, repealing laws which hinder needle exchange programs, augmentation of activities, and a round needle exchange, like the provision of bleach kids, and providing treatment information, slot information, et cetera, what is available, and referral slips.

The plan also calls for utilizing needle exchange when it is legalized, either as a pilot program, as your bill had proposed, and basically as a bridge to reach two out-of-treatment injection drug users and bring them into treatment or bring them into the system and provide information, whether it be prevention information, treatment information, early intervention information.

Drug treatment on demand is the most effective strategy for reducing HIV infection among injection drug users. However, that costs a lot of money, no doubt about it. Estimates at this point for San Francisco are $30 million in terms of our comprehensive plan. But San Francisco is roughly 700,000 people. It could be, if you tried to expand it statewide, it would be quite a lot of money, no doubt. And we understand this, and so we have in the plan taken -- it calls for -- excuse me. It calls for steps that can be taken right now; for instance, more efficiently utilizing the current slots that are available, identifying them, and making use of them. And we can expand from our current treatment slot capacity of around 3,000 by an extra 400-500 depending upon the numbers of people that we actually do bring into treatment. We currently serve about 6,000 people in treatment. There's an estimated 16,000 injection drug users in San Francisco.

A privately based underground needle exchange program named Prevention Point does exchange around 9,000 needles a week. They estimate that they serve actually around 900 people in that week. So depending upon your estimates, either reach all those people we do not reach in treatment right now through this underground program, or we actually have an extra, let's see, 4,000, 5,000 people left to reach.

Going on with our plan, our comprehensive plan, the department supports a

significant expansion of treatment slots. The resources must be identified for additional treatment slots, no doubt. And because the plan calls for comprehensive, integrated-linked services, it actually does build upon services that are already in place, namely, street outreach, HIV testing, and early intervention services.

Four. Like the National Commission on AIDS, we believe that universal health insurance must be enacted or else the problems of financing that we've seen so far will only double and triple in the next two years. Dr. Sauseda has spoken about how the caseload of AIDS will go up by roughly 30,000 to 35,000 people in the next two years, and most of these people will be living in the next two years; and many of these people will be coming from socioeconomic statuses that are lower than in previous years, and they will have a great impact on Medi-Cal as well as general assistance.

The policies, however, of Medi-Cal, Medicare, and the Social Security Administration for disability will in the next few months actually go into flux. In fact, the announcement today of the Social Security Administration's new policies, it's actually being printed in the register, and they're going through the two months' worth of open-comment period. It's all being driven by the new definition of AIDS, and that new definition is going to strain our resources because we will basically see a doubling in the number of cases of AIDS, defined AIDS, in San Francisco. We're estimated to go from 3,300 current living cases to about 6,000 cases overnight.

So social security and Medi-Cal, Medicare, all have an incentive to redefine their definition of AIDS and who is eligible, not to say that these policies are naturally rational; but this will cause more delays in trying to find resources for people with AIDS. If Medi-Cal does pay for case management for persons, then how do we get them onto Medi-Cal if their definition of AIDS is different from a medical definition, et cetera?

With relation to Medi-Cal and irrational policies, San Francisco does have an example of one that is very unusual. Gangcyclovir is a pharmaceutical product, is reimbursable, if given on an outpatient basis. However, the first two weeks of therapy are normally an inpatient infusion therapy. And because it's inpatient, as opposed to outpatient, you can't get reimbursed; so we're left high and dry. However, if the reimbursement does become available for the outpatient, for the inpatient side, it's not necessarily going to be able to cover our costs. And that is one of the other recommendations of the national commission, that in the interim, before, if -- the next steps before the universal health insurance reimbursement rates...

CHAIRPERSON WATSON: Let me ask you, is that a state-reimbursement regulation?

MR. LEUNG: The reimbursement regulations related to Gangcylovir or overall, yes, it is a state...

CHAIRPERSON WATSON: Now can the department do something about this? I mean it seems a bit ridiculous. You're trying to keep people out of the acute-care facilities; and then we have...

MR. LEUNG: In order to start, you have to have a 12-hour period of infusion therapy, which is normally given on an inpatient basis.

CHAIRPERSON WATSON: Well, Mr. Sauseda, this is something that you might want to take a look at.

MR. LEUNG: The National Commission did call for the amounts of reimbursement to be at least commensurate or at least enough to bring out of the woodwork providers who would then be willing to participate because what we would then find is that people would then go to their natural provider, their neighborhood provider, as opposed to overfilling to above capacity, the local health district clinics, the county hospitals, et cetera, which is what's happening right now, that we have waiting lists and waiting lines at San Francisco General Hospital for our clinic services primarily because Medi-Cal's reimbursement rates are so low that nobody could even barely make the costs of producing the forms at $9 an hour and things like that.

One last thing to consider in any legislation or measures related to universal health insurance is an examination of appropriate profit margins for therapies and for drugs that have been licensed to date. Most of the focus to date has been on AZT and the related drugs -- DDI, DDC. But other drugs are also now becoming part of the arsenal in the fight against AIDS. Erythropoitin, or EP, is a drug used to fight anemia, and AZT tends to bring on anemia. That drug is more expensive than AZT, about twice as expensive now. That drug was originally licensed for end-stage renal failure, people on kidney dialysis machines. But once it got approved, it can be prescribed for other illnesses, for instance, anemia, from taking AZT.

The appropriateness of the cost -- I'm sorry. The appropriateness of the charge allowable for that drug is subject to review, but it hasn't been reviewed by the FDA because they have other things on their docket at this point which is part of the problem that we all face now.

And in conclusion, I'd like to say that we are quite honored to have been invited here to testify before you. And with regard to what San Francisco provides and things like that, I can provide you with some of that information. And again, I am sorry that Dr. Hernandez was not able to attend and she does send her regrets.

CHAIRPERSON WATSON: I think that you have pointed out some critical obstacles

that tend to be somewhat bureaucratic, that stand in the way of treating this deadly disease the way we should. I'm hoping that our efforts would result in a higher priority and less in bureaucracy and more understanding. And let's cut right through it and get right to trying to find ways to treat and to prevent, as well as cure, this dreaded disease.

Thank you so much.

MR. LEUNG: Thank you very much.

CHAIRPERSON WATSON: Now we're going to get back to the agenda, and we're going to call for Alan Harris to make comments now.

Thank you. And I hope you catch your plane in time.

MR. ALAN HARRIS: I am Alan Harris, the AIDS Regional Coordinator for the United States Public Health Service. I'm also a Commissioner on the Los Angeles County Commission on AIDS and a Member of the Los Angeles County HIV Health Services Planning Council.

I want to thank Senator Watson and her staff not only for the invitation to share with the committee preliminary Public Health Service fiscal year 1991 AIDS financial data for California recipient organizations but also for the leadership, Senator, that you and the committee have provided for public health in this state. We certainly commend your efforts in that respect.

I hope the information that I'll be sharing today will be of some interest to state government, local governments, and local AIDS planning agencies prepare their budgets in 1992 for the forthcoming year.

Based on preliminary data, for federal fiscal year 1991, which was the year that ended September 30, 1991, the Public Health Service awarded nearly $191 million in support of AIDS program activities among 348 California organizations. At that level, California received slightly more than 10 percent of the $1.885 billion 1991 national PHS AIDS appropriation. Our support includes new financial and direct assistance -- direct assistance is personnel, equipment, and supplies -- which is provided prospectively for generally a 12-month budget period in support of AIDS and related activities.

Our assistance was provided through grants, cooperative agreements, and contracts. In some cases, particularly for reserach projects, the financial assistance includes program funding from appropriations other than AIDS. In all cases, the financial assistance does not include previously awarded and unused funds which PHS generally would reauthorize to recipients in support of subsequent years of their multi-year projects, which generally are three to five years in length.

I've prepared two exhibits that describe the preliminary PHS '91 funding. And

there are some extra copies here for members of the audience as well.

The first exhibit outlines the fiscal '91 preliminary funding by PHS awarding agency and by general purpose.

The second exhibit describes that funding by awarding agency in contrast to prior-year levels fiscal '89 and fiscal '90.

Over the three years, you can see the public health services provided more than half a billion dollars in assistance to California organizations for AIDS and HIV-related activities. The largest share of that money has been provided by the National Institutes for Health at $261 million over the three-year period.

Given questions that have come up earlier, as well as the focus of the committee's hearing, I'd like to identify very briefly the service that the National Institutes of Health AIDS Clinical Trial Groups are providing to cumulatively nearly 3,500 adult and adolescent volunteers who've enrolled in those clinical trials and 182 children who've enrolled cumulatively in California's Pediatric AIDS Clinical Trials and trial groups. These eight clinical trial groups are university and medical school organized networks of hospitals and clinics whose participating physicians accept patient volunteers to enroll in clinical trials of experimental therapies for HIV disease and for opportunistic infections. Specific clinical trials of AIDS and HIV experimental therapies are sponsored and supported by the National Institute of Allergy and Infectious Disease, which is the major AIDS component of the NIH.

These statistics that are reflected in the last two exhibits, one on children and one on adults and adolescents, indicate that in all cases, except for women and for blacks who were under-represented by comparison with California's cumulative AIDS cases, the ACTGs were generally the volunteers, or the enrollees in the ACTGs, were generally representative of California's cumulative AIDS cases. That's among adults and adolescents.

For children, the representation was, in my opinion, fairly representative across the board, both on sex and race characteristics.

It should be noted that California's adults and adolescents in volunteers represented 23 percent of all of the volunteers who enrolled in clinical trials nationwide. And the 182 children from California represented 16 percent of the cumulative nationwide enrollment.

I hope this information has been interesting and may be helpful. I look forward to answering any questions you may have now or working with your staff in the months ahead. Thank you.

CHAIRPERSON WATSON: In looking at the California AIDS Clinical Trials, when I look at the African American group, it looks like the clinical trials are very low

comparatively. Almost no research is going on at a time when it seems like this is one of the highest risk group at the current time. Maybe that's the reason because very few of the clinical activities have really addressed the African American community. Can you explain?

MR. HARRIS: These are only the AIDS Clinical Trial Groups. They do not include volunteer enrollees and the Compassionate Youth Trials, which are sponsored by individual drug companies. They do not include volunteers.

CHAIRPERSON WATSON: Do you have any of that information available to us?

MR. HARRIS: No, I don't. I can't...

CHAIRPERSON WATSON: Can you get what's available and share it with us, please.

MR. HARRIS: I can try. I'm not aware that it's generally available publicly.

CHAIRPERSON WATSON: See, I guess what I would surmise from all of this is that the clinical drug trials done in the private sector and in the academic community have not really been addressing what's going on in the minority communities. And I guess what we see with the increases is a result of the lack of the trials dealing with those communities. And I would say to the private sector why; and I would say to academia and the public sector we've got to do something about it. We've got to increase the study groups. You've got to go out there in the grassroots, bring these people in, and have them be part of the study groups, if we're ever going to get a clue as to how we address prevention and treatment and other kinds of activities relative to AIDS.

MR. HARRIS: My thought and suggestion would be that it's terribly important for the King/Drew Medical Center to be able to participate in clinical trials.

CHAIRPERSON WATSON: It certainly is. And Dr. Jordan who is in the room is going to testify a little later. I don't think there's anyone that knows the dearth of activities in this area any better than him, and particularly the few number of doctors even willing to treat these cases, it's appalling and it's really scandalous. And I can understand why AIDS is raging throughout our community and other communities like ours because of the lack of attention. I wanted to bring that to your attention and ask you to take a look in this area, supply us with any information you can gather as to what the pharmaceutical companies are doing.

MR. HARRIS: I will. Thank you.

CHAIRPERSON WATSON: All right. Thank you for your testimony. And I'd like to go on to the next presenter. Bob Frangenberg, Director of AIDS, L.A. County.

MR. ROBERT E. FRANGENBERG: Good morning, Senator Watson.

CHAIRPERSON WATSON: Good morning.

MR. FRANGENBERG: I'm pleased to have the opportunity to address you today,

and I'm going to go through some statistics as well as both about the disease itself and about the funding of the disease here in Los Angeles County.

Los Angeles County is the second-ranking metropolitan area in the United States in terms of both the present and cumulative AIDS cases. As of October 31, we have approximately 4,000 individuals living with AIDS and about 36,000 people who are infected with the virus. Our cumulative totals are 13,647 cases.

The County Department of Health Services has two mechanisms that fund AIDS programs in Los Angeles. One is through the AIDS Program Office, and the other is through the medical facilities, particularly four facilities.

The AIDS Program Office is responsible for policy and program development of prevention and treatment services, while the department's medical facilities provide direct patient care to persons with HIV/AIDS. The majority of funding for these services fall into the budget of each individual facility; however, some funds for dedicated outpatient services are provided to certain facilities through the AIDS Program Office.

Projected expenditures for fiscal year 91-92 for the AIDS Program Office is $38 million; $14 million of this, or 37 percent, comes from county funds, $18 million from federal funds, and $6 million from state funds.

The county funds expended through the program office are for education and prevention programs, community-based outreach clinical services, case management, home health care, residential care, drug-abuse treatment for people with HIV, day care, and dental care.

The $18 million in federal funds will be spent in two broad programmatic categories. Ten million of this money comes to us through the Sutters Disease Control for prevention and education activities, counseling, and testing activities, and surveillance activities. And nearly $8 million comes through us from the Title I of the CARE Act which support medical outpatient services by and large and some other support services and outreach services.

Seventy-one percent of the CARE Act Funds are being expended on patient services through contracts with community-based organizations. Twenty-four percent are supporting services in county facilities, while the remaining five percent are for administrative services. We already know that our 1992 CARE Act Formula grant will be $5.4 million, up from $3.9 (million) for next year, and the year starts February 1, 1992.

The State Office of AIDS allocates money to the county. We get $737,000 for our anonymous test sites. We get about $4 million for the AIDS drug program which funds a variety of drugs. And then we have $287,000 that go to Martin Luther King/Drew Medical Center for primary care or early intervention services. We get

another $1.1 million from, through the State Block Grant, and that goes for a variety of services as well, including counseling and testing in juvenile halls, a prevention center at the Gay and Lesbian Community Services Center, an injection drug use program with the Los Angeles Center for Alcohol and Drug Abuse, and in some surveillance and epidemiology services in our department.

HIV- and AIDS-related expenditures for inpatient and outpatient care at the county medical facilities are supported by several revenue sources. The primary revenue supporting care is Medi-Cal whose smaller amounts come in from Medi-Care, patient revenue, and insurance.

During fiscal year 1990-91, the medical facility spent a total of $34 million on HIV- and AIDS-related care, with $9 million spent on inpatient care and $25 million on outpatient care; and, $16 million while $34 million total was spent out of general funds, county general funds.

It is important to note that a trend toward greater reliance on outpatient medical services rather than inpatient services have been taking place in the county. This should inherently provide a more effective and efficient use of our financial resources, even though it provides inpatient services, that is -- I'm sorry. Outpatient services provide a lower reimbursement from Medi-Cal. Average is about 80 cents on the dollar, inpatient; and about 20 cents on the dollar, outpatient.

Thirty-seven percent of the cumulative adult AIDS caseload in Los Angeles County is comprised of people of color. When you relate that to the county census, you have 11 percent of the county residents are Asian/Pacific Islanders and Native Americans; and 2 percent of the AIDS cases are among that group, those groups. Hispanic represent 38 percent of the county population and 20 percent of the AIDS cases. African American people represent 11 percent of the population and 16 percent of the cases. And whites represent 40 percent of the population and 62 percent of the cases.

The behaviors which put adults and adolescents for all ethnic groups at risk in Los Angeles County are as follows: Male-to-male sexual contact is 80 percent of the cases coming from that behavior; male-to-male sex with injection drug use is 7 percent; injection drug use 5 percent; transfusion recipients 2 percent; male-to-female sexual contact 2 percent; and hemophilia or coagulation disorder less than 1 percent.

CHAIRPERSON WATSON: Excuse me. Which category would you put the transmission of AIDS from a professional health provider to a patient?

MR. FRANGENBERG: I would say that it's not in here, I suppose. I mean these are -- we don't really have a category that's outlined, you know, that keeps track

of that.

CHAIRPERSON WATSON: We ought to start looking at that category, since we've had a case and a death and who knows. Maybe we can start at least bringing some attention to that particular category too.

MR. FRANGENBERG: Los Angeles is significantly different from East Coast cities and somewhat different from other cities in California in the lower percentage of cases which are related to injection drug behavior. Even when the behavior categories are examined within each ethnic group, gay and bisexual men comprised the predominant group affected by the HIV epidemic and at risk for HIV infection.

For example, 68 percent of the African American adult and adolescent cases, 73 percent of the Hispanic cases, and 80 percent of the cases among other people of color are attributable to male sex. An additional 10 percent of African American cases, 6 percent Hispanic cases, and 3 percent of cases among other people of color are attributable to a combined behavior of male-to-male sex and injection drug use.

The statistics are useful...

CHAIRPERSON WATSON: Excuse me. Your last statement on page 6 says: "Los Angeles is significantly different from--" other "--East Coast cities" and so on.

What's the backup information? I didn't know whether the following paragraph would back that up or if that stands alone. If it does stand alone, you might want to expand on it.

MR. FRANGENBERG: Okay. We've been doing studies in Los Angeles County for sometime on people in treatment. And ever since 1986, we have found that about 5 percent of those people have been, 5 to 6 percent of those people are infected.

In the studies that we've done in people outside of treatment, on the street, we've done some studies, and we find that that number is about 8 percent. In New York, the number of people who were infected through injection drug use or sharing of needles is 60 percent, so it's dramatically different on the East Coast, in New Jersey and New York. San Francisco, I don't know precisely what the percentage is, but I think that it's more in the 15 percent range than it is in the 6 to 8 (percent) that we have here. So that's the basis for that comment.

CHAIRPERSON WATSON: Is your point here that the instance of AIDS being contracted through injections is lower here in Los Angeles?

MR. FRANGENBERG: It seems so.

CHAIRPERSON WATSON: More than other cities in Los Angeles?

MR. FRANGENBERG: I'm sorry?

CHAIRPERSON WATSON: Lower than other cities in Los Angeles?

MR. FRANGENBERG: In Los Angeles County or...

CHAIRPERSON WATSON: Excuse me. In California. I'm sorry.

MR. FRANGENBERG: In California, yes, it's my understanding that it is lower than San Francisco. I couldn't tell you about other cities in California, but I can tell you about San Francisco and Los Angeles.

Well, we used these numbers that I've just given to you to look at trends and to target our prevention and education program. Prior to 1987, 83 percent of the adult cases for all races were attributable to male homosexual/bisexual contact. This figure now has dropped to 77 percent in 1990. Conversely, the percentage of cases linked to injection and drug use rose from 2 percent prior to 1987 to 6 percent in 1991.

Over the same period, cases linked to injection and drug use, in combination with homosexual or bisexual contact actually dropped from 8 to 6 percent. Cases attributable to homosexual contact rose from 1 percent in '87 to 2 percent in 1990. Thus, though, homosexual and bisexual contact may be viewed as the riskiest behavior for HIV transmission, injection drug use and heterosexual contact have increased in recent years.

The ethnic distribution of new cases has also changed over time. Prior to 1987, 70 percent of new cases in the county were white cases. And in 1990, only 56 percent of the new cases were diagnosed in whites. These statistics for African American are 14 percent prior to 1987 at 18 percent of new cases in 1990. For Hispanics, they are 15 percent prior to 1987 and 23 percent in 1990.

Another way of looking at these are through the trends of the incidents. And as you can see in the white community, the incidents have changed. From 1984, it was 22 per 100,000; and in 1990, it was 89 per 100,000. For male, African Americans, the statistics were 19 per 100,000 in '84 and 122 per 100,000 in 1990. Hispanics were 7 in 1984, 7 per 100,000, and 53 per 100,000 in 1990.

I don't have earlier statistics for women, but I have the 1990 incidents for women. It's 2 per 100,000 for white women; it's 4 per 100,000 for Hispanic women; and 9 per 100,000 for African American.

Primary behaviors which put women at risk are heterosexual contact, which is 33 percent of the cases, injection drug uses, which is 28 percent, and transfusion recipients which constitutes about 23 percent of the female cases. And most of these transfusions occured prior to the assessing of blood supply.

As the local face of HIV/AIDS has changed, so has our approach to the prevention and related medical services. For instance, community-based organizations serving people of color and women now constitute a majority of our contractors for our HIV education and risk-reduction programs. We firmly believe that our preventative aspects on high-risk persons of color will be maximized

through the expertise of community-based organizations. These organizations have vast experience in targeting programs to their communities and providing effective outreach at a culturally adept context.

We have 15 contracts with community-based organizations that are specifically targeted to people of color. I've listed them and I put the targets down, but I won't read them. And I've listed also the number of, the amount of money that goes to each contract.

CHAIRPERSON WATSON: Yes, there's a question.

DR. TATE: Bob, I have a question.

MR. FRANGENBERG: Sure.

DR. TATE: You mentioned earlier in your testimony that approximately 38 percent of individuals in Los Angeles County are ethnic minority. And you've given the providers and the amount of allocations you give them, but generally speaking, approximately what percentage of your budget is dedicated or given to ethnic minority providers?

MR. FRANGENBERG: I think it's a little later in the speech, but 65 percent of the prevention and education and education money goes to minority providers.

DR. TATE: So that's prevention and education.

MR. FRANGENBERG: That's correct.

DR. TATE: And then does the county also do, give money for treatment?

MR. FRANGENBERG: Yes, we do. I have indications of what that would be, but I don't have...

DR. TATE: Yeah, I would just like, even if it's just a ballpark figure in terms of just like a percentage of your budget.

MR. FRANGENBERG: Well, what I have is the percentages of people who are getting AIDS drugs through our medical facilities. And, for example, at Los Angeles County, USC Medical Center, 47 percent of the AIDS drugs that are dispensed through there are to African Americans; 35 percent are dispensed to whites; 12 percent to Hispanics; and 1 percent to Asians. So that's an indication at LACU. You see, there are four different locations that I have, statistics like that on, but it's an indication of who's being served, what ethnic groups are being served at those facilities.

DR. TATE: Just one last question.

MR. FRANGENBERG: Sure.

DR. TATE: Then I'll let you continue. In terms of treatment, do you define treatment, or could you define what treatment is for AIDS victims? Is it just the drug, or do you also provide counseling, other kinds of forms of therapy, mental health?

MR. FRANGENBERG: Well, yeah, that's a very good question because it's changing pretty dramatically, I think, not only here in Los Angeles. But actually it's a broad spectrum of services that are available. I mean we have -- in Los Angeles, we have a fairly good continuum of care. It has -- it's very spotty in some ways in terms of what, whether or not there are enough slots available for residential care or primary care or mental health care. But there's at least something happening all along the continuum. But that's the challenge here, at least, is to not only increase the slots that are available in each of those kinds of care.

One of these we're finding is that people are much more acutely ill when they first come into the system than we had anticipated. And we're finding that many of them are coming in with T-cells that are below 200, generally indicating that they are going to need and would require pretty extensive care, not always, but generally speaking, you can say that they would provide, be in need of more care. So that's been something that we've had to try to work with, especially with our CARE Act dollars which are funding primarily primary care. And by primary care, we mean whatever that person walks through the door with. I mean if they have needs that are HIV-related, they're to be taken care of in our primary-care centers.

DR. TATE: Thank you.

MR. FRANGENBERG: Well, I would also say that we have a variety of contracts that are not specifically contracted with minority-owned or specifically for an ethnic group. But many of the contractors work with people of color as well as a broad spectrum of people.

CHAIRPERSON WATSON: Let me ask this: How much effort have you been placing in finding people of color to contract with for these programs?

MR. FRANGENBERG: In my view, a lot. We have worked with the community and with advisory groups, the AIDS Regional Board, our own HIV Planning Council, the CARE Act Planning Council, the Commission on AIDS -- I mean a whole host of providers to try to identify community-based organizations that can, are interested in, can and are willing to contract with us to provide services. We do it on a sole-source basis in some cases, and we also do it through an RFP process.

CHAIRPERSON WATSON: What is the percentage of non-minority providers that are working on the minority communities?

MR. FRANGENBEG: I'm sorry. I really don't have a figure of that.

CHAIRPERSON WATSON: I would be interested in knowing that figure because I'm seeing maybe a pattern here. Number one, there's been very little research done on these minority groups. Contracts are going probably in larger numbers to non-minorities that deal with the minority community; and the gap that is occurring

in outreach, knowledge given to the people in the streets about their behavior and how to prevent certain things from happening. So I'd like to be able to document. I'm just seeing a pattern, from what I'm hearing this morning, trying to figure out what the problems are and how we address those problems. And I think the information that you could provide would be very helpful. Maybe if we could give extra points to those minority providers and an extra effort, we might be able to find like kind that can relate better to the problems that are faced and the risks that are running rampant in our communities.

MR. FRANGENBERG: Well, I'm just going to touch on anonymous testing briefly. We have a contract with the State Department of Health Services and then contract with community-based organizations ourselves to provide anonymous testing. And they are Regional Center in East Los Angeles, Valley Community, and North Hollywood, South Bay Clinic in both Manhattan and Gardena, East Valley Community, and Minority AIDS Program.

We're very interested in some of the things that Wayne talked about this morning, about the additional funds that he's trying to get for these projects because it's very important. As he mentioned, some of our waiting times before Magic made his announcement, we didn't have any waiting time in some of our clinics; and now we have two-month waiting periods.

To give you an idea about who are going for testing, about 2 percent of the people who are being tested in our anonymous test sites are Native American; 4 percent are Asian and Pacific Islanders; 6 percent are African American; about 20 percent are Hispanic; and about 67 percent are white.

This is a little bit of what we're projecting as an unmet need in our 92-93 budget. We approximate that we have a $29 million unmet need for AIDS and HIV service in Los Angeles County, and we think that that's roughly in these kinds of categories: $3 million in education and outreach and prevention services, $23 million for outpatient and inpatient services; $2 million for testing, about $900,000 for residential, and about $800,000 for dental care.

We have tried to look at these and make some decisions about which groups we think need to be addressed, and we think that those groups are adolescent women, substance abusers, gay men of color and gay white men.

CHAIRPERSON WATSON: We were just commenting on page 13 at the top. And for the month of October 1991, there's a picture that you provide of the racial distribution for anonymous testing and counseling services.

MR. FRANGENBERG: Right.

CHAIRPERSON WATSON: Sixty-seven percent of those receiving services were Caucasian; only 6 percent were African American.

I think that tells a story; and as I mentioned before, it's a pattern that I see occurring here that says that we, rather than neglect these areas, we've got to increase the services to these areas or else the numbers are going to grow epidemically.

MR. FRANGENBERG: Yes, I agree. We saw the same thing when we looked at these numbers. And one of the things we're also interested in and concerned about in trying to get some strategies to deal with are the high rate of infant, African American infants, that are born HIV-positive. And we're going to start to work, or one of the ideas is to work with the WICK Program because in Los Angeles County, for a variety of reasons, most of the African American women do not come to county facilities for prenatal care. And so we have to find other strategies to try to reach young African American women and at least provide them with counseling and testing information about how the virus...

CHAIRPERSON WATSON: That's the reason why you'll hear many of my questions going to outreach because it's becoming clearer and clearer to me that a concerted effort has to be made to meet the needs of these high-risk communities. And as I understand it, that the fastest spread of AIDS is among African American women during their childbearing years. We're seeing them in the county hospitals now, the neonatal wards, costing us up to $100,000 a year to keep them there. And I would certainly hope that you could design a program in the county which gives a priority to these underserved communities who are at such high risk.

MR. FRANGENBERG: We do have outreach programs, Southern California Youth and Family Services...

CHAIRPERSON WATSON: Yeah, I know you do.

MR. FRANGENBERG: We do have some.

CHAIRPERSON WATSON: But your own statistics are saying that probably you don't have enough of the programs or they're not well funded enough or you don't have the expertise because of -- even with your own distribution of testing, it's very, it's the lowest among the top three groups.

MR. FRANGENBERG: I agree. I understand.

CHAIRPERSON WATSON: And so something is not right with these figures. Maybe something's not right with the priorities you've set.

MR. FRANGENBERG: We're certainly aware...

CHAIRPERSON WATSON: In spite of what you have already, you've got to do more.

MR. FRANGENBERG: Let's see.

CHAIRPERSON WATSON: Can we skip over to 15. We're going to have to move along.

MR. FRANGENBERG: Sure.

CHAIRPERSON WATSON: Page 15. Let's talk about unmet needs.

MR. FRANGENBERG: Oh, I'm well into unmet needs.

CHAIRPERSON WATSON: I was ready for unmet needs too.

MR. FRANGENBERG: I really just, I've really told you that we have a $29 million unmet need, and I've sort of outlined what they're in.

I think that some of your comments are relevant and important. I do think that there have been some significant progress in Los Angeles County over the last few years. I think there's a long way to go, and I think there are a lot of things that can be done and need to be done. I think that some of the initiatives that the state has done, and also the federal government, especially the CARE Act, has at least helped us get additional resources to provide additional services, both prevention and services and treatment services. And I'd be willing to answer any questions you may have.

CHAIRPERSON WATSON: Yeah, I would agree with you that you've done, made some progress; and I think we have to make more and, in terms of the funding. We don't have enough funds, but we've got to look at the funds we do have and the equitable distribution. Now some communities require more than others. But I think the emphasis in the beginning, in the early '80s, was on the white male gay population. And trying to turn that around -- because they went after the problem immediately. And we saw almost immediate decreases in the spread of AIDS in the white male gay population. And at the same time, guess what? The other groups started to expand in terms of the infection of HIV. And I haven't seen the state, the feds, and the county turning around and looking at where the greater spread is. So what I would encourage the county to do is to start looking at your own figures and looking at these unmet needs and set some priorities that can go after the problem in these under-represented groups, giving them a top priority.

I think I've made that point several times now, and I think you have it.

MR. FRANGENGBERG: I think I do.

CHAIRPERSON WATSON: So thank you for your testimony.

MR. FRANGENBERG: Sure.

CHAIRPERSON WATSON: All right. We'd like to call on now is -- I want to follow up with the county's testimony with Dr. Phil Jordan who is Director of the AIDS program at Martin Luther King Hospital. And following Dr. Jordan, do we have Phil Wilson here? I didn't see Phil. Okay. And then we'll take Dr. Tuckson. Is he here? Okay. Fine.

Dr. Jordan, if you'll come right up, please. And then we'll follow down the agenda with Cleant Stain and Germaine Maisonnet; is that correct? Okay? Dr. Jordan, please.

DR. WILBERT JORDAN: Good afternoon, Senator Watson.

I think we have to look at AIDS when we're dealing with the minority communities and to have an approach that emphasizes keeping the HIV negative, negative, as well as providing adequate and appropriate care for those who are positive but not waiting until the person becomes positive before we've done something to prevent them.

As of December 30 in my practice, in both King Hospital and in South Central, I had seen 37 women; that was December 30, 1990. As of June 30, 1991, that increased to 72 women. Two of those women had gotten infected through blood transfusions and two through IV drug use. Six to eight had become infected through heterosexual transmission. Of them, a great number were partners to men who are bisexuals and they did not know it.

There are two issues when one looks at the issues of women. When that woman learns she's positive, most often, in about 35 percent of our cases, they learn second-hand, i.e., that a child is born ill and they learn because the baby is sick or friends may tell them. What she learns, she learns that her male partner has known he was positive for sometime, maybe even being treated, and has never told her. So she has to deal with several issues: One, she has children; two, she's positive; three, her husband, her male partner, is bisexual -- she did not know it; and four, he has known that he had a deadly disease and never told her. She needs a lot of psycho-social support. She needs to see a psychologist or a psychiatrist.

Most of the patients we see come in with nothing. If they have Medi-Cal, that's a plus. Psychiatrists don't take Medi-Cal; psychologists don't either. And she is faced at that point with a great need. She has several severe, big pains to deal with.

CHAIRPERSON WATSON: I just want to interject this; I can't help but telling you this. A friend of ours son committed suicide about three weeks ago. His companion did not know, A, that he was black. He was living as a caucasian. And she had had a baby and he was afflicted with HIV. So she got a triple whammy there. And she's devastated. And I don't know if, out where she lives, way out near San Gabriel, somewhere there, if there are programs available, I do think the psychological punch that carries, or that's carried with kind of revelation, is addressed. We carried legislation several years ago to provide a whole series of treatments. And number one, just by the fact that there's a revelation that my, God, this person that I had contact with is this, is this, is this, and I think that's a major part of the reason why people succumb so quickly because, number one, they don't have the strength to be able to stand up and cope and fight because they've been so devastated; and we haven't looked at providing the services. I'm

glad you raised that issue. I just had to say that.

DR. JORDAN: Thank you.

CHAIRPERSON WATSON: Dr. Tate.

DR. TATE: And I just want to piggyback on that because when Mr. Frangenberg was up here, and he mentioned about the continuum of care that's offered, I mean I would like you to talk about the real world then and these women that since L.A. County says that they do offer this continuum of care that would go from testing to, as far as I'm concerned, the psycho-therapy of some sort to hospice, why isn't it available for these women?

DR. JORDAN: Maybe it's not a big deal. Let's see.

DR. TATE: Yeah, you know, what's going on.

CHAIRPERSON WATSON: Being hit from you is what you're saying.

DR. JORDAN: (Gap in tape)... half of my patients. But I cannot say if that has been done definitely as a study. But we need to be able to either make a decision of testing all women, record their blood and see if they're positive, or being able to profile who is at high risk so that both they and their physicians will know who is at high risk and test those so we can identify them before it becomes too late. We're losing a lot of time.

CHAIRPERSON WATSON: What I hear you saying is that you don't know of any studies that are focusing on women of all colors?

DR. JORDAN: Correct, that identify which of these --

CHAIRPERSON WATSON: As a category, women as a category.

DR. JORDAN -- are at high risk of being HIV-positive.

CHAIRPERSON WATSON: Okay. Would you make a note of that, because that's something I'm very interested in. And I just left a press conference where we were talking about breast cancer. Most of the cancer research has been done on men prior to the '90s. And breast cancer is at an epidemic level. So I equate cancer with AIDS. I think it's really kind of the same form of disease that attacks the body. I think you're pointing at something that is a great need that we have really not focused on, so we're going to follow up. We'll try to see what there is going on in the country, and then we might have a proposal or resolution or something. Thank you.

DR. JORDAN: These are my black patients. And this date, I've shared with you previously, but I have not, because I'm the one doing it -- it may have to do with it -- my white, Hispanic, and Asian patients. Eighty-seven of my patients are married men; 23 of the wives know it -- they have married knowing they're husband is bisexual; and 64 of the wives did not know that their husband was bisexual. And again, so you have a large group, and this is an issue that has to be dealt with.

When you look at the 341 men who are homosexual of this group of patients as of December 30, 202 identified as being bisexual; 105 identified as being strictly homosexual; 34 said they were neither, though they were having sex with men. And I found that interesting. When you look at where that group at 34 had that initial sexual contact, it was in jail. And again, jail is, jail is an institution in the Black community. We have to deal with that. That's a fact. A lot of Black men have been in jail. To be very graphic, if I'm married and I'm put in jail and three men grabbed me and threw me down and have sex, I am not going to go home and tell my wife. That's the last thing I'm going to tell her. You profile that person what he will do when he gets home, he will be rougher but very sexual to reaffirm his manhood. But if he does get infected, if he does go in and out and if he does play the part of the passive role in jail, when he comes home, she may be happy because he seems to be so amiable and sexual but he's also infecting her.

I think it's important to understand that in terms of infection, the female is easy to get infected from a male than visa-versa.

CHAIRPERSON WATSON: I'm becoming more and more cynical as the minutes go on. And what I think I might do is ask the Department of Corrections to do a study on sexual contact in their facilities, both at the adult level and at the CYA level. You know, they will tell you that, oh, we can't dispense condoms because it's illegal to have sex in prison.

DR. JORDAN: That was my next point. Thank you for saying that.

CHAIRPERSON WATSON: I think I'll put the responsibility on the Department of Corrections because they have supported bills that would require testing throughout the entire system without a program to address. Once they have all this data, what are you going to do about it, was my question. I got no satisfactory answers, except we'll isolate them or quarantine them. But I didn't hear the steps in treatment. And so I think that what I will do is hold the department responsible for giving us a picture of sexual activity. And then we can get some other community-based group maybe to do research on what happens when these people return back into the community.

DR. JORDAN: Thank you. That's very important, because the two other points I wanted to mention, in terms of jail, is one. Some jails do not provide condoms because, again, men don't have sex in jail. I think it is stupid for us to allow that philosophy to go on when we know it does happen, and these men are coming back out to your sisters and your daughters, and in some instances, you know, and once in his room. That's important.

The other issue is drug users. And though we're seeing an increasing number in drug users, again, as Mr. Frangenberg stated earlier, it is less than on the

East Coast.

We have a problem. When I have a patient who's a drug user, I can scare the hell out of him and make him want to go to be treated at that moment. But most times, if at that point in time, he says I'm ready to go -- let me go get rehab right now, dry me out -- I have no place for him to go to. So if I succeed in getting him to where he wants to now and then he has no place to go for six weeks, or sometimes longer, in that period of time, he's going to spend drinking or drugging himself worse because he's scared even more.

If I succeed, and I'm lucky to get him into a place and he comes out dry, I've done very little but prolonged time because in our situation, we're not talking about one person in a very middle-class structured Beverly Hills environment where he or she is using drugs but the rest of the family are stable and are good supports. We're talking quite often about one person who happens to be HIV positive and using drugs. But he has a whole support system who are also HIV negative but also using drugs. So when he comes out and goes back to the same support system, what are we to expect? How do we really expect him to go out to the same group and refrain when his whole support system are all using drugs?

We have to deal with drugs in this country like we did smallpox in India and Africa. We vaccinated around the infected group. The best way is not just to deal with getting that HIV-infected patient into a program but getting his whole support group into a program. Either we decide that they all are worth it or not. It is costlier to have them go back and forth in the hospital, getting medicine, being treated for AIDS, than it would be to put him and his whole support group in a drug rehab program.

CHAIRPERSON WATSON: I think a key word, I just heard you say is: Are they worth it or not? I think we have to do a lot with that attitude: Are they worth saving?

DR. JORDAN: Yes.

CHAIRPERSON WATSON: And if they are worth saving, then you're going to see a redistribution of resources. And I think that's the main question. As I see it within this area of California and in this county, that question comes up time and time again because I don't see the resources going to those poor people. And we're poor people -- we were out at Martin Luther King yesterday. That's a hospital that serves nothing but minorities, and we don't have the same resources that we have in some of the other hospitals. And I guess it all boils down to is what the concept of worth is by the people making the decisions and how then we distribute the resources.

So I think fundamental to everything you're saying is the question of, do they

feel they're worth it.

DR. JORDAN: It's very important. Mental health, as I mentioned earlier, is an important issue. And just in the community itself we need to have more available mental health practitioners to be able to work to help those persons.

Now two other issues I want to mention. About a month ago, a drug called clorithromyacin became FDA approved. It is a drug that you use to treat a particular type of infection in AIDS patients. Before then, there were several drug, combination drugs, you had to use and you got very little results. MAI was one of those illnesses that when the patient got it, it was bad news because it was very hard to treat.

Well, about a year-and-a-half before this drug became available, it was available. It was made by Abbott Laboratories -- it's still made by Abbott Laboratories in Indianapolis. And if you had money to fly to Ireland for it and come back here and take it. Congress has passed legislation that allows for AIDS patients to be able to buy these kinds of medicines for their personal use. And we have established in most of the major cities' buyers' club as the only buyers' club here, that for those persons who could afford it, they could get it. And so what has happened for the past year-and-a-half prior to this past month, those middle-class patients, and most of them are white, were able to buy it. And it cost about $450 a month. It went down, at the end, before it became available, to $300 a month.

Of all the patients I had, I had only four who could afford to get it. The other patients that I got it for, I paid for it myself. The same is true right now for DDC. It's available through a buyers' club. And my point is we're going to see a lot of drugs becoming available that are effective. But unless the person has the available funds, we're going to see the drugs available for a year or year-and-a-half but only those who can afford to purchase them be able to take opportunity of it until it finally becomes available. And the majority of people who will suffer or who will still die when they could be alive will be minority patients. And there has to be established to me some kind of slush fund that would address this issue and allow those persons to take advantage of those medicines too when it's there.

I do not think we can really make the impact we have to make in the minority community unless we also deal with self-esteem. I don't know what the Friday Night Live Program is. I understand it's in some of the middle-class areas. We need a Sunday through Friday Night Live Program in the minority community. We're talking about kids who have no self-esteem to offer. And when one self-esteem is destroyed, is low, et cetera, often their sexuality is the one thing they have.

And we have to understand it and deal with that. And education has to be coupled with empowering patients' self-esteem. And we cannot provide the same kind of educational model that works very well in Beverly Hills, that works very well in West Hollywood and put it in Watts. It will not work. It may provide some of us with jobs, but it will not work. And that's important. The issue here is keeping those HIV-negatives, negative, not simply providing some of us with jobs. And if we do not deal with self-esteem in a way that we need to deal with it in South Central, it won't work. And what will work in Watts may not work in East L.A. It has to be flexible enough that public work in those communities, they can use it, rather than being forced to adhere to one structured program. That makes no sense. And when we keep doing that, we lose out, particularly, minority communities.

It was mentioned earlier that the definition of AIDS will change. Many of the patients we see come in with low T-cells. And we will see an increasing number of AIDS patients when the definition changes. The problem we have now, if a patient comes in with 200 T-cells and he has pneumonia, that qualifies him, pneumocystis pneumonia, for AIDS. He then, if he has been diagnosed, he can get to the hospital. If he's been lucky enough to not get an infection and he or she comes in with a T-cell count of 10, which means they have much less of an immune system, which means if they get an infection, the chance of living through it then is zero, so you want to do everything you can to keep that person from getting an infection. At the same time, they become penalized because if you keep them healthy, they can't get that benefit. And if they don't get that benefit, Medicaid follows social security disability. So if disability says no, Medicaid says no, so we're sort of trapped. If I sit back and let this patient get an infection, which would then qualify him or her to get the Medicaid, we're paying severe Russian roulette with five bullets in the gun. And that is a huge problem that minority patients face all the time. We need to have that system changed so that patients whose T-cell counts are 200 can get their benefits without having to run the risk of dying from a disease, which is what we're doing right now.

CHAIRPERSON WATSON: Let me raise this question with the Office of AIDS. Is there a treatment model, comprehensive treatment model, for the minority community based on all the elements that have been described by Dr. Jordan as being necessary? Is there anyone in the Department of AIDS who has the same kind of knowledge on what's happening in the minority communities as Dr. Jordan? Can you respond?

MR. SAUSEDA: The second part of your question is easier for me to respond to; and the answer is no, we don't have anyone in our office that's as familiar as Dr. Jordan is, clearly.

CHAIRPERSON WATSON: Why don't you give Dr. Jordan a grant to do a study, to provide you with the information or you can then model a program that will meet the needs of this community that clearly has not received the kind of resources? And our hospitals are filled with the babies born of the mothers that have not the information and know how to take care of themselves. Could you do that? Could you bring him on so that he can -- he's the only doctor that I know in the African American community that has the information. He came to me years ago and said, look, this is the picture. And we've been going on the road, but there's nothing being done. I don't know of anyone else in the Department of Health Services that's been able to describe the program needed and the problem as existing in Dr. Jordan.

MR. SAUSEDA: I agree with you. I think that the kind of experience, the day-to-day experience that Dr. Jordan has, is tremendously important for us in developing our programs. I certainly --

CHAIRPERSON WATSON: You ought to be talking to him.

MR. SAUSEDA: Yes.

CHAIRPERSON WATSON: You ought to sit down and spend hours with him, as we have done. You ought to get into his psyche because, believe me, he is closer to the problem than anyone. There are only two doctors out in the Watts area who are willing to treat patients. And one doctor was shakey.

So if the department really wants to do something, you ought to be talking to Dr. Jordan -- forget the other one. You need to be talking to that man. Any other contracts you put out there, in this area, are not going to be as effectively researched as the one that you put into the hands of a man that's been doing this on his own, with no outside help. And he's been clamoring at our doors, you know, knocking, would you please listen to what I have to say? And finally, we got most of the members of the Black Caucus to come down and sit for a few minutes to listen. This man knows it, and he's described it better than anyone I've seen. And the bureaucrats need to really start listening to someone like him because he's given you the clue as to how you put together a program that will meet the needs of the people who are carrying that virus, who are at risk of carrying that virus. So you don't need to respond. I'm just giving you a message.

MR. SAUSEDA: The point's taken.

CHAIRPERSON WATSON: Thank you.

Did you finish, Doctor?

DR. JORDAN: One last point. And thank you for the nice words.

What Magic did, it obviously shocked all of us; but it finally made many people care. And unfortunately, if people had cared ten years ago, as hopefully as

many people are caring now, maybe we wouldn't have had to have Magic do what he had to do at this point in time and deprive us of many more years of fantastic basketball.

I think it's important for us to understand that we have to learn to take an attitude of not being so judgmental as a "civilized society" and in the process forgetting how to care.

CHAIRPERSON WATSON: But you know what, doctor? We've got to stop glorifying Magic because Magic told you what he was doing. You know, he got calls and letters and comments from all kinds of women that wanted to have sex with him just because he's Magic Johnson. He says I feel good. Once that virus is in the body, you're going to die. And he might be feeling good at that point in time, but I think much more needed to be said. And I resent Wilt Chamberlain saying, well, I had sex maybe with 22,000 -- you know, the cavalier way that this is being treated and the glorification. Yeah, we all love Magic, but he's got AIDS because he ignored -- and he's in a position to have the information. And I think somewhere along there, we've got to stop glorifying this -- and women throwing themselves at the feet of these people. What kind of message is that sending out there, women who are the bearers of our children, are saying, I'm willing to run the risk. My, God, that's sick. It is really sick. And when I saw that, I said, oh, boy. All these little kids are going to say it's all right to go out there and do the same thing because we all want to be like Magic Johnson. That's real sick.

I think Magic's lifestyle was wrong, and you can tell everybody you heard it from me. And I think all these other athletes who, you know, start putting the stripes up their arm because the women throw -- boy, we've got to turn that around. And now all these athletes are drug addicts. You know, I mean, my, God, no wonder our kids are nearing the same behavior because look who gets all the attention and the gratification and the bucks.

You see, we equate our success in life by the amount of money we are paid. And athletes and entertainers are paid more than teachers and doctors. And so we better start changing these messages around. Those of us that get the press better start telling the true story or else we have a lost generation, and particularly the esteem level of our kids. We're losing them; we're losing this whole battle. And, you know, I'm talking to the general audience.

You have been able to point some of these things up, and I get a little angry when I see us talking about the glorification, you know. Magic is a human being, and that's one thing that really came across. And if he can get AIDS, anybody can get it. But he did a little more to go after it, okay? He went after it, and he knew, we've been saying, you know, you guys better be careful. No sex is safe, so

you better protect yourselves.

DR. JORDAN: Thank you. Getting back to the point of self-esteem again, until we do something in terms of incorporating self-esteem in our education program, teaching kids that they are important, not someone else, but they are, and allowing them to see the beauty in themselves, this will continue, which is why it's ultimately important that we appreciate self-esteem. The patients that we've done the best at King have been those who we've sent to a self-esteem section. Those patients have behavior change; those patients see themselves differently and act better. And until we can do those things, we are not going to see a significant change in a large number of patients because they don't see themselves as being worth anything. Thank you.

CHAIRPERSON WATSON: Too many people laughed at John Vasconcellos when he's talked about self-esteem -- we need to study it. And there were cartoons that made fun of it; there were people in high places that made fun of it, and I would say the general public did. But he proved them all wrong. And I think what you're telling us is getting to the truth of why we're at such risk. And as long as you don't care a thing about yourself -- you don't care a thing about others -- that's why this guy on the news today could spit blood at everybody else -- he didn't care about himself -- he knew he was dying. So he's going to take a lot of people with him. And I think that's the mentality of a lot of our kids: You know, my life is worth nothing; and when I go, I'm going to take you with me. I'm going to dust you, and too much of that's going on.

Thank you so much for your sensitive testimony, and I would hope that the people in the Department of Health Services and the AIDS office will talk to you and will spend time with you and will bring you in as an in-field expert to advise them. Thank you, Dr. Jordan.

As a word to the wise, I'd like to call up now Cleant Stain, Director of South Central AIDS Program, Watts Health Foundation. Is Clement here? All right. Dr. Germaine Maisonnet, Director of the AIDS programs for Vacaville. He's not here. All right. Is there a Phil Jackson? I thought it was Phil. I don't think Phil -- is Phil Wilison here?

Okay. Then we're going to move into -- no, he's not here -- our community-based organizations. I don't see Doctor -- or the Reverend Carl Bean. Okay. Elma Colbert is represented. All right. We have -- I know Paul Davis, Valarie Taylor. Would you like to come up in lieu of Dr. Bean? If so, just come right up to the mike.

All right. You may decide who's going to speak first.

MR. DARRYL LUDD: I will start first. My name is Gerald Ludd. They had a

misprint in the agenda. I'm Gerald Ludd, the Operations Administrator for Minority AIDS Project.

My main concern here is dealing with the financial aspect of AIDS and the funding. I want to thank Dr. Jordan for his presentation based on his information really led into what my concern is, your comments to Mr. Sauseda and to Frangenberg, also with the statistics, really led into what I have to say.

I primarily deal with the financial aspect and the funding of the Minority AIDS Project and the concerns of other minority projects within South Central.

Our main concern is in the funders themselves and their proposals and what they're requiring in those proposals as it relates to those people in the people-of-color arena. We say South Central; we have no boundaries as far as the people we serve. But we primarily serve as minorities, and a majority of these minorities are comprised of the people out of the prison system, homeless, and what have you. So we're also not dealing with just HIV, but we're dealing with dual- and tri-diagnosis which is drug addiction or alcoholism. But as the funding sources prepare these grants for you, they write them in such a way that it's a general grant. That's for overall AIDS agencies, but they're not really addressing those issues in the minority arena.

As we write and ask for these funds, we have to write them in such a way that we can get the grants themselves. But along the way, the funding that we need from direct -- indirect sources -- corporations, and what have you -- need to take up that slack. But in the funding sources themselves, you need to re-look at the people of color themselves and the need, which I've heard several times here, the need which is necessary to service these people.

The funds, as far as a percentage, we have increased in Minority AIDS Project, are in the South Central area as far as the people that we're serving. But whether they're men, women, children, which we do have our increase in women and children, but the monies have not increased. And those are the type of things that we want to address today. And as we write these proposals and as the funders actually make these funds available, they need to take into consideration the need is not the same; the need is different when you're dealing with dual- and tri-diagnosis and the method in which the funding actually pays you.

Our problem is in the Black community; and why a lot of the Black businesses close is because we're actually open to fail based on how society or how the grantors set up the actual perimeters for, or your guidelines for, that particular program. We don't have the money to wait two to three, four months to be reimbursed. So we have a reimbursement problem at all levels that we're dealing with. Primarily, that's my main concern. And we do and we are planning on writing

up some type of statistics to send to you and others in government so that they can understand what we're talking about when we're talking about figures covering expenses. I think you know a lot about what's going on, and we're trying to readdress it so that if we really spoke the way we wanted to speak to some of these grantors, we -- I don't think it would be funded.

CHAIRPERSON WATSON: You know, I get real tired with the department coming in and saying but they are not sending up their proposals correctly. You know, we've got an epidemic out here, and I'm saying to the department, hey, don't bring that in to me. What you need to bring into me is how we're going to get the funds where they're needed. We've got X number of dollars, and you find some way to correct the proposal. You find some way to have the application look like you want it to look. You find some way to have them account for those monies, but get the monies down there in a timely fashion so that we can try to save lives, apply treatment if we can; and, if we can help people as they go through their demise because of AIDS. And I think to use the excuse, well, they didn't dot an "i" -- they' didn't cross a "t" or put a period in the right place, or they didn't write in the right box -- is an excuse for not doing much.

So I would agree with you -- and I've had to say this to the department and the Office of AIDS -- don't spend your time talking about the deficits. You spend your time with me talking about how we're going to solve the problem and get those monies down so services can be delivered.

MR. LUDD: Thank you, Senator. Paul Davis, head of our Health Education Department, and Valarie Taylor, our nurse, will cover other aspects.

MR. PAUL DAVIS: Good morning, Senator, and members.

One of the things, in terms of education and prevention, is over the last five years, the numbers in terms of people-of-color community is increasing. And one may say, well, we've been doing education out here; and therefore, for 1991, everyone should know AIDS does exist and how you're able to transmit it.

But in the people-of-color community, we are still behind. And when the announcement of Magic Johnson came out and our phones began ringing off the hook, there were still people thinking that it was caught by mosquito, that it was still toilet seats and so forth. And so that sort of gives you a level of there is still a large amount of education that's needed in the people-of-color community. I know to a large degree that a lot is basically going to treatment and not saying that there's not money needed in that particular area. But particularly in the people-of-color community, there is still a great need for education.

And one of the things I think we've made a misnomer is that, yes, it's on TV. But one of the things I've observed in terms of the people-of-color community, they

don't watch the 6 o'clock news or the 5 o'clock news or the 7 o'clock news. They turn to Channel 5, Channel 9, Channel 11, and get the reruns of Lucy because they've seen enough problems in their community already that they deal with on a daily basis. And it's like I don't need no more bad news. So a lot of times, they don't get this type program. They don't necessarily watch the specials on AIDS and so forth. And it took some of us a long while to begin to realize that in 1991 persons should know all of this information. Many of them don't read the various periodicals and magazines. Many of them cannot read, period. And we need to take that into account when we're talking about the whole thing of education.

When we're particularly talking in terms of the undocumented population, which is a population we work with in our AIDS project, again, if it is not in the appropriate language, they have not gotten the information. So a large media campaign to a large degree in our community does not work. The best that we've found is the one-on-one, meeting with people, talking with them in small groups.

Holding group meetings, we've done that; we've tried that. But a lot of persons in our community are not coming out after 6 o'clock. They've worked all day; they are tired. They're not coming out because they're afraid of the whole thing of gangs and so forth, and they have to ride the bus.

South Central is a very large area based on -- let's say, if you take from Pico on south. So it's a very large area. People are not necessarily going to come out in large groups that you may find in the West Hollywood or Hollywood area. So you don't have the advantage of getting that information.

One of the populations that we service at the project very heavily is the population of the homeless, which I feel is a very under-served population. And it is an invisible population within our community because in some cases you cannot clearly distinguish those persons are homeless. But in fact, they are homeless. The homeless today are no longer the stereotype of the whino in a doorway, and they are found all through South Central.

To a large degree in this particular under-served population, you have a problem of not just being you tell the person you need to practice safe sex. If the person is homeless, he has no money for condoms. Condoms are not in his budget. And that's one of the reasons we need a program where we constantly visit certain areas of the homeless in passing out free condoms.

Even if the person feels that they are at risk, they do not have the money to go to get tested. I mean it requires $1.15, $1.25, to take that bus to come over to the Minority AIDS Project to get your test and then the same amount to come back the following week. And if you're concerned, in terms of where you're going to eat and where you're going to sleep, that is very important.

Even if you find out somehow, if our van picks you up and you find out and you get your results back that you're positive, how do you go for treatment? For a long time, the only place we could refer persons is to Dr. Jordan's clinic which is all the way in South Central. Again, you have the money of transportation.

There's also, I think Dr. Jordan raised, in the question of self-esteem which I think is an important part in the people-of-color community in prevention and education, that that is a piece. That needs to actually be worked on. And even if you say, well, the person gets G.R. here in L.A. County, the amount of money that person gets in G.R. usually only lasts the person for the first three weeks. And a large number of them, we find that, for that last week, they are on Santa Monica Boulevard to try to get enough money to maintain their room for the last part of the month. So those are some real issues that we have to look at in terms of that whole population.

Even if we look at the issue of reaching gay men of color, we have to look at different strategies because the traditional strategies do not work. A large percentage, first of all, there's a very diversified community there; and secondly, that you have to look in terms of with that community how they perceive themselves. And a lot of them do not perceive themselves because early on in the whole thing of education and prevention, we made some major mistakes. We talked about certain groups. We talked about persons being gay, and we talked about persons who are IV drug users. And a lot of persons in the minority community says that's not me because there are a number of men who have sex with men but do not consider themselves gay.

We need to look in terms of the PR that we have out because a lot of persons do not see people of color on the posters, on the brochures, in terms of -- so that's an area that needs to be looked at.

Again, in terms of the basic needs in this area, more one-on-one street outreach to go where people are, to go out to the bars, to go out to where the homeless are, to go out to the parks, the people who are hanging around the liquor stores, and do a one-on-one in terms of getting information to them.

Also, in terms of testing, we need more testing sites in the minority community. One of the things that happened after Magic Johnson made his announcement where we were doing testing at the project, about 15 people on a Saturday, the first Saturday; it increased to 115; the second Saturday, it increased to 123. And we've had to expand now to Tuesdays and Fridays, and the phones are still ringing in terms of people who want to come in. There's a backlog in L.A. County of people who now want to get tested and cannot because it is booked up for three months, so that is an issue that needs to be looked at. And one of

the other things in the minority community is there is a need for more monies in terms of grants because most agencies do not have large sums of money that they can pay staff, pay the rent, and so forth, even if they get the grant, and then wait for the funding source to reimburse them; so some way of not looking just at the fee-for-services but some way to give an advance up front to get the agency off the ground. Thank you very much.

CHAIRPERSON WATSON: Thank you.

MS. VALARIE TAYLOR: Good afternoon, by this time, Senator Watson. Can you hear me?

CHAIRPERSON WATSON: Yes.

MS. TAYLOR: My name is Valerie Taylor. I'm currently the nurse case manager, acting Minority AIDS Project, and Director of our In-Home Nursing Services. We have -- that's called Pilot Care Program, and another In-Home Nursing Service that we are providing at the project is Medi-Cal Waiver.

I'm here for a couple of reasons, one representing client services -- our project director was not able to be here. And the other is a patient-client advocate. By the time clients get to me, they're very depleted. These people are no longer just home-bound; they're bed-bound. Home-bound is one thing; bed-bound is quite another.

My two programs, one is funded by the state, which is a pilot, CURE, and the other Medi-Cal Waivers, is funded by HURSA. 1991 was a devastating year for Pilot CARE programs. Anyone who was, who took the risk to even decide to provide In-Home Nursing Services took a risk in itself. That's a very costly thing. Health care is is costly; nursing hours are costly. 1991, we were told we will provide you with these hours, but we'll also cut those hours.

When people come into, when my clients, people of color and minorities come to the point that they are bed-bound, they're coming into the system very late. There is no longevity usually once they get to that stage, so aggressive intervention needs to happen once we have taken them out of the acute facility who at this point want you to take them out of their bed. It costs a lot of money to maintain a client like this in the acute setting. So once you get that person home, we're obligated as health care providers to be an extension of what would happen in that hospital. We need to provide them with levels of care that the state or might the state is not willing to or is unable to provide us with.

If we go into a home and a person requires eight hours of care and we can only, with the dollars available to us, provide four, we're either saying we'll give you four and hope and pray that you live to the next day; or we'll give you what you need, and we'll hope and pray we get reimbursed for four hours when we

gave you twelve. I have difficulty making the compromises in these areas. It gets back to are they worth saving. I thought that that was integral when that was said in this room.

I've been a nurse for 25 years next month. I've never, in this particular arena, I hear that question a lot. Who's to say that; who's to judge? Most of my clients coming on into the program here, at the Minority AIDS Project, 35 percent of them have no health insurance. When they come to me, 80 percent of my client base has no health insurance. So that isn't even an issue. It's a big, big need; but it's a need that the entire country has. We have a health insurance; we have a health problem and a health care system that is not working. Even with that, with no health insurance, if you wanted nursing care, we went into something called Medi-Cal Waiver to at least give us the luxury of saying we can provide you with this care; we know you need it. And the government said fine, we'll let you have this. But before you can have this, you need to have a Medi-Cal card. My clients don't have Medi-Cal cards. They can apply, and we do offer that service at the project. It takes 30 to 90 to 120 days just to get that application through, and usually it takes six months before they actually have the card in hand. Unfortunately, most of my clients have already expired.

We have, but that's the option. We've given you something; and we told you, you can use it. But you have to be alive to use it. I don't know how fair that is, and I'm losing my -- this has been going on for two days, so excuse my voice as we go through this. But that's the option that we're left with. So either we provide care with not enough hours and not enough money, or we say, fine, the government will give you this if you can live long enough; and that disturbs me greatly because then I don't know are they worth saving. I think they are.

The state is going to, again, in '92, we will be experiencing again another cut in nursing hours provided. The government on the Medi-Cal Waiver system, we're being forced to use a system that I really think is there but my clients are not -- I can't get them in it because the cards are not available or they can't get in the system to get the cards. So if we went to the Medi-Cal Waiver system, the reimbursement for a care-giver on that system for just an in-home attendant is $4 less than a home attendant can make going through another agency. Why would you come to a community-based if you can get $4 more going someplace else?

So you're saying, I've given you a card if you can get it. Now that you've got it and you live this long, I can't get you a nurse because the nursing services, they're in business, not that they're not compassionate, but they're in business. The reimbursement for those kinds of care-givers aren't really creditably licensed; home-care services is $4 below. Our project has been

absorbing that cost. That is not a long-term situation. It is certainly short-lived with us because we don't have the funds to do it. But we are leaving people who are now not only just home-bound -- bed-bound. And In fact, as you said very visually, they are in fact dying. I don't know what happens when people get bedbound. Is the quality of their life considered less worthy -- because you don't see that. They're at home; they're in a home. You don't see that. But the nurses that are there and wanting to help and the programs we must have in the minority community, there's only one pilot-care program in South Central. It's ours.

I receive referrals from other agencies, and I'm not at liberty to say the other agencies at this point, and they are referring clients over because they will not absorb the cost, and they can't. But it has been our philosophy and our mission; and not just since I came to Minority AIDS Project, myself as an individual, health care provider and registered nurse, I could not in good conscience turn someone away because they cannot pay and because they don't have health insurance and because they don't smell so good and because they can't get anything else. That has never been the mission of the project. It has never been my own personal philosophy.

And I'm here to say as the advocate for my clients who could not get here. If they could get here, they'd be here. If it was on stretchers, they'd be here. If you're going to say we'll give you nursing in your home, let's do it the right way. If you say we're going to have hours, make the hours available. And if you're going to say we're going to give you a Medi-Cal card, give it. But when people get to this level, you shouldn't toy with them.

I thank you.

CHAIRPERSON WATSON: Thank you very much. We certainly appreciate that testimony coming from one of those projects that's in the community and dealing with people who are dying every day. It has a great impact on us. Thank you.

MS. TAYLOR: Thank you for your time.

CHAIRPERSON WATSON: Yes. I'm going to go through my agenda just to see who's here. I'd like to first ask Dr. Elsie Lu to come up; Elma Colbert, Cynthia Davis, Suzie Rodriquez, Mario Solis-Marich, Mike Neeley, Kazue Shibata, Helen Fitzgerald, Joel Tan, Corinne Tanon, and Paula Starr. If any of those people are here, they may come up now to the table. And be sure that you identify yourself. Great.

If you cannot sit here, then please sit in the front row. Then that will indicate to me that we have people here that are on this list.

We'll start with you, Dr. Lu.

DR. ELSIE GO-LU: Thank you very much, Senator.

It's always an honor and a pleasure for me to speak before you and to provide

some information that may be helpful in decisions that you may be making. Specifically, I'm the Deputy Director for L.A. County Department of Mental Health. And I have primarily the forensic mental health services which relate to the incarcerated mentally ill as well as my responsibility for the HIV mental health services for the County of Los Angeles.

I also sit as an advisor to the AIDS Commission of L.A. County for mental health issues, and I'm a member of the AIDS regional board. So I come to this committee basically very briefly to tell you about the HIV mental health needs in the ethnic minority communities.

The State Department of Mental Health through the state budget and the state legislature provided funding for mental health services four years ago for about a million dollars for mental health services for the State of California. And since then, there has been no augmentation in that budget. L.A. County obtained $376,000 of that to provide services for all of the mental health needs here in Los Angeles County. And that is actually insufficient funding, so we have primarily used some HURSA funding, have worked with the AIDS program office, have gotten another $100,000 for the AIDS program office, to provide some services. And during this past year, through the Title I of the supplemental funds, have actually lobbied to have another $641,000 added to the mental health needs of the people with HIV.

Let me just tell you about what the funding currently provides for. We have actually provided funding through community mental health CBOs -- the Gay and Lesbian Center, APLA, Minority AIDS, Milagros, sort of a little piece of funding spread out through the community, sort of like seeds so that they could spread and have some impact on the population. And yet we feel that barely scratches the surface of the great need that his here. For example, of the population that we have in our HIV day treatment program, 29 percent of the population is Afro-American, and 29 percent of that population is Latino. The rest of them are white and a small Asian group.

But basically for someone to be mentally ill, that is a stigma. For someone then to be HIV-affected, that is an additional stigma. And for usually someone that have mental health needs, they are multiply diagnosed also with substance abuse. And, of course, added to that, is if you end up being mentally ill and having HIV and then being incarcerated, you have actually a lot of problem with almost very little help, shall be given to you.

A couple of years ago, we participated with the AIDS Program Office in a HIV-strategic plan. And we meet a needs assessment for the mental health needs and a comprehensive plan also. If we have the money that is truly needed from this community, this is the level of services and programs that are needed here. And

just to give you some ideas of the target population that would be served, there are those that have advanced HIV brain disease. And that would cut across different ethnicity.

For a specific purpose, for example, what we were able to help is someone with early dementia. They may need a psychologist or a professional person's help. In order to get them SSI or actually in some cases, they may have been driving around and have forgotten their driver's license several times. And instead of being incarcerated, basically we could help by having diagnosed them and said that their problem is due to dementia. So to have sufficient mental health professionals to provide the psycho-neurological assessment in order to determine this would be very helpful for this population.

Then we have the chronically mentally ill who then get affected with HIV. We have provided a lot of training to board-and-care facilities in order for them to be able to deal with this type of problems because they are mentally ill, chronically mentally ill, that are in board and care who are basically in board and care. You realize that there is consentual sex relationship that therefore you had to teach the board-and-care provider how to be able to deal with this kind of problem in order to have AIDS prevention. That's one of the areas we had focused in. And as I talked to you about the persons with multiple diagnosis; and right now, actually in all the programs that we have, there is very minimal mental health services in those programs.

We have primarily concentrated on a lot of educational programs in order to use the minimal funding that we have. We have provided training to our own mental health clinics as well as the private clinics that have contracted with the county in how to deal with this population and deal with the services.

The plan itself go into a full range of services from acute...

CHAIRPERSON WATSON: Let me just ask this -- in listening to Dr. Jordan's testimony, he, providing services in Watts, are there programs -- are there places, facilities where the people he described can go, the people that he realizes are dealing with the psychological shock, where do they go and can they go into these programs? Are you training the county health professionals? To what extent are you training them in the mental health program? How many are available to treat the people that he described?

I got the feeling from listening to him that there was almost nowhere for him to send these patients.

DR. GO-LU: Actually, what he...

CHAIRPERSON WATSON: Or that the waiting list was long.

DR. GO-LU: Yes. He is actually correct in what he had presented to you. The

issue, as you're aware, is with the diminished funding in the community mental health programs, that we have to focus our services to a target population of the chronically and severely mentally ill.

We have, primarily in our master plan, included crisis intervention. And we got it in through efforts of the CBOs and the HIV resource mental health group, that at least for those that have HIV-infected, that there will be eight crisis intervention sessions available to them. But, of course...

CHAIRPERSON WATSON: How many sessions?

DR. GO-LU: Eight sessions.

CHAIRPERSON WATSON: And where are these sessions?

DR. GO-LU: That would be at county-operated clinics. Of course, then there is a priority listing and the waiting list is long, as Dr. Jordan presented. They may be waiting a long time, and depending on where that availability of services.

CHAIRPERSON WATSON: Yeah, I guess what you're doing is supporting the contingent, if there is a serious problem here. There's not enough of this training and not enough people to deal with the patients. The waiting lists are too long, and they're going to have to wait and maybe their lives will not last long enough to be able to be treated when they need the treatment.

As you say, crisis intervention, and my definition for crisis is something that is happening right now. And if this is crisis intervention, then I think what's being offered cannot really deal with the number of people who are in crisis. That's one point I want to make.

The next point is -- and I'm not blaming you.

DR. GO-LU: I understand.

CHAIRPERSON WATSON: I'm trying to describe the problem and the emergent needs as they relate to that problem.

We just realigned the way we appropriate monies to the county for mandated services which no longer are going to be mandated, but they are required of the county to deliver; and one of the areas is in mental health.

Now the counties appear to be elated over being re-aligned. I never showed that elation. I think you were up there when we had some of these discussions because the reality is you're going to get a smaller pot of money, and they said that's great. But what we did, we took our oversight away. There are no longer mandates, to be sure. Now maybe you're going to do the right thing, but I'm worried about the other 57 counties. In reality, I was worried about my own county because I've not seen a lot of evidence in the past that they were going to do the job the way it needed to be done. But, however, all we're asking for is date of collection.

What I'd like to say, and I hope that you can do something along these lines, is lay out of a plan, a model for us, as how you're going to -- the dollars will not increase, as you know. They probably will decrease. But now you can handle those dollars differently. It's stump money; we put it on the stump; you run up and grab it. And we're saying that those dollars have to be spent in those categories for which they were attended. And you can only comingle 10 percent of that money. So what I'd like to see is count the county showing some kind of model or strategy for taking those sessions you're talking about to the people.

If we really zero in on the problems, you know, transportation problems -- not wanting to travel at night -- the fact that the streets indeed are dangerous and these people indeed are at risk, then how do you solve that? How do you put those programs for people who are in crisis to receive?

DR. GO-LU: I realize that we went from 40 county-operated clinics to about 22.

CHAIRPERSON WATSON: Yeah, yeah.

DR. GO-LU: So that there is a greater geographical distance. But on a monthly basis, from the funding that we did receive from the state, we have every clinic identify a HIV liaison who comes; and we provide updated training to them. And in order to be at least aware of the most current way to deal with the HIV affected and their mental health needs.

CHAIRPERSON WATSON: Yeah, but you're identifying one.

DR. GO-LU: One area. In our day treatment program, we are aware of the transportation need. But basically, we know that. And so we have a van. We have about a 20 -- there's a certain radius you can pick up here only in L.A., and we need those day treatment center one exactly here in this community; but there is no funding currently right now for that because we do have that and that's located in...

CHAIRPERSON WATSON: Well, that's going to be your decision, you know. We're saying: This is money for mental health; now you run the program.

DR. GO-LU: I wasn't aware that in the target population HIV was one of the ones, but maybe that's...

CHAIRPERSON WATSON: Well, I think you're hearing the need --

DR. GO-LU: Uh-huh.

CHAIRPERSON WATSON: -- expressed today.

DR. GO-LU: Okay.

CHAIRPERSON WATSON: You can't really separate them out any more. When we start targeting a population, we talk about mental health services, they should go to the homeless, the HIV-positive, the person with cancer, you know, and all, that

whole radius, categories of clients out there that have real emergent needs and are in crisis; and I think that's where you're trying to zero in. How do you address the crises that they're in?

DR. GO-LU: I understand that.

CHAIRPERSON WATSON: Dr. Tate?

DR. TATE: Yeah, I just wanted to piggyback on that because the dilemma that I think the county is in is that now, because funds are so tight, this targeted population definition that they're operating under is so, so narrow, that those people don't fit crisis as defined now by the county, that crisis now means, excuse me, however it's so narrowly defined, that, you now, you have to have, I don't know, hallucinations, delusions...

DR. GO-LU: Danger to self and others.

DR. TATE: ...dangerous to self and others, and, you know. So I think that when you look at re-aligning L.A. County and appropriating dollars for various types of interventions, that, as the Senator was saying, certain populations, I think, need to begin to come to the forefront as really maybe opening up the door in some areas for crisis intervention for particular types of services so that when we integrate the Department of Health Services with the Department of Mental Health and the Department of Corrections and other county departments, we're working together in a whole continuum rather than a fragmented service delivery system specifically for HIV-positive and AIDS individuals.

CHAIRPERSON WATSON: We have in our hand a double-edged sword. I remember when we sent some programs out to the county years back. And one of the counties said they took the definition, and they revised the definition and said we simply don't have any of those. So therefore, there was a whole population that went untreated.

I am hoping that in L.A. County, the largest county with the most number of cases, that you might start to look at the definitions and see how restrictive they are and how can we broaden those definitions to serve people in crisis. And you'll have that in your hands.

DR. GO-LU: I will have that; and as you're aware, I will be presenting this to our new mental health director when she arrives.

CHAIRPERSON WATSON: Now the new mental health director is...

DR. GO-LU: Dr. Areta Crowl.

CHAIRPERSON WATSON: Yeah. All I know about her is what's on paper, and I would hope that we could meet with her and talk about designing a program --

DR. GO-LU: I will convey that to her.

CHAIRPERSON WATSON: -- for meeting the needs of people in crisis, you know,

and particularly those who are in crisis because they learned they were HIV positive, as well as some of the other areas too.

DR. GO-LU: Thank you for that support.

DR. TATE: Just one other question, Dr. Lu. Before you arrived, Dr. Jordan spoke a little bit about studies, or the lack of studies, of prisoners and their sexual behavior, as well as HIV and AIDS victims and what we don't know about what's going on in the prisons. Since you're in charge of forensics...

DR. GO-LU: Forensic mental health.

DR. TATE: Okay. Just with regards to forensic mental health at the county jail, what's going on, if anything? Do we have any knowledge base, any data, with regards to HIV AIDS?

CHAIRPERSON WATSON: Are condoms available?

DR. TATE: Yeah, are condoms available? What about sexual activity? Just generally, can you give us a picture?

DR. GO-LU: The medical director for the Sheriff's Department medical services actually is the person that works and establishes the policy regarding AIDS in L.A. County jail system, and he has collected some data. But you're aware that there is no required testing; and therefore, it would be only for those that had voluntary...

CHAIRPERSON WATSON: I think she's going in a little different direction because I raised the question with Dr. Jordan.

DR. GO-LU: Okay.

CHAIRPERSON WATSON: And my question was -- well, he really started it. He said, you know, in the prisons it is acknowledged by some of us that there is sexual contact, usually forceable sexual contact. These people come out of the prisons and the jails, and they go back to their partners in civilian society; and this creates a problem. So we were trying to find out what are they doing to acknowledge the fact that there is sexual contact in jails?

Now, you know, I've heard this -- I'm putting you on the spot, Dr. Lu. But we've gone through this in Sacramento. We get people in from Corrections that, oh, sex is prohibited. So this is a game we all play. And, you know, this is a game I'm playing right now by asking these questions. I know what the answers are.

DR. GO-LU: My personal opinion is, yes, I do agree with you. Those types of behavior do occur in the jail. But you also realize that anything that is not given to the inmates by the sheriffs are considered as contraband. And therefore, until the sheriffs approve condoms, it cannot be brought into the jail setting. And actually, it could be used for a lot of acts that may be dangerous also to others. So I think that's part of the rationale provided.

CHAIRPERSON WATSON: Well, why does the administration allow personnel in the jails, the county jails, to allow this behavior to go on and do nothing about it? It goes on. I can bring you any inmate will say that he hears screams and all. If they hear it, why don't the guards hear it? And why doesn't the administration of the county jails do something about the problem? Do you have any idea? I know you're the wrong person to ask, but you hear rumors.

DR. GO-LU: I believe that the -- if it's heard -- this is what I'm told, they do prevent it from occurring.

CHAIRPERSON WATSON: But they don't hear it. They all of a sudden have a hearing loss.

DR. GO-LU: The ratio between a deputy and an inmate is very high in L.A. I mean you have two deputies observing and watching a cell of 250 inmates. And if you have not come and visited the jail where the ability to see and hear all the time of every cell is not quite visible at all the times. But I'm told, and we have approached the subject, that when they hear it, they do prevent that too.

CHAIRPERSON WATSON: Well, I don't understand how three or multiple inmates can get one inmate, and to have a sexual act. And the people who we pay to guard do not know that.

If I know it on the outside and if I know that at any given day, you can have over 500 prisoners test positive for HIV, something's going on in that environment and somebody ought to be aware and doing something about it. You just happen to be the person here from the county who's on the hot seat, Dr. Lu.

DR. GO-LU: I understand.

CHAIRPERSON WATSON: And I'm not holding you to blame for these situations, but I'm making some statements that I hope will be heard.

Okay. You wanted to finish.

DR. GO-LU: Well, actually, I just -- you had asked if there was some kind of plan, and I believe that I'd like to share this strategic plan, the mental health piece of it, with your committee.

CHAIRPERSON WATSON: Thank you. And we'll have someone pick it up. You don't need to go over in detail. Just tell us.

DR. GO-LU: No, I won't do that. Well, I thank you. And if there are any other questions, otherwise...

CHAIRPERSON WATSON: I think I've raised all the points that need to be raised.

DR. GO-LU: I think -- I heard you loud and clear, and I'll convey this to both the Sheriff's Department and to my department.

CHAIRPERSON WATSON: You know, years ago, I carried a bill to extend the

Robbins rape laws of evidence to prisons and jails and so on because I was alarmed at the number of homosexual rapes and the number of sexual contacts within lockup facilities. Most people here are going into the county jails -- the homeless, the mentally ill -- are going there, people with some kind of addiction and so on are going into the county jails. So I guess if we're going to look at a facility that is closer to home, we're going to look at the county jails. And I'm alarmed at what goes on inside. It's scandalous as to what goes on in the county jail.

DR. GO-LU: In addition to what you say, it's also primarily the largest ethnic population.

CHAIRPERSON WATSON: You've got it.

DR. GO-LU: And the county's concentrated in the jails.

CHAIRPERSON WATSON: And when we use the figure one out of four African American males, a lot of them are sitting there; they're sitting in California Youth Authority; they're sitting in the state and federal prisons. And we're seeing the AIDS incidents going up, particularly in this population. We've got to start being sensitive and doing something, so you've got the message.

DR. GO-LU: Thank you.

CHAIRPERSON WATSON: Thank you. All right. I'm going to go right down my list. Elma Colbert. All right. Cynthia Davis.

DR. CYNTHIA DAVIS: Elma's right here. She's coming.

CHAIRPERSON WATSON: I beg your pardon.

DR. DAVIS: There's Elma.

CHAIRPERSON WATSON: Oh, okay. Elma Colbert.

MS. ELMA COLBERT: Hello. I'm Elma Colbert. I'm with Charles Drew Medical Center, NOBCO, Southwest College.

CHAIRPERSON WATSON: You want to pull that mike right up in front of you, please. Just pull it right over so it's in the direction of your mouth. Thank you.

MS. COLBERT: Okay. In Southwest College. I'm a community worker there and I do outreach. And I'm also a counselor for testing.

CHAIRPERSON WATSON: You're talking in this direction. You're mike is in that direction.

MS. COLBERT: Okay. Okay. Is this better?

CHAIRPERSON WATSON: We're trying to pick up your testimony.

MS. COLBERT: Okay. And I'm also a person that's living with HIV. I guess, first of all, I should say that my concerns are that more studies should be done for women. And it's too many times that women test HIV or women are HIV-positive; and other things have gone on; they're not tested for other things.

I'm a person that's been, received January 1, '84, and I have to yet, be, have GYN services or any other services through the county which I have been a patient there since being infected with the blood. There are 10 to 26...

DR. TATE: Excuse me. Let me understand that.

MS. COLBERT: Sure.

DR. TATE: Repeat that again.

MS. COLBERT: I will. I received blood January 1, 1984.

DR. TATE: Okay.

MS. COLBERT: They informed me that the donor had died in '85.

DR. TATE: Uh-huh.

MS. COLBERT: At that time, I had been under medical care since '85. And since '85, not one doctor, not one, has given me a smear -- I haven't been to a GYN clinic.

DR. TATE: You haven't had a Pap?

MS. COLBERT: No.

DR. TATE: Is it because they won't accept you because you're HIV-positive or...

MS. COLBERT: I just think that we're on the back burner.

CHAIRPERSON WATSON: Have you requested...

MS. COLBERT: Pardon me?

CHAIRPERSON WATSON: Have you approached the...

MS. COLBERT: Yes, yes. And if it had not been that I have a friend that's a medical doctor, that has no knowledge about this disease, if not for him, I would not have had any physicals or anything else since I've been diagnosed as being positive for the virus.

You complain; you talk about things that are happening with you. There's no money or they can't do anything about this until something, more major happens to a person. How much more major can a person be than to be a person that has ten T-4 cells? I have ten. I have one helper cell, and everything else. I'm totally without most things that would make a person function or make the immune system function.

I'm an advocate for women, and I should say because I hope that not one other woman that's infected with this virus has to go through or deal with the same things that I've had, that I've gone through, or not being listened to or not being heard. I think that if you have one person that has ten T-4 cells, and then you have another person with 200 T-cells, the person with ten is alive, doing well, that more studies should be done on that person than opposed to the person that has died already with 200 T-cells.

I hope I'm not sounding selfish, but deal with us that are living and that are doing okay because when I say I have ten T-cells, you would expect me to roll in a wheelchair at least, you know. So find out why we're doing well. More studies should be done for women; and then the ones that are doing exceptionally well, more studies should be done on that as opposed to just dumping us off with a bunch of medication that has been basically tested on men, not on women. We're just lucky so far that it's not causing other problems to happen. I'm on a new medication now. So sometimes it's, for the last three days, I'm sort of high and low. That's what's happening right now. I'm on I and H, which I feel I should have been on a long time ago. But due to the backup and due to the fact that I wasn't physically having any problems, then it was overlooked. It was something that just was not dealt with.

So I'm sorry for the up and down. But a person that's living with this virus, we have a lot of concerns; we have a a lot of issues. I was sitting there laughing when you were talking about Magic because we have a lot of support systems that we kind of deal with each other. And we're all having negative and bad feelings about that because this man was getting glorified for being HIV-positive. And we then have been living with this disease all this time, still can't come out of the closet, you know. Issues where -- I work at Southwest College. The women there on that campus is so unaware. More education, more understanding, more -- I don't know what more could you give them. But they need more because when we go out to lay out literature to talk about AIDS, it's even to the point -- some people feel like if they read that, if they touch that, then they're going to get the virus. That's how unaware they are, you know; as opposed to, and I go no, it's if you pick it up and you read it, then you'll find out how not to get it.

Women need to be more in charge, more control. In my situation, my being in charge or my control would be me talking and demanding and asking about medications and things that are available for me to take. A woman that's not positive for the virus, her taking charge and her control would be being able to get more skills and communication to deal with partners. And women don't have that. And I was really surprised when I got to Southwest College. More things like that need to be dealt with. Women need to see and hear more about how they can communicate and negotiate skills to deal with their sex partners. And women need to know that they have that control, they have that control, without hearing it repeatedly and someone continuously reassuring them and reaffirming the fact that if you stand up for what you believe in and what you think is right, I think less women would be positive now because they would not submit to doing anything with their sexual partners that did not feel right or did not set well with them. And I'm just one of those people

that happen not to be a person that was infected sexually. But the issue still stands. The majority of women that are becoming infected today are women that are infected through heterosexual relationships, and they just need to take a better charge and a better stand.

CHAIRPERSON WATSON: Thank you so much for your tetstimony. It is reaching home, and I think we've come to the same conclusions pretty much at the same time.

All right. Cynthia Davis.

MS. CYNTHIA DAVIS: Right here.

First of all, I'd like to thank Dr. Tate and Senator Watson for giving me the opportunity to present to you this morning.

My name is Cynthia Davis. I'm a health educator. I work for the Charles R. Drew University of Medicine and Science which is associated with Martin Luther King Hospital.

I have worked in the community since 1984 developing family-life education, sex education programs, primarily for at-risk youths, Blacks, and Hispanics. I am currently coordinating two AIDS education and prevention programs for the National Organization of Black County Officials which is based in Washington, D.C. -- that's NOBCO. They received a grant from the Centers for Disease Control in 1987 to develop a model program targeting the Black community that could be replicated around the country where they had their constituency. So I coordinate two projects for NOBCO, and I provide technical assistance to two other programs.

On a local level, one of the programs that Elma Colbert works for, I wrote the grant or wrote the proposal for that program at Southwest College which is primarily targeting women of childbearing age and a local program that's funded by the Department of Health Services, Office of AIDS, primarily targeting school-age populations in South Central, incarcerated populations in the general community.

In my written testimony, I'm going to sort of skip around, since you have it, and you can refer back to it. In the packet of information that I've left with you, I've given you reference material focusing on AIDS and HIV and its impact on adolescents, young adults, and women because those are the populations that I primarily serve.

Just as background information, as of October of 1991, there have only been a little over 758 cases of AIDS reported among adolescents. That's 13- to 19-year-olds. That's on a national level. And locally here in L.A. County, we have approximately 30 cases of AIDS reported among adolescents.

I think, that even though the numbers are low across the board, both on a national and local level for adolescent populations, that we should still be vigilent in terms of providing comprehensive education to that population, given

the fact, that with the long latency period, from the time of initial infection until one is diagnosed with AIDS, which can be from one to ten years, that many people who are in their 20's probably contracted HIV in their teens. For far too long, HIV has been considered a gay, bisexual, white male disease. In our community, that still is a misnomer. Again, I've been involved in doing direct community outreach for close to eight years now with school-age populations primarily in the Compton Unified School District and the L.A. Unified School District.

When we first went into those schools in grades 5 through 12, just coming into the room, a lot of the students were thinking, well, why were we there? Did we have AIDS? Is that why we were there? There was a lot of misinformation concerning how the virus was transmitted, thinking you could get it from the toilet seats, mosquitos, et cetera.

From anecdotal information that we have gathered, many of the kids are engaging in at-risk behaviors through sexual activity because of drug use. Kids who are in classes for mentally disturbed kids, we're finding that a lot of those kids are being, have been sexually abused. And so we know that it is going on. If you look at the rates of teen pregnancy in L.A. County, as well as the rates of sexually transmitted diseases among adolescent and young adult populations, we're at epidemic proportions. And as far as STD goes, the rates of gonorrhea and syphilis have been at epidemic proportions in South Central since the mid-80's. So it's all of these things are indicating to me that we have a whole community, a whole generation at risk for HIV infection.

DR. TATE: Ms. Davis, let me just interrupt you here. Of the 30 reported cases of adolescents and youth that have acquired the disease, do we know what it's been attributed to, if it's sexual behavior, HIV -- I mean IV drug use?

MS. DAVIS: Some of it -- the numbers are low, but some of it has been due to same sex between men, homosexual, bisexual contact, and heterosexual contact, and IV drug use. You can get that information from the AIDS Program Office, the Department of Epidemiology. Unfortunately, in their monthly report that comes out, they do not break it down by gender. So we don't know the number of males, ratio of males to females. And they don't break it down again by transmission category for the adolescent population; and you have to go and make further inquiries on your own to get that information.

I think other co-factors that have to be considered in implementing effective programs have to do with the fact that we're dealing with a population that has low literacy, a population unemployed, the incarcerated population, and again the drug use that is going on, and early sexual experimentation. Research has shown for the

past 20 years that in major inner-cities annually that the rates of early sexual activity are just decreasing in where in a lot of major inner-cities you have children who are young as 10-, 11-, 12-years-old initiating sexual activity.

I wanted to briefly, to talk about some of the barriers in terms of funding. I don't think none of the previous speakers really talked in depth about the Ryan White CARE Act and the fact that with this money being available for the next four years, how that is going to impact people-of-color communities.

I serve as a board member of the AIDS Regional Board which is responsible for allocating Title II funding, and I serve as an alternate, recently identified as an alternate for the CARE Council, Title I funding. And I also chair the Minority AIDS Consortium which is a group of service providers primarily targeting medically underserved communities in L.A. County. And we have been meeting for three years, and we try to network and share information and resources and problem solve around the issue of AIDS in people-of-color communities.

For the last several months, the consortium has made an attempt to access some of that money, and it has been a constant battle to "get our fair share" of this money as it becomes available. And so that's one major barrier that we feel that, in our communities, that we still are underserved in terms of getting our fair share of the resources. Again, the Ryan White monies was primarily for primary care, not primary prevention or education. The money was for treatment, early intervention, et cetera. And so there's a need to do more lobbying and advocacy for money for education to prevent HIV infection, in the first place. It's just going to be more cost-effective in the long-run. Both at a local and a statewide level, we feel that again that there has been insufficient funds coming to minority communities to target women, adolescents, homeless populations, incarcerated populations. And we would hope that you can support us in our efforts to get more funding for those populations.

I talk a little bit about strategies. But what I would like to do is, to save time, is to go over my list of recommendations. In February of this year, I participated in the first public hearing on women in AIDS in Los Angeles County that was sponsored by the L.A. Commission on the Status of Women and Councilman Robert Farrell. And the recommendations that I presented at that time still hold true today. And I will not go through all of them, but I just wanted to indicate that there is a need for more early intervention programs, for women and youth; there's a need to expand the AIDS Clinic at Martin Luther King Hospital, the Oasis Clinic. Dr. Jordan now is having specialized services for women, adolescents. And we would like to see that the services for adolescents be expanded at that clinic and services for women.

There is a need to develop a mobile unit to target street youth in South Central. There is not a lot of providers targeting kids who are on the street, which could be former parolees, kids on probation, as well as gang members. And we would like to have a mobile unit where we could send street outreach teams into the community and South Central, do testing and counseling, and referral to the clinic at Martin Luther King Hospital. And that is a concept that we would like to see implemented as soon as possible.

We feel that, still, that there's a lot of denial going on in our community, a lot of fear, ignorance, and homophobia. And it wasn't until Magic Johnson again made his disclosure that people really began to take ownership of the issue and really personalize it, that it could happen to them. And again, we were all inundated with requests for people wanting testing and counseling in our community; and there were not enough providers out there to meet that need. There was one local high school that called the clinic and wanted to know would they be able to provide free testing to their high school students because the kids were so concerned, they wanted to be tested. And this clinic was just inundated with, again, people wanting to come and be tested. Even if you test positive, where are you going to be referred if there are no, if there's no infrastructure in your community? So bottom line is what we feel that a infrastructure needs to be built in our community so that we who have the expertise in the community can be given the resources to meet the needs of that community.

Thank you.

CHAIRPERSON WATSON: I appreciate your comments, and certainly throughout the morning and afternoon we have been trying to zero in on the fact that it looks like the minority communities -- specifically the African American community has been somewhat set aside as we approach the distribution of resources.

I'm interested in the packet that you've given me. I just flipped through out. But almost every item in here talks about women and AIDS and so on. Were we mistaken when we said there haven't been a lot of studies on women with AIDS?

MS. DAVIS: No, you were right on track. And one issue that really concerns me has to do with the sero-prevalence. Again -- and you mentioned it and you seemed very well aware of what's going on -- but for women of childbearing age -- that's 14 to 44 -- I've been following that data for the last couple of years and trying to make more people aware of what's happening. But with the testing of these core-blood samples, doing random samples, last year I got the information that from the pool of women tested in Alameda County, they were projecting that 1 out of every 100 Black women in that test group was HIV-positive. And for L.A. County, it was 1 out of every 300. Well, the most recent data, L.A. County now is

at the top of the list in that it has increased by 50 percent, meaning that now they're projecting that 1 out of every 174 Black women of childbearing age, out of that population that were tested, came out HIV-positive. And that really should give people cause for alarm. If you have your childbearing population in that gene pool infected with HIV, you're really looking at genocide down the line because there will be no future generations if everybody's infected and if all the women are infected.

CHAIRPERSON WATSON: I was just going over the titles that the audience might be interested in knowing what some of the titles are: "Epidemiology of Women With AIDS in the U.S., 81-90"; "Researchers Waking Up to the Needs of Women With HIV". And then there is a report put out by Act Out, "Women's Treatment and Research Agenda, Women With HIV".

So it looks like there's been a wake-up call and that it was called before Magic called it, but I'm going to have to look at this information very closely. I see there's some analytical reviews that have been done and so on. So maybe there is more attention being paid now at the current time to women with AIDS. We certainly will follow up, and I appreciate you supplying us with this information.

MS. DAVIS: Well, we have a window of opportunity ...gap in tape... at least the incidence and the prevalence to get like it is in New York ...(gap in tape)... in '87 in New York and New Jersey.

CHAIRPERSON WATSON: If you don't mind, I would like to request of you that you do this, and that is, that you send us a letter to Sacramento outlining what you think the needs are in terms of research for women with AIDS or research on women as a whole. Can you do that...

MS. DAVIS: Sure, sure.

CHAIRPERSON WATSON: We'd appreciate that.

MS. DAVIS: Thank you.

CHAIRPERSON WATSON: Thank you so very much.

All right. We're going to go down our agenda here. Suzi Rodriquez.

MS. SUZI RODRIQUEZ: Yes. Good afternoon. And I want to start by thanking you for inviting me here today and to tell you a little bit about what I do. I am currently the Co-Chairperson of the Title I Care Council in Los Angeles County. I'm a member of the AIDS Regional Board. And along with Cynthia and Mario at the other end of the table, we're also members of the Mayor's City AIDS Advisory Committee.

I work for a community-based organization in East Los Angeles called AltaMed Health Services. We've been providing services, predominantly primary care services, to a largely Latino population, for over 20 years in that same community.

Like Cynthia, I'm not going to go word-by-word of my testimony because I've given you copies. But I'd like to talk a little bit about some of the problems that we're finding in the Latino community. We also feel that as people of color, we are underfunded and under-represented in terms of programming.

One of the problems that we have currently within the Latino population that doesn't seem to be the same kind of problem that is occuring in the African-American community is that we don't have an overwhelming number of providers who are willing to get into the arena and provide HIV services. We still have a lot of denial in our community also, and the denial spreads not just within the realm of sexual preference and sexuality but also in terms of drug use.

The community that I represent has, by conservative estimates, the largest number of injecting drug users in Los Angeles County. And yet, when we attempted to open a Methadone Maintenance and Detoxification program, it took us three years to be able to overcome the NIMBY syndrome because the people in our community were just absolutely convinced that there was no drug problem in the community.

As I said, our agency is a primary care agency; we're a community health care center. And we've always done what is considered to be relatively safe programming. We have a teen pregnancy program. We do a number of programs for the Latino elderly, and we provide primary health care services. But when the AIDS epidemic, especially the way that we heard it being reported from back East in New York specifically, and how it was affecting the Latino populations, our agency made a concerted effort to get into the AIDS arena to be able to address the problems that would be facing our community. And again, there are not an overwhelming number of providers who are willing to get into the arena.

We're pretty new in the direct-service arena. We've been given many -- most our money comes -- our Drug Services money comes from the Los Angeles County Drug Abuse Program office. And we receive federal funds from the Bureau of Health Care Delivery and Assistance, from the Office for Treatment Improvement, which for those of us that are involved in the drug arena, it's been like a blessing that there was a new entity developed for treatment.

I dislike the fact that we're often, as treatment providers, pitted against prevention and education programs about which should take a priority and which is more cost-effective. I'm having -- I'm a recovering person and I know that treatment works, and so I'm always going to advocate for more treatment dollars; and I feel really fortunate that the Office for Treatment Improvement was established on a federal level. And then we were able to access dollars through the Ryan White CARE Act to provide community-based early intervention services. So I'd like to talk just a little bit about what we've learned in this short time that

we've been delivering services to our population.

We find that most of our patients are of Mexican origin. Many, many of them are undocumented. Most have a relatively low level of formal education in schooling. So I agree with what Paul Davis was talking about earlier in terms of appropriateness with written and printed materials. We put a lot of money into those kinds of things without taking into consideration that people may not always have the literacy level to read what we're spending the dollars to put out. And some people, AIDS Project Los Angeles, for instance, there's been some very creative ways to reach into communities of color that I think need to be expanded on; and I hope they'll talk about some of their projects.

Most of the people that we're dealing with are alone in the United States; they're not here with the support system. And all were infected, either by sharing needles or by having sex with men who are infected. We find that there's a definite gap in culturally appropriate services for gay and bisexual Latinos, especially those with drug problems and treatment needs.

And I'm going to take a sidestep for a second to tell you that I used to work for the Los Angeles County Drug Abuse Office. And my job at that time was to go into facilities of incarceration and speak to people who had been arrested on drug-related charges and make arrangements for them to go to treatment. What would happen in those cases was when I had clients that were gay or bisexual, there were no appropriate drug-treatment programs to service that population. And unfortunately, most drug treatment providers believe that changing your image is directly tied to rehabilitating yourself. And so if you're a gay or bisexual man and you have long hair or you're a transvestite, most times you'll go into a drug treatment program; and the first thing they'll do is tell you to cut your hair and to change the way you look. If you're a lesbian, you go into drug treatment programs, they make you wear dresses and send you to charm school. So we've got some real problems going on here. And there's a gap in the service base. There's not people that are doing outreach into the gay and bisexual community of drug users, and that's a real problem. And I would hope that people would pay some attention to that. We also feel that it's imperative that the clinic staff be culturally appropriate to the population that they're serving.

Recently, my agency went down to Olvera Street, and many of the people here know about the transient Latino population that's in Olvera Street. We had been told time and time again that there was no way to do follow-up testing with these folks. We tested 140 people at the Health Fair at Olvera Street. We had 120 come back for results, and we know that that is because the staff was reflective of the target population. The majority of our staff are Latino. All of our staff are

bilingual, and we're well staffed with representation of gay and bisexual men.

Some of the recommendations that I would like to put forth today is that we also believe that linkages must be made with historically gay HIV/AIDS programs in order to provide appropriate staffing, training, and service provision for gay and bisexual clients. In the case specifically of my agency, when we looked at where the gaps were in service and we recognized that there was a gap for Latino, gay, and bisexual men, we knew that we did not have the infrastructure to take care of the needs of that specific population. We were very fortunate to be able to link up with AIDS Project Los Angeles and develop a whole, entire innovative program that includes cross-training and for them to be able to give us the needs that we, to fill the needs that we had to find appropriate staff and that -- I just can't even tell you how valuable that was for us. But it's very difficult to get community-based agencies that primarily deal with people of color to look at those gay and bisexual agencies as being valid and there as a resource. And I think that we, those of us that are doing those kinds of things, need to help break through the stigma and role model for that kind of linkage.

We believe that there must be continuous and on-going education for and to the community. In the Latino community, we've got to access the church on a much greater and broader basis. We have found that there are many people within the church who are willing to look at what their role should be, but it needs to be vastly expanded.

We believe that there should be intensive training and pre- and post-test counseling required for all case managers and that again clinic personnel should be reflective of the population that they are serving.

We believe that HIV-testing should be encouraged to all program participants, and we believe that a system of comprehensive care should be instituted that includes pre-test counseling, HIV testing, post-test counseling when delivering any results. Too often we find that if someone tests negative, they don't get any post-test counseling; and that's really a shortcoming. If the client is found to be positive, there should be an expeditious way to admit that patient into a medically managed program where one case manager will follow the patient during the course of the disease.

We believe that there should be increased outreach done to the injecting drug-using population. My agency feels very strongly that the sero-positivity rates remain low for this population only because the data being collected is gathered, is reflective only of those people who are accessing treatment. We would also like to ask that consideration be given to the legalization of needle exchange programs that are tied directly to increased treatment availability. I know it's a

really hot issue, but it's something that definitely needs looking at.

DR. TATE: But Senator Watson is introducing that next session.

MS. RODRIQUEZ: Well, again, I would like you to know that there is many of us that will do whatever we can to help you support that form of legislation.

CHAIRPERSON WATSON: You missed my discussion about my bill early on.

MS. RODRIQUEZ: Yes, I did. I'm really sorry because we have a whole network of people that would be willing to support that.

We also believe that staffing and programs should include a financial analyst to assist patients with accessing appropriate programs, such as Medi-Cal and Medi-Cal -- Medi-Cal and Medicare. And that's about all that I have to talk about today.

CHAIRPERSON WATSON: We certainly appreciate your testimony.

Is there someone down there that wanted to say something? Okay. Because it zeroes right into the ethnic community and its treatment that is specific to the culture; and that's what we need to hear more about. This is a very valuable piece for us as we try to reform the system so that it will address those specific needs. Thank you.

MS. RODRIQUEZ: Thank you.

CHAIRPERSON WATSON: May I ask the indulgence of the other members that I have seated at the table here, if you will. Dr. Reed Tuckson has come into the room, and he was scheduled to speak at 3 o'clock. He's a little early. I'd like to indulge him now, if I may, because I know he has a heavy schedule. He is from Drew University, and he was scheduled with the Hospital and Physicians and Clinics panel. So if you'll allow us to do that, we'll take you up now, Dr. Tuckson. Welcome.

DR. REED TUCKSON: Well, thank you very much. And I very much appreciate your indulgence, as well as the other members of the panel for allowing me to go forward.

I will make some very brief comments. First, let me just say that I am, I've enjoyed my three months as President of Drew University of Medicine and Science. I emphasize the three months to say that my comments have to be tinged with a little humility. This community of Los Angeles, I'm still new to and I'm learning. And I have learned enough in my career, Senator, to know that it is very important to spend time in a community before you become arrogant enough to make too specific recommendations. However, please consider my testimony as part of a team at Drew. I think that Cynthia Davis Callahan, and also Wilbert Jordan, are certainly experienced and competent to be able to make very specific recommendations, all of which I endorse.

I would say this, though, that as a person who's been fortunate to be a leader in the national fight on this issue, and a number of national commissions and still active, there are some important principles I would hope that you keep in mind as you go forward and consider these issues.

First is that, as you are well aware, the HIV disease exists in the context of a series of other very dramatic and contributory health problems, naturally the tragedy of it. As we think about funding for HIV disease, I think we always have to remember the context in which it occurs for people of color and people who are poor and the relative relationships between them. As you've just heard in the last speaker, HIV disease and the clear relationship to IV drug abuse is, of course, important. HIV disease is related ultimately in many ways to violence. I've been very concerned with the number of women who become addicted to drugs because of the violence in their community and thereby find their way to HIV disease.

We find that the issues of self-esteem that lead to behavioral choices that are incompatible to survival are common throughout; and so that as we look at how we approach HIV disease, I only remind us that we have to look at the total health package and the total health set of challenges that confront people of color, and that is very important. Similarly, to do the education that we need to do to try to change behavior, to be able to support behavior, I think we have to face square ahead the issue of being realistic about learning the knowledge, the attitudes, and the behaviors of the people that live in our community.

I am very concerned by the recent decision by the Secretary of Health and Human Services to cancel a study designed just to elicit such information about the knowledge, the attitudes, and the behaviors, of the sexual behaviors of our children. I would hope that as we go forward that we would be courageous enough, insightful enough, and thoughtful enough to really make sure we understand exactly where our young people are so that we can in fact tailor health education messages that will reach them where they are and not make assumptions and not burden this process with politics.

I have been a health commissioner for a major urban metropolis for four years. I have had my hands tied all during my tenure and have been unable because of politics or because of all matter of competing interest, been restricted or limited in our belief to teach our young people in a way that we can reach them and save their lives. And I would hope that as we go forward we would not be bound by some of that.

Similarly, the techniques that we use, I would hope that a comprehensive curriculum could be developed, a curriculum that was culturally specific and sensitive but was creative and dynamic and that could be incorporated into the

educational system not as a burden for the teacher to have to teach, in addition to many other problems, but could be incorporated into a curriculum in a constructive and positive and useful way, a partnership, a true partnership, between health and the educational system. I would hope that we would be able to be creative about some of the ways in which we do public service announcements. I would hope that funding wouldn't go just for another commercial that just does and repeats some of the, with the same technology but utilizes perhaps ways of empowering people.

Example, I had a chance to participate not long ago in an experiment that I thought was fabulous where a live radio docu-drama was conducted on the radio that dealt with real-life issues of a woman who was a single parent whose man in her life was an IV drug abuser but she didn't know it. And she was reminded of the importance of using a condom, given that he was also not faithful to her; and she had to have a conversation with that man. And they did it on the radio as part of the docu-drama, and then he was very good and convinced her that perhaps that wasn't necessary and was very smooth and very persuasive. And then we stopped the docu-drama at that moment and opened up the phone lines and allowed the women to call in and be the star.

It's very fascinating to hear those women. What would you say to that man and what would you do and then put the man back on the radio and then have him argue with the woman. The women didn't always win. What happened was, that night, there were a lot of women who had been in the gymnasium practicing on their techniques, practicing on arguments. And they were very empowered that evening, in that particular city, and they knew exactly what to say. And so there are ways which I think we need to be a little more creative, a little more dynamic, as we think about those kinds of interventions that will empower people, not only that gives them information, Senator, but things that give you information in a way that facilitates the changing of behavior, acting on information, not just giving it out.

I would say that I really am excited by Cynthia Davis Callahan's suggestion to you in education for mobile units. We need to reach out. I've spent many, many evenings and many different cities in this country walking the streets. And I will tell you that the people who are prostitutes or IV drug abusers don't listen well to health educators. They listen well to people who are from their constituency. I remember walking the street and having an addict on the street say to my coworker, another addict, "I remember when you overdosed right there on that spot." And here that addict is now back to talk about the need to change behavior. So I think those kinds of mobile outreaches, efforts are important.

And I would say to you also that what you know well, Senator, is the

importance of community-based infrastructure and organization that will make a difference. I am very concerned that funding is about to run out from the federal government anyway, funding community-based institutions in the fight against AIDS, particularly our churches. And the reason why that it is in jeopardy is because they have been unable to prove effectiveness. They've been unable to do the kinds of studies that are required to show that in fact the money's been well spent.

Drew University has, I think, a responsibility as one player in this community to support in an intellectual and research capacity our community-based institutions that are on the front lines, to prove the point of what works. And when things don't work, to be able to make those suggestions to how to enhance that work. That's a research agenda that is not being addressed. I know Drew University doesn't have any money to do that sort of thing. This is not a commercial for Drew. It is a commercial for being more intelligent about how we conduct community-based programs and not continue to give lip service to community infrastructure but in fact to do it well.

In the one minute that I'm sure is all I have left, let me just very quickly say that -- and again, my comments are a companion to my team's comments of Cynthia as well as Wilbert Jordan, so they'll cover things that I won't cover. But I would say to you that I am particularly concerned about the, as we move forward to develop the clinical trials for women and children and other people of color, men and women who are, the clinical trials to give us more information, there is a strange paradox.

To get access to comprehensive health care now, you almost have to be HIV-positive for those women. And I'm very concerned about the ethics of that. Across the country now, what we find is the clinical trials are being developed to take care of people that are HIV-positive; yet they're the same women, if they were one week before diagnosis, wouldn't be able to get access to care. And so I remind you that this issue is, of HIV disease, again exists in the larger context. And, of course, once the study is over, then those comprehensive support services for the HIV-positive women go away. And so what we have to continually address is a lasting health care infrastructure for people of color, as we deal simultaneously with the overwhelming and extraordinary urgency.

Lastly, I would just say to you that even as we work through these problems, the health care professionals who are going to be in our communities, they're unavailable to take care of the comprehensive and multiple needs of persons who are living with this disease. We have to be very, very attentive to that. I'm not sure where those practitioners are going to come from, and I think that we're going to need to be very supportive of those institutions that are dedicated to training

those professionals who will remain in our communities and be there to manage with compassion and care versus living with this disease. And so I will stop there. I've taken up my full allotment. I appreciate your indulgence as well as the rest of the members of my panel.

CHAIRPERSON WATSON: Thank you, Dr. Tuckson. I think you have pointed out much of what has been said earlier today. And so you do have a handle on the gap of what's needed. What you will find as you try to learn this community in more depth is that we have some political problems, and we have attitudes that have prevailed. California is really a very conservative state, and one of the problems we face is trying to open up a debate in Sacramento, large enough so we can put into that debate the resources that are necessary to do the kind of innovative things you've just described. We get stumped and stymied because of these attitudes that prevail. And the more conservative the administration is, the more stymied we become because once those bills get to the desk, they can be vetoed. And once that belt comes out, and beats us up with it, then they die in committee. So as you are going about trying to learn the community, you will be learning the politics of AIDS. And I think in some way the question has to be raised: Is there racism in the way we relate to AIDS? And I think as you go about doing your research and becoming oriented and acquainted, you'll find that maybe the answer will be yes. And there certainly is an attitudinal problem; there certainly is a cultural problem that we're dealing with. And so it goes to the social dynamics of this particular disease.

DR. TUCKSON: Well, Senator, I would just quickly say that in my three months here in this State of California, it doesn't take much work to get a sense of what you're saying. I am amazed that the number of people that I have already encountered with this disease is quite extraordinary. And the degree of apathy relatively and the degree of urgency in addressing the Hispanic and the African American with this disease somewhat concerns me. And it doesn't take but a three-month sojourn here to reach that conclusion. And so I hope that we're all able to work together.

CHAIRPERSON WATSON: Well, you said something that is of tremendous interest to me. You said Drew University ought to take on some of this. We don't have the budget, but we ought to be looking at some of these aspects of AIDS. And I would think that with your innovativeness that you would look at Drew as being a center to give some guidance and leadership. South Central is really all over L.A. County. But coming from South Central, I think you could be a beacon light. And you, coming from the nerve center from Washington, D.C., certainly have the national perspective on this. And when it comes down to the local area in which

your university is located, you can really be that light to give guidance to the county, to have a place where the researchers might come to do some research on this issue.

DR. TUCKSON: Well, I appreciate the challenge, and I would say to you that you can fully expect us to reach that challenge. We will do it one way or the other. But I will tell you, Senator, that it is very, very hard when all of your resources are going towards just trying to maintain, seeing the patients that we're seeing now. And I will tell you that this is the tragedy that, the story that is not told. It's why I began my presentation very specifically by saying that HIV disease exists in a larger context.

All of the resources in the health care system are devoted now towards meeting the needs that have long been there before HIV disease became prevalent. And to be honest, we're doing an inadequate job of meeting hypertension, cardiovascular disease, cancer, and so forth and so on. Now this new phenomenon drops in the middle of a system that is as weak as wet tissue paper. It is inevitable that you will have a disaster, and that is the disaster that we are now experiencing and will continue to experience. And so as we look to our smart people at Drew, I must tell them to be thoughtful and to develop new research ideas and new interventions, for HIV disease means that you cannot then be with your patient who has another disease. You must stop that work and do this other work. That is immoral set of choices to place on any health care provider or any institution. That's what we're talking about. And that's the picture that I think that is so often lost in all of this. We don't have enough resources to do the work we have to do now. Now we have to find some other way to add more hours of the day, find more people to be able to address these new needs; and we're not doing a good enough job of it, but we will continue to try. We look for others to give us some help.

CHAIRPERSON WATSON: You have Drew/UCLA. Now there's an arm for you. And I've been trying to, for quite a while now, talking to the chancellor, to take a look at this sociological research that he says is not scholarly enough to start looking.

You know, we've been talking about tenure of minority professors out at UCLA for a long time because they focus in on the sociological research. They find it not scholarly enough though to grant tenure. We've had this debate over a number of years.

DR. TUCKSON: Senator, can you indulge me with one more comment then.

CHAIRPERSON WATSON: Yeah.

DR. TUCKSON: This is a critical issue. Everywhere -- I'm on the Board of the American Public Health Association. I serve on several committees of the Institute

of Medicine. Everywhere we go, we hear lip service to the rhetoric of how important it is to have a community-based infrastructure with which to solve problems. Yet, when we look at the way in which we spend our money in the health care research community, we spend lots of money to study the latest drug which will solve just a very small part of it. But to prevent the illness, to prevent the problem, which is an ultimately community-based initiative, we spend very little time and energy; and we don't respect that. But we give rhetoric to it as being important. And I am just amazed that anyone could be that short-sighted in this day and age to think that this is not worthy of scholarly pursuit. Ultimately, this is what's going to save our community. And I think that if we don't put that kind of intellectual attention and effort into it, we play games with people's lives and we do ourselves a disservice.

The funding -- the last comment -- I promise will be the last comment. The issue that is of great concern is, when we fund community-based organizations to do this vital work, we fund the disease of the month. And if it's this month a certain disease, and the next month, it will be HIV disease and then it will be something else, the money runs out; the community institution goes away; then a new one springs up. What's not left is a viable, connected, stable, self-sustaining community infrastructure. And so this business, if we continue to approach this casually, intellectually, and financially, we wind up never having in place the mechanism and the tools and the resources and the intellectual brain power which will sustain us year after year after year.

CHAIRPERSON WATSON: You might want to take advantage of your relationship with your parent organization, UCLA, the Department of Health Services, the Office of AIDS, and my office, and see what we can do through Drew to address the issue that you're mentioning. You know, the disease-of-the-month concept is very real and, you know, we put our resources where there is a great amount of political pressure. And so I think you're putting your finger right on the problem. But I think you have a broad enough base to call on to get something moving. So I will have Dr. Tate follow-up with you, and maybe we can put something like this together.

DR. TUCKSON: I appreciate that, and I would never, ever find myself modifying anything that you might say. I would just half suggest a different choice of words other than UCLA being a parent. They are associated with us, but we have a tremendous pride at Drew, as you well know and share. And we are an institution in and of ourselves. But I think the point you make is an important one, and that is, UCLA has a responsibility. I go over there -- I was just there yesterday, and I couldn't believe -- I looked at those -- all those giant buildings with all those

people and all that money and they're solving, working on some problems of importance; but they're not working on the problems of importance...

CHAIRPERSON WATSON: My words were not coincidental. I chose them very carefully because UCLA, being part of the UC system, gets its funding from the state.

DR. TUCKSON: Oh, in that context, yes.

CHAIRPERSON WATSON: And we can move on the state university system to do certain things with Drew.

DR. TUCKSON: I appreciate that.

CHAIRPERSON WATSON: And therefore, you see, in the funds you don't have, and this is something we've been dealing with over the years -- and you know the history of how Drew came about. And we've been pushing and pushing and pushing. As I said, this debate started many years ago. And so that organization can see, if they prioritize correctly, that you at Drew had the resources to do what needs to be done.

DR. TUCKSON: I continue to learn from you.

CHAIRPERSON WATSON: I'll leave it there without exposing too much of my intentions.

DR. TUCKSON: I continue to learn from you.

CHAIRPERSON WATSON: Thank you, my dear, for being here. We'll continue this conversation later on.

DR. TUCKSON: Thank you so very much. I appreciate it. Thank you very much.

CHAIRPERSON WATSON: All right. Let's move on. Mario Solis-Marich, AIDS Project Los Angeles.

MR. MARIO SOLIS-MARICH: Hi. Calvin Williams is going to start our presentation.

CHAIRPERSON WATSON: All right. Very good.

MR. CALVIN WILLIAMS: Senator Watson, Members of the Health and Human Services Committee, good afternoon. My name is Calvin Williams, and I'm a public policy specialist for AIDS Project Los Angeles. While it would be difficult to discuss during this brief session all the issues relevant to bisexual and gay men of color, I would like to discuss one issue that I believe is of paramount concern.

When the question of AIDS education is discussed, the general misperception is to focus on a limited segment of the population. However, AIDS is not specific to whom it will attack; and unfortunately, too many bisexual and gay men of color have become infected with HIV and/or have died from AIDS due to the lack of sensitive and tailored information regarding HIV and the AIDS epidemic.

Presently, the number of people of color who have contracted AIDS continues to

rise. The National Commission on AIDS in its recent report declared, and I quote: Gay and bisexual men are the largest segment of people with AIDS among Black and Hispanics, 36 percent and 40 percent of cumulative cases respectively as of June 1991. A total of 28 percent of gay and bisexual men with AIDS are Black and Hispanics nationally.

Within the county, the numbers are even more staggering. Within the Hispanic community, the gay or bisexual men constitutes 73 percent of reported cases. In the Black community, gay and bisexual men constitute 65 percent of reported cases. And within the Asian and Pacific Islander community, gay and bisexual men constitute 80 percent of reported cases.

Despite these realities, epidemiologic and behavior studies and HIV disease have virtually ignored gay and bisexual men of color. In addition, there is yet to be specific target programs funded either from the federal or state governments that address issues specific to bisexual and gay men of color. Those education campaigns that have been initiated by private social services agencies have been sporadic or limited at best. Leadership is needed from the top. State and local agencies must begin the process of addressing funding priorities if we are going to stem the growing numbers of people of color contracting HIV or dying because of an AIDS-related illness. The lack of leadership and the limited revenues available to social service agencies that are dealing on the front lines of the AIDS epidemic for this population must be addressed.

The feasibility of servicing the needs of the growing HIV and AIDS population cannot be achieved through the work of only a few agencies, nor can a handful of agencies reasonably educate the public on ways to prevent the spread of this deadly disease. However, through joint efforts between social service agencies and the active participation of the state and local governments, our collective ability to save lives and bring about more coordination and the delivery of services for persons who are HIV-positive or who have AIDS can be realized.

But before coordination between state and local agencies can occur, and before unity can be achieved, the state must take a leadership role in appropriating additional resources that will provide a meaningful base in which to provide services to gay and bisexual men of color who are impacted by HIV or AIDS. Moreover, the proliferation of the AIDS epidemic demands that sensitivity be required of all public and private entities that receive public funds.

Since many gay and bisexual men of color are presenting themselves to community health centers throughout the state, specific contract language must be required for those agencies to ensure that gay and bisexual men of color receive sensitive, adequate, and professional medical services. Let us collectively move

forward in the war on AIDS. Let us drop the meaningless rhetoric and dedicate ourselves to improve in the quality of life for all those afflicted.

Time that is spent debating questions of policy can be more appropriately used by designing programs that benefit those who are ill and dying and preventing the further spread of this disease. Let us move forward. A large and a much maligned segment of our population is depending on us for their very lives.

CHAIRPERSON WATSON: There is a feeling that prevails that the AIDS project in Los Angeles is the recipient of the resources and that some of the community-based programs that really reach out to the grass-roots community received less because that money goes through the AIDS Project of Los Angeles.

Would you comment on that. There seems to be kind of a tug between those grass-roots organizations and AIDS Project.

MR. SOLIS-MARICH: Senator Watson, if I may, my name is Mario Solis-Marich, and I'm the Director of the Public Policy Department of AIDS Project Los Angeles. I also sit on the executive management team of the agency.

They are definitely our intentions within the community around funding issues, and there will be continued pressures because there's not enough money for the growing epidemic and the intense crisis that we face, especially on the community-based level.

Currently APLA provides case management and psycho-social services to over 70 percent of the people with AIDS in Los Angeles County. We have the only dental clinic for our people with AIDS in Los Angeles County. We have the largest Food Bank program and the Necessities of Life Program which provides food to 650 people with AIDS a week from all over Los Angeles County.

Our client load, the demographics of our client load, reflect or mirror the demographics of people with AIDS in Los Angeles County. And so, in fact, we do -- 75 percent of our funding, we raise privately; 25 percent comes from government sources; and we do have a large budget; we do a big job; and there does need to be more money to go around to all community-based organizations.

One of the things that we've attempted to do to address that need is we've established massive public policy efforts, both in Sacramento -- excuse me -- in all areas -- the county, Sacramento, and in the federal government. We support the largest AIDS activist -- AIDS lobby in Washington, the AIDS Action Council. We provide them with a third of their budget. It was through their lobbying and their direct efforts in Washington, D.C., that Los Angeles received over $7 million through the Ryan White Act.

We've been able to therefore use some of our private donor dollars to effect public policy and to get more dollars for AIDS from the federal government

distributed here in Los Angeles County, and that's one way that we've been, you know, trying to expand our resources and have an impact with other community-based organizations. We do realize we cannot be all things to all people, and we tried to establish cooperative efforts with those community-based organizations that are willing to work with us. And that kind of leads me, if I may, to the point that I wanted to talk about this afternoon, and that is, earlier, Suzi Rodriquez from AltaMed Health Services spoke. And when I heard AltaMed Health Services, their representative here speaking about gay Latinos, it made me feel really, really wonderful because in fact I am a gay Latino. And that institution is the largest Latino community-based clinic in the United States. And it makes me feel good to see them doing what they see as necessary, basing the issues that confront a community-based organization as they address issues surrounding homophobia and access to all members of their community.

The particular project that we're jointly working on, we believe, will have a major impact on gay Latinos and especially gay Latinos who are injection drug users or have other substance abuse problems. Currently, 80 percent of Latinos in L.A. County that have HIV are gay and bisexual men. Two-thirds of gay and bisexual Latinos are actually gay and bisexual men, period, have some addictive behavior problem. Unfortunately, there has been no leadership from the administration here at the state or federal government with the Bush-, you know, Reagan-Deukmejian machine, to address the needs of substance-abusing, lesbian, and gay people. With HIV, this is a crucial, crucial issue. And it's not only the direct transmission of injection drug use, but it's also the correlation between being high and being able to maintain safe, sexual behavior.

The program that Dr. Rodriquez alluded to was a program that was in fact inspired by a person with AIDS. And currently, we have the 3,200 clients at APLA; but this particular person with AIDS was a staff person. His name was Jose Perez. And he was a gay Latino who was a recovering injection drug user. Jose Perez worked constantly with me -- I should say constantly on me -- before he came to AIDS Project Los Angeles to serve as a policy specialist to get me to work more closely with, you know, pull together HIV services, substance abuse services, in a Latino cultural context. He worked very, very diligently to create a joint medical advisory committee where AltaMed had cultural sensitivity. And through APLA, we have access to some of the finest, you know, AIDS outreach in Los Angeles County pulling those resources together to create treatment protocols and to make sure that all people in East L.A. receive a very high degree of service. This is a long-term project that's been very, very difficult to pull both agencies together; and unfortunately, it still has a ways to go. But we believe that these are the

type of efforts throughout the county with other agencies joining together that really should be funded.

Jose Perez died on November 11 of this last year. His efforts are sorely, sorely missed. But this next year, as we move forward to completing this project, we constantly hear his voice, and we constantly feel his presence as he's pushing this and other projects throughout the country along. Thank you.

CHAIRPERSON WATSON: Thank you for that insight. We appreciate everything.

Okay. Mike Neely.

MR. MIKE NEELY: Good afternoon.

CHAIRPERSON WATSON: Good afternoon.

MR. NEELY: Before I begin my testimony, I'd like to say something before you go charging off to the Department of Corrections on the problem of HIV transmission within the prison system.

Sexual contact is a very important means of transmission. However, there is another very, very prevalent means of transmission within the prison system that nobody's looked at, and that is, through the tattoo machines. And I think that unless we look at all of those aspects, we're going to miss a part of the problem.

Now to get on with my testimony, and in the interest of time, I'm not going to do all the reading like everybody else. We'll just hit on some of the high points.

I'm Mike Neely. I'm the Director of the Homeless Outreach Program. What I want to talk about basically is HIV and the AIDS epidemic and how it impacts the homeless community.

One of the things I want us to understand is that by definition, the homeless individual has no resources except for public resources. However, as we begin to look at the public resources, those resources are definitely going into other communities which are not necessarily poor, which are not necessarily undereducated, or not necessarily under-represented.

Homeless people have a very serious and unique kind of problem in terms of HIV infection and dealing with the care system. A person who is infected and who is homeless in Los Angeles, in the State of California, is without care. By that, I mean very simply that the system is designed on an either/or basis. Either they deal with the medical problems of the individual or they deal with the survival problems of the individual.

The best way to illustrate this, I would imagine, would be by a small example that I've come up with, and that is an individual who goes to the clinic, gets their medication; they come back to the shelter. The shelter then either takes the medication away from that individual or allows that individual to take the medication on the time schedule of the shelter.

Then the person -- let's say that person has night sweats or diarrhea or some other things where that individual just can't sleep that evening, one of the problems that eventually that person runs into is the next morning, they've got to get up because the shelter rules say you have to be up at 7 o'clock and you have to be out of the bed.

Now if the individual takes medication and that individual has side effects, one of the things that happens is that now you have to leave the shelter and the clinic, or wherever he may have been getting his medication, and says, well, that's just normal and there's nothing we can do with you.

So then the individual says, well, wait a minute. This medication is making my life more difficult. And in that situation, the individual may then elect to not take the medication. And in not taking their medication, then that individual then has to make a real life-and-death kind of choice. This isn't the fault of any individuals. This is just the way the system is set up. This is real life. This is what happens every day.

We have a very serious situation in terms of -- I'll probably be the only person up here that says that we don't need any more money. What we do need is a better allocation of the money, and that allocation of the money -- I just heard someone talk about the efforts of getting $7.8 million into the county or the City of Los Angeles, the County of Los Angeles, wherever it went to. For the homeless population, I think that the total allocation was like $120,000 or $140,000. At any rate, that was less than 2 percent.

So we are totally and completely ignored. We don't have the ability to have the largest lobby in the country; we don't have the largest lobby in any place. One of the things that the Senator made very, very clear just a minute ago, one of the ways that Sacramento does business is who provides the most political pressure, gets the most results. Homeless people do not have that ability. Homeless people do not have the ability to even get to Sacramento Street, let alone to get to Sacramento, California.

Those kinds of issues are issues that we have a real problem with. You take this and you couple it with just the normal problems of day-to-day existence, and then you infect us with a disease, a very serious disease, and then somehow or another, people ask us to compete, to compete for funds, to compete for attention, to compete for any kinds of services. We're not even in a position to compete for public health services as they currently exist today. And this was our only source of public health services.

And I want to make it very clear, that the population that I'm talking about is the population that was on the streets that is affected after they are on the

streets. A lot of times, people will try and confuse the issue by throwing in the sympathy factor, and that is, individuals who contracted the disease and then become homeless. I understand that that's a very serious problem, but that's not my population. Those are not the individuals that I have to deal with. I have to deal with the individuals who, according to our records and all of the stuff that we see, about one in five of those individuals are infected.

In the tuberculosis clinic, which is located right in the middle of skid row, 25 percent of their patients are HIV-positive. This is the kind of problem that we have to deal with, and this is the kind of situation that we have to try and compete. And as it stands right now, the playing field is not very level. And as Dr. Tate can tell you, I'm a very big advocate for categorical funding. I think that the homeless population does need to be culled out. I think that some very serious, serious monies have to be devoted to that because when we look at it in the long-run, the basis of homeless service providers is to get people back into the mainstream as quickly as possible. If we're getting people back into the mainstream as quickly as possible and those individuals are undiagnosed, carriers of the HIV virus, then what we are doing is getting the HIV virus back into your community as quickly as possible. And that, we have to look at and that we have to act in some way or another. Thank you.

CHAIRPERSON WATSON: Thank you for that insight on the homeless. I think it's very necessary to keep in mind that we've got a lot of people out there on the streets with needs as well as in institutions. We appreciate your comments.

Kazue Shibata, Executive Director for Asian Pacific (Health) Care Ventures.

Okay. Helen Fitzgerald.

MS. HELEN FITZGERALD: Thank you. I'm Helen Fitzgerald. I'm with Prototypes-WARN. And we'd like to thank you for inviting us to take part in this testimony. I'm honored to be in the presence of Senator Watson. I had the opportunity to hear her speak at the Black Women's Conference held in Compton several months ago, and I was really empowered by your speaking. And I'd also like to thank Ruth Slaughter (?), the Director of Prototypes-WARN for feeling that I can come here and present our agency and the problems that we encounter on a daily basis while doing straight outreach.

WARN is misspelled on the agenda. WARN is an acronym itself, and it stands for Women and Aids Risk Network. Okay.

We were one of the first projects in the nation to provide AIDS prevention and education specifically for women of color. I wrote a piece describing many of the women of our targeted population, and I would like to share that with you in hopes that you can better understand the women that we work with.

It is unanimous that all women are at risk for HIV and AIDS. However, the women of our targeted population are injection drug users, sex workers, and partners of injection drug users. They are considered by society to be hard-core, low-class, and socially unacceptable. Our women come from broken homes, broken marriages, and they have children in the system or may have been of that very system themselves. They are mothers with and without children, teens without families. Many of our women are homeless. Some are undereducated and most are unemployable. In their lives, they have experienced child abuse, sexual abuse, and sexual assault. They have been the victims of physical violence as adolescents or as adults.

Our women suffer the loss of hopes and dreams, and they have become accustomed to broken promises. They have been set up to believe that they cannot trust anyone and that no one can be unconditionally interested in their welfare. As a result, these women have adapted behaviors that may be labeled pathological and psychological. But we realize that for them, these are probably the only means to cope with life.

As an outreach worker with Prototypes-WARN, a senior outreach worker, and team leader for the South Central area, we are very familiar with HIV and with addiction. And we know that for our women in our target population of HIV and addiction is only a symptom of a much deeper, emotional, and psychological problem.

Our staff of outreach workers have been trained in HIV pre- and post-test counseling. We have been trained to do outreach to partners of injection drug users as well as injection drug users. And we have been trained by the Foundation to offer emotional support for women or for people who are living with life-threatening diseases.

The problems that we encounter on a daily basis while doing outreach is that it gets very frustrating to do outreach for a community or to provide services to the women when there are no services to refer them to.

We have -- I want to backtrack for a minute. We did, back in the summer, in one of the parts in South Central -- I'm very nervous -- I need to say that. One of the parts in South Central where we do AIDS outreach, AIDS prevention education, we had encouraged our women and men of that population to be tested. And we worked with another AIDS agency to have these people tested. We had 25 men and women to be tested for the HIV virus, and three of those were staff members, including myself. So it was 22 people to be tested. Out of those 22 people who tested, 12 were HIV-positive; and only one showed up for the test results. And we feel that that was because of the fact that it took a very long time for them to get their results. Many of the people were homeless. And when we asked them -- and we knew

who they were, that they go to get their test results -- they would say that they lost their paper so that there was no way of keeping track with them.

Another thing is that when, if you're HIV-positive and you're a woman, there's no services for you; there are virtually none. And if you're HIV-positive and addicted, there are no services for you. So basically, it gets really frustrating in trying to do our job and trying to provide the AIDS prevention education and trying to promote the behavior change. And so we find some relief in meeting a woman as where she is at the moment. If her problem may be that she needs food or shelter, this is what we would try to provide for her. We try to build a trust because we know that our women have been set up to believe that they can't trust the system. So our outreach workers are, including myself, were indigenous to our target population.

I don't know. I'm a recovering addict, and I know what it was like for me to go into drug treatment. And I thank God that I had insurance, that I didn't have to deal with the county facilities. My understanding, there's 36 beds available with the county. And of those 36 beds, there are only a certain number for women; and our agency works specifically with women. So it gets to be very discouraging.

There's only three of us under the contract that I've worked for, so we have to work with the other projects within our agency to do our outreach, and we work with a state-funded outreach worker and are funded by the Children's Hospital to do teen outreach.

So there's not enough outreach workers because if one of them -- our outreach worker, she does routine outreach work. When she's at the juvenile hall doing teen outreach there, then one of our sites may go unvisited that day. We may not be able to provide education to a certain area. So we see the need for more outreach workers. We also see a need for more HIV test sites.

We had an agreement -- not agreement -- but we did work with one of the testing facilities or clinics in East L.A.; and it worked very well for us because they would let us come in and we would bring our women in, and we had priority testing. But what happened was, as a result of our testing -- and they only had one phlebotomist. So she was not able to accommodate the clinic's need as well as our needs for the women in the street. So they limited us to one day a week, which is on a Wednesday after 5 o'clock. And some of the areas that we do outreach in, because we're in South Central -- were in Figueroa; and were in the Avalon Heights areas. So some of those areas that we're in during the day that we would want to be in after 5 o'clock, so it makes it difficult for our women to get tested.

We also would like to see a receiving center, something like out, like a receiving center in the South Central area and in other areas that women or men who

are HIV-positive and are waiting for a slot in the drug treatment center can come in. They could start getting treatment; they could start getting detoxed while waiting for these drug treatment facilities. Like I said, when I went into drug treatment, I was really fortunate to have insurance. And what happened as a result, when I first went there, they couldn't find my insurance. So at home, feeling hopeless and helpless, feeling like there was no hope for me -- and what I did was continued to use more. But then they found my insurance record and their hospital called for me. And it took me from the day I went to go into the hospital, and from the time they accepted me, it took me at least a month to get back on my own and I had insurance. So I know what it's like for women and men who are dependent upon the county. Our staff is multi-cultured and language sensitive. I don't know. There is a need for more Latino outreach workers.

One of our women today had to -- our staff was -- we had to go to another facility because they needed someone to talk to, a person who's HIV-positive and who only spoke Spanish. So she was supposed to be here to support me this morning, but she got here late. And like I said, there's only three of us who's on this team. And I feel that we are really overworked; we're underpaid; and our job is very dangerous. I mean when I put on my tennis shoes and my sweatshirts and my Levi's and become color-conscious of the neighborhood that I'm in, I'm also sometimes afraid for my life. I put my life on the line on a daily basis. Thank you.

CHAIRPERSON WATSON: Thank you for that testimony. Prototypes-WARN -- you said that's an acronym. What does it stand for?

MS. FITZGERALD: Women and AIDS Risk Network.

DR. TATE: Women and AIDS?

MS. FITZGERALD: Women and AIDS. I have brochures here about our project.

DR. TATE: Did you speak earlier about how you're funded?

MS. FITZGERALD: We are -- the project -- I'm funded through the Drug Abuse Program Office. We also receive funds from the Los Angeles Children's Hospital. We're state funded. And there are projects that are funded by NIDA and NOVA, award the one project.

DR. TATE: Which are these funds?

MS. FITZGERALD: I wouldn't know. I'm not sure.

CHAIRPERSON WATSON: Thank you so very much.

MS. FITZGERALD: Thank you.

CHAIRPERSON WATSON: All right. Joel Tan, United -- Colors United.

MR. JOEL TAN: (In Filipino _____.) Good afternoon.

CHAIRPERSON WATSON: Good afternoon.

MR. TAN: My name is Joel Tan. I'm the founder and co-facilitator for Colors United Action Coalition of Los Angeles. I'm also an HIV educator for the Filipino Americans working on an Immigration and AIDS project that works specifically with immigrant families and Asian Pacific Islander youth gangs.

I would like to acknowledge and thank Senator Diane Watson and the Senate Committee on Health and Human Services for giving me the opportunity to speak on behalf of the Colors collective and the issue that faces us in the community.

Colors is fairly new to the lesbian and gay bisexual community, and so I'm going to give a little bit of a history; and it's somewhat of an activist culture of Act Up, Queer Nation, as well as other groups, colored groups also. Colors United Action Coalition is a co-gender, multi-racial collective that includes lesbians, bisexuals, transgenders, gays, heterosexuals, men who have sex with men, women who have sex with women, men who love men, and women who love women. We are dedicated to empowering and educating communities that have been marginalized by the Euro-centric-patriarchial establishment, through voter registrations, HIV/AIDS, prevention, education, and outreach, grass-roots political lobbying, and community educational forums. The group was founded shortly after the AB 101 veto marches in the lesbian, gay, bisexual, people-of-color communities, to confront the segregation that exists between the white establshment and people of color in the lesbian and gay community. Our membership consists of women and men, lesbian, gay, bisexual, transgender, and heterosexual from the African American, Asian/Pacific Islander, Native, Latina/Latino, and Caucasian communities. Diversity is our ideal, and we believe that we can make positive changes by learning from and celebrating each other's diversity.

We confront and process difficult issues, such as racism, AIDS phobia, lesbophobia, homophobia, heterophobia, and other social disorders that plague our society and keeps us separated as people.

Colors United Action Coalition is a rich stew of human resources that has members and supporters from the AIDS Health Care Foundation, Black Men's Exchange, United Lesbians of African Heritage, Gays and Lesbian Latinos or Nidos, VIVA, Gay Asian Pacific Support Network, as well as many other groups that are committed and connected to their home communities.

Since there is such segregation in the lesbian and gay community, people of color have different needs. I believe that the community still has more work ahead of them and education when confronting HIV disease and AIDS in the lesbian and gay, bisexual, transgender, people-of-color communities.

Cultural-sensitivity policies must evolve into racial and ethnic competence and accountability. My experience has been that the sensitivity has only provided

translated materials that was written for the Euro-centric-patriarchial experience.

Open-door policies are ineffective to people of color, since we need more than an open door to guarantee us a safety that everyone needs to access AIDS services. More facilities must be built in South Central, Monterey Park, Lakeview Terrace, Montebello, Rosemead, East L.A., and Carson, just to name a few. These facilities should be staffed by locals of that neighborhood who are dedicated to the improvement of their communities. Cultural sensitivity and open doors has its limitations. It's now time for us as a world collective to renew our commitment to take a step beyond just being sensitive and to being competent. It is time to walk through these open doors and invite people into our agency through a needs base and effective outreach.

People of color are dying, and sensitivity will not save our lives. Competency, effectiveness, and our accountability will. There are smaller groups that are established in the heart of the people-of-color communities that have little to no access to local, state, and county resources. Much of the funding and attention that goes into the larger, well-known establishments are not often shared with these little-known, smaller organizations that are at the primary contacts and representatives of people in their community.

Also, from my experience with the lesbian and gay community, I'm aware that people know very little about the subcultures that are neglected in lesbian and gay culture. These are bisexuals, transgenders, MSMs, men who have sex with men, women who have sex with women, who do not identify as lesbian, gay, or bisexual. These are people who may have been incarcerated, as it's been mentioned over and over. MSMs and WSWs are a recognized population -- the Asian and Pacific Islander communities, Latino/Latina, Native, and African American cultures, and they have been for a long time. These are also people of color who identify -- they're also people who identify, people of color who are identified, as MLMs, men who love other men, and WLW, women who love other women, do not identify with the Western Euro-centric label of lesbian or gay.

These populations thrive in the Echo Park area where many MSMs, who have wives and families at home, search for anonymous sex around the lake with other men. Men who love men and women who love women congregate in small private clans, in restaurants, in tight communities in the San Fernando Valley and Hollywood areas. They often don't participate in the lesbian, the white lesbian and gay community.

There's a large population of gay men in the skid row area. There are MSMs, men who have sex with men, and WSWs in the low-income housing projects where there are women and men who may have adopted this sexual culture while they were incarcerated. Many downtown bars feature African American, Asian Pacific Islander,

and Latino drag queens and gender benders as their star performers. Many of the Hollywood streets are littered with drag queens who pose on the corner as working girls.

Who reaches out to them? How many even know how to begin to understand these populations? Does HIV education reach them in a language they know and understand? These are the questions and challenges that we face. These smaller, hard-to-find populations do exist, and we must reward them with the same education, access to treatment and prevention that the mainstream community has been given. We must give more to people of color and women, women's communities, who are at least five years behind in the struggle against AIDS.

In closing, I'd like to lay some challenges before this committee. I challenge everyone to recognize lesbian, gay, bisexual, transgender, MLM, WLW, MSM, WSW peoples as belonging to a sexual culture that dictates the specific needs. We can no longer settle with the narrow confines of sexual preference or orientation. We are a thriving, growing culture that has family systems, spirituality, traditions, language, herstory, history, and legends. Investigate and be aware of populations that have been neglected by the Euro-centric-patriarchial establishment.

Racism and classism is alive and well in all communities, even in the lesbian and gay community. Challenge yourselves on how we may all be able to service the marginalized within the marginalized within the marginalized. Keep challenging yourselves to access the wealth of knowledge that belong to organic intellectuals. These are people who may not have academic standings, but these are the true experts that live, work, and speak from the community's needs, issues, and integrity. Challenge education materials and program designs and see if they are effective, accountable, and competent to the communities they are assigned to. Challenge to advocate for hiring policies that will hire from within the community and promote peer education. Challenge outreach strategies and make sure that they come from a needs-base assessment. Let us make sure that these strategies will enhance and become part of a community's ecology rather than disturbing it with alien ideas and outsiders.

We all have got a lot of work ahead of us, and I'm looking forward to the day that we'll have to look for other jobs, not because our AIDS contract was not refunded. And, you know, the one thing that I'd like to say is the other syndrome that I keep hearing here -- and coming from an Asian Pacific Islander perspective as a man who loves other men, I'm still a little discouraged about how Natives and Asian/Pacific Islanders are put in the "other" category because we haven't shown enough dead bodies. There are dead bodies. They're decomposing in homes where

there's a great deal of fear in the Asian/Pacific Islander cultures -- or they're being sent home to the Philippines, to Thailand, where they are made to pray 24 hours a day to get rid of this disease. So I hope we could break out to this other syndrome because in lesbian and gay cultures, these transgenders, MSMs, are also broken into that.

There's a great deal of profit, monetary profit, to be made with marginalizing, but that is unethical and immoral.

(In Filipino _____.) Thank you very much.

CHAIRPERSON WATSON: You certainly have placed in front of us a great challenge because you described structures and substructures and sub-substructures that most people are not even aware of in terms of a breakdown. And we have to become educated. I think the need is so great, we treat those with AIDS. But when you start looking at the sub-sub-substructures, we don't even know how to move into those categories.

I think this very new group that has come up around the veto of AB 101 could be very instructive to society because you just broke it down. I thought I was pretty sophisticated. You know, you talk about homosexuality and lesbianism. Then you broke out a category called men who love men and women who love women who don't consider themselves in that category. And I guess that's one of the reasons why the information we have doesn't reach, because when we say this is targeted towards the gay male or the lesbian female, we miss some who don't consider themselves in that category.

MR. TAN: These are -- men who love men and women who love women -- these are categories that are alive and well in a lot of tribal cultures, in the Philipines. I hear also that's in African American culture. And when you come up to somebody and say are you gay or lesbian, what they see on TV, because TV is very racist, they see white lesbians and gays and they don't associate that with that because they can't break away from their community as easily and they have another system that they work under.

CHAIRPERSON WATSON: Now I heard you mention "Queer Nation". Is that not a derogatory reference?

MR. TAN: Oh, that whole thing with Queer Nation is -- I'm not going to speak about Queer national.

CHAIRPERSON WATSON: I think that, I don't know why Queer Nation, unless it's kind of satirical thing they're doing, because Queer Nation conotates that it deviates from what I hear you saying, brings people together and saying this is, for some people, a very normal way of life. I think "queer" does not connotate that particular...

MR. TAN: Well, I mean, as far as I hear from other Queer nationals -- Colors United is its own autonomous body. Queers, it's also all-encompassing, they feel. By not putting the negative power back into the word, they feel like they would, that's their opinion. And like I said, right now we use people of color, and I hear a lot of sisters and brothers saying, "They're colored", with pride.

CHAIRPERSON WATSON: Well, I don't think the definition as we all understand, "queer", like "weird", does what you want it to do. That's coming from my opinion and my standpoint. I don't think -- these other breakdowns make sense to me. But that one does not, and I just throw that out. You don't even have to respond.

MR. TAN: Okay.

CHAIRPERSON WATSON: Thank you very much. We appreciate your testimony.

DR. TATE: Joel, can we get a copy of your testimony, either now; or could you send me a copy.

MR. TAN: I'll send you a copy.

DR. TATE: Okay.

CHAIRPERSON WATSON: Corinne Tanon, Health Educator, with the American Indian Free Clinic, I understand has been here since about 9:15 this morning.

MS. CORINNE TANON: Right.

CHAIRPERSON WATSON: We want to commend you for your tenacity and your ability to sustain all this information thrown at you and still be here willing to testify. So we'll call on you right now.

MS. TANON: Okay. Great.

CHAIRPERSON WATSON: And give you your opportunity to do what others have been doing all day.

MS. TANON: First of all, I want to thank you for inviting me to come and share this information which is so important to all of us here. I'm kind of nervous, so I want to -- first of all, I want to talk about the demographics, community demographics. And then I'm going to go into health issues and then gaps in health care and AIDS and how that's affecting us as Indian people.

According to the 1980 Census -- I'm referring to the 1980 Census because the 1990 Census, we feel, are not a good count of our population. According to the 1980 Census, California has the largest Indian population. There are approximately 225 American Indians from 200 different tribal affiliations. In L.A. County alone, there are 90,000 urban American Indians and is the largest urban community in the nation. Out of the 90,000 American Indians in L.A., 54,000 are below the poverty level, and there is approximately 45 percent unemployment.

The Indian population is a young population; and the nationwide average age is 20.4. In L.A. County, the average age is 17.3 years of age; 67 percent of the

Indian population are 25 years or younger.

Indians are three times more likely to die young, between the ages of 24 and 40, the Nunn Indians. Average life expectancy is 44 years of age. This is lower than the migrant farm worker.

According to the L.A. Unified School District, the Indian High School dropout rate is 23 percent. This figure increases when you include those that never attended, enrolled into high school. The average age of Indians living in Los Angeles is 17.3; 67 percent of our urban Indian adolescents are drunk -- or use drugs moderately to heavy.

Health issues, Indian suicide rate is seven times that of the national rate. Indians have the highest rates of heart disease and diabetes. Twenty to 25 percent of all American Indian children suffer from mental illness, just as alcoholism rates is 41.3 deaths per 100,000 versus 17.4 deaths for African Americans. In the white population, it is 6.4 deaths per 100,000.

Gaps in health care: Health care is expensive to nearly all segments of society but especially to many Indian people. They may not be able to afford health care due to the lack of insurance or other needs that are more pressing. They will go to a health care facility only when a need is acute. Therefore, they will not hear about the message of AIDS prevention. And that's why it is so pressing to have outreach at those places where they congregate -- sport events, pow wows, community functions. But the high rates of sexually transmitted diseases and alcohol and IV drug use among American Indians, hopefully the State of California, may understand the importance of funding as a preventative measure.

The source of continued funding is always contingent upon the outcome of census demographics and socioeconomic and political strategies. Because we are a small population of 90,000 American Indians in Los Angeles County, we are sometimes mistaken for Hispanics, Filipino, white, African Americans. The community is well dispersed, and this may contribute to the political under-representation and social misrepresentation in the communities. We are poorly represented in every segment of society. I can only speak for myself. We have no political clout, and our voices aren't being heard. The theme is reflected in the decision-making of our city fathers and government.

According to the HIV/AIDS and American Indians' Handbook for Tribal Leaders, stated the following: Since September 1991, the Center for Disease Control has approximated 305 American Indians diagnosed with AIDS. Dr. Emmett Chase, AIDS coordinator for Indian Health Service, estimates that there are 12 to 13 new Indian AIDS cases identified each month. The fact is the annual rate of increase of new AIDS diagnosis is greater for Indian people than for any other racial group. The

number of Indians diagnosed with AIDS grew by 91 percent from (19)89 to (19)90. While other racial groups have a higher number of individuals with AIDS, the number of Indians with AIDS is rising at a rate proportionately faster than for other groups.

Percentage increase in AIDS cases from '89 to '90: whites, 8 percent; African Americans, 13 percent; Hispanics, 5 percent; Asian/Pacific Islanders, 17 percent; and Indian/Alaska Natives, 91 percent.

The time of prevention is now. Indian people can benefit from the experiences of other populations which have dealt with the AIDS virus for the past eight years. We must act now before the virus wipes us out like the smallpox epidemic of the early 1800s.

According to the Center for Disease Control, found that Indians and Alaska Natives have experienced a higher rate of gonorrhea and syphilis. This study indicates that we are at risk. The transmission categories for these cases are 54 percent, were homosexual/bisexual transmission, and the rest by blood product transmission. This contrasts with white transmission which is 76 percent homosexual/bisexual; 15 percent shared needle; and 2 percent heterosexual.

The percentage of Alaska Native and American Indian women with AIDS is 13 percent of the total number of American Indian and Alaska Native cases, in contrast to 4 percent of the white women. According to CDC, has been working with Indian Health Service to evaluate the HIV in the American Indian population. It is estimated that for every 1 million American Indians and Alaska Natives, approximately 1,000 individuals are currently HIV-infected. Then it could be estimated that for over 85 percent of these individuals do not know that they are HIV infected.

The time of prevention is now. We must act now before the virus wipes us out like the smallpox epidemic of the early 1800s.

I have quote here from Chief Funnycoups (?) -- he's Crow, or was Crow: "With the white man's education, you are his equal. Without it, you are his victim. Please stop us from being the victims of the disease of AIDS by funding our communities."

Thank you.

CHAIRPERSON WATSON: Thank you very much. Something that we picked up when we had other hearings and we listened to representatives of the various ethnic groups, is that among Indians -- and correct me if I'm not correct -- is that there is a higher propensity towards addiction?

MS. TANON: Right. That's true. That's correct.

CHAIRPERSON WATSON: And having that higher propensity, and I don't know if

it's genetic or what it is, there necessarily would come along with it an increase in the risk of AIDS?

MS. TANON: Exactly, because we have a high rate of alcoholism. And with that, you have the high-risk behaviors involved with that which leads to sexually transmitted diseases. So at this point right now, we have a high rate of STDs, sexually transmitted diseases -- gonorrhea, syphilis. So that means, yes, we have a high risk of contracting AIDS right now.

CHAIRPERSON WATSON: I think if we look at addiction itself, we might be able to learn something about the increase among American Indians. It's startling to see that you've gone up 91 percent in a two- to three-year period. And I guess that's because you have fewer cases.

MS. TANON: Right.

CHAIRPERSON WATSON: And now more cases are being detected.

MS. TANON: Exactly. That's true.

CHAIRPERSON WATSON: But I think, and one of the things that keeps coming back to your theme, is that we don't know that much about addictive behavior.

I, you know, if I can just look at it historically because the purity of the system of the Native Americans; therefore, once the toxins gets into the body of the addictive substance, it's a quick reaction. And that's off the top of my head. But we need to look at it, and I don't think we know enough about addictive patterns among the various ethnic groups and why do some become addicted much quicker than others and why is the high-risk behavior then increased with that addiction. So I think these are some of the things that we need to learn more about as we look at the various cultures and how we deal with them, particularly with this disease.

MS. TANON: Exactly.

CHAIRPERSON WATSON: Thank you so very much. We appreciate your long wait and your testimony.

I'd like to now go back to Cleant Stain, the Director of South Los Angeles AIDS Program at the Watts Health Foundation. Welcome.

MS. CLEANT STAIN: Thank you.

CHAIRPERSON WATSON: We did call on you earlier.

MS. STAIN: Okay. I'd like to thank you for the opportunity for being present here today, and I'd also like to concur with my other colleagues and echo some of the same concerns, and that is, that HIV/AIDS does not occur in a vacuum. There's still many other health and social problems that exist within our community, which is South Central.

Oftentimes while my staff and myself are involved with people infected with

HIV or AIDS, we find ourselves overwhelmed with the number of problems that exist within their situation. And oftentimes, prior to working with AIDS-related issues, we must first assist with other social problems. For example, there was one case when we were going into an individual's home. We thought we were going to assist the person with AIDS with housing issues, which is a social concern. When my staff and I arrived to the individual's home, we walked into a 3-bedroom home with 18 people living in that home, massive overcrowdedness. There was battery going on. The lady we were talking to had, you know, bruises under her face. And so when you go into a home or many times when you're working with people with HIV, you want to know will the real issue please stand up or will the real client please stand up and everyone stands up. So before we can even begin to deal with many AIDS-related issues, we have to deal with other issues first.

As you know, South Central Los Angeles is geographically dispersed and ethnically diverse, and many of the people living in that community are economically depressed. Within this community, there's only one anonymous test site, and that's at the Minority AIDS Project; and they're open two days a week. So anonymous testing is a big concern in our community. There's only one drug reimbursement program for people to access clinical trial drugs within the community.

There's also a lack of coordination between the federal, state, and county government. For example, we've just received funding from the Ryan White Title III-B which came directly from the federal government. And one of the goals or objections of this program is to provide primary care to people infected with HIV and also to increase the number of people who get tested within the Watts Health Foundation system so we can identify what our sero-prevalence rate is.

When we -- and prior to doing any testing, we have to first do pre- and post-test counseling. So as I was on the telephone trying to access this service through the State Office of AIDS and with our local AIDS Program Office, we were unable to get anyone to come out and actually do training for our staff so that we could follow the guidelines of our contract, which is, you know, testing. And ethically, there is no way that we should be drawing blood for HIV without doing the pre- and post-test.

DR. TATE: Why weren't you able to get someone from the Office of AIDS to come out?

MS. STAIN: We were told that their priority, the priority for training, was for people who, for contractors who were state funded under the early-intervention program.

DR. TATE: And yours came straight from CDC?

MS. STAIN: No, it came from the federal government. So we're all Ryan White funds, Emergency Act funding. But because we got ours diverted from another direction and we were not able to access some of the same services, and that was about a month-and-a-half ago, so what we had to do is look within the community; and we were very fortunate that Martin Luther King Hospital had people who were trained and certified for pre- and post-test counseling. And they came out and gave, took time away from their caseload and from what their regular job was, to come and train staff so that we could go out and perform our contract. That's a big problem.

The drug reimbursement program is another problem. As we start identifying more cases who are HIV-positive within our system and within the community, people who are coming in, not only from within our system but from outside of our system who are coming in for services, we're finding that, you know, drug reimbursement is going to be a problem to have the clinical drugs on site for our program. When the telephone calls were made to the county, and hopefully that will be worked out that we will be able to disperse the medication. But what ends up happening with the Drug Reimbursement Program as it stands now, is you can have the drugs on hand; but then the eligibility paperwork is very time consuming, so there's no funding to pay for a staff person to actually do the eligibility screening, which is very important to see who actually qualifies for the drugs.

I guess within our system it may not be too terribly bad of a problem. But if we have people who come from outside of our system who present a voucher, then we can be overloaded, because when you look at the geography of South Central, we are at the southern end of South Central. And if we are distributing drugs, and the next place that's distributing drugs is at Hubert Humphrey, which is like maybe ten miles away, so that can present a problem.

Currently, at Watts Health Foundation, we have six funded AIDS programs. We've just been funded with three new programs that we're very excited about. And I'd like to just list the programs briefly. We're funded by the Los Angeles County AIDS Program Office to...

CHAIRPERSON WATSON: Can you kind of bypass that.

MS. STAIN: Okay.

CHAIRPERSON WATSON: And just hand us that in print.

MS. STAIN: Okay. Well, basically although the programs that we have funded meets some of the HIV needs, the funding is very limited; and we're unable to hire enough staff to actually make an impact within the community. For example, with the education grant, we're only funded for three staff people. When you look at not only Watts Health Foundation, but you look at South Central, the number of

agencies who are actually funded to do education, there are very few. So we've got maybe four or five programs in South Central that have two to three staff people, you know, to do the education; and the area is very large, so that's another problem. So we would like to see within the funding mechanism that when funds come down for agencies, not only for our agency, that enough funding is allocated to the agencies to actually hire staff people to do the work. That's about it.

CHAIRPERSON WATSON: We appreciate your comments also. I've heard you testify before, and that's been several years and the need is even larger now than before.

What would you say the percentage of increase in the area where you work has been, say, in the last five years, the increase in HIV-positive?

MS. STAIN: Well, as you know, with HIV-positive, many of the clients are not coming in for testing. So, you know, I can only speak to what we know which is the actual AIDS cases. I think with the education that's going on right now, I know for us right now, we've just started confidential testing. And we're already backed up two weeks, so we need more staff people. I was reviewing budgets this morning prior to coming here to see how we can, you know, what can we do with the money to bring more staff people in so we can actually meet the need of the people. We're starting to see families who are coming in. We're seeing young women, young pregnant women, who are coming in with risk factors of having sex with men who are incarcerated.

So, you know, from what I'm seeing right now, the cases are increasing; but I don't see the whole picture for South Central. And we don't -- the demographic profile or the profile information on people who are actually HIV-positive is not really showing up. I think that outreach -- we need to have outreach, and the outreach that we need to have is to educate about testing. You know, people have information about AIDS, what is AIDS, and how to contract it. People are not internalizing their own risk factors. So we need to have some targeted outreach or targeted education with specific risk-assessment questionnaires, you know, toward specific populations like for women. If you ask a woman to look at her risk factors and, say, if you had multiple sex partners, well, for that woman, you're asking her if she's a slut. So she may say in her mind, no, I don't have multiple sex partners. But if you ask a woman have you, have you ever exchanged sex for money or have you exchanged sex for drugs or if you, you know, just really specifically asking about sexual behaviors that they may have been involved in, a ride home. I mean, you now, they may not be honest in answering the questions when you're asking them, but it's something that will provoke a thought for them that may motivate them to get tested.

I think what we need to do is increase the number of people who get tested, to

identify who they are, because with the early intervention treatment that's available, there's no reason for anyone to, in the old days, which was four years ago, to...

CHAIRPERSON WATSON: When you say "identify who they are", you mean in the population identify who is a carrier.

MS. STAIN: Right. Identify who the carriers are. Not for me to identify but for them to know who they are, for them to know for their own sake so that they can be referred or go into some early intervention programs, because when I spoke four years ago, what we were seeing was people falling into the emergency room with chest pain thinking they had a bad cold, only to find out that they had pneumocystis pneumonia which gave them an AIDS diagnosis. Do you understand what I'm saying?

CHAIRPERSON WATSON: Yeah. Do you think we ought to require blood testing before one gets a marriage license?

MS. STAIN: I don't know. I think if I were getting married, I would want my partner to be tested. But that's a personal thing. I can't speak for the general...

CHAIRPERSON WATSON: You think that's an idea we ought to pursue?

MS. STAIN: I think so. I think that if it was, that maybe one way to stop some of the transmission. It's something to consider.

CHAIRPERSON WATSON: All right. Thank you very much.

MS. STAIN: Okay.

CHAIRPERSON WATSON: We appreciate you coming and testifying for us.

Paula Starr. Is Paula here?

Okay. Let me go back over. Phil Wilson, I don't think is here. Germaine Maisonnet, Doctor. Kazue Shibata. And Paula Starr was the last one we had.

Is there anyone with new information that feels that he or she needs to come to the mike? And if you can give us some new information, I think we've heard almost everything.

MR. CLEO MANAGO: I'll attempt -- I mean what happens usually at these type of testimonies, people who are invited are the ones that you usually see. The ones that you usually see are there for sometimes for political reasons or various reasons. What happens a lot is that -- I think it's been reiterated here that language and geography has a lot to do with the barriers.

The reason that AIDS has increased in the Black community is because of barriers. And I want to introduce who I am so you can know that I'm not just somebody who sells toys, but I work in this field.

My name is Cleo Manago, and I'm the founder of the Black Men's Exchange. It

is a national organization that primarily provides support services, empowerment services, and general education about health with AIDS emphasis to African American men. Usually these African American men are the ones who are referred to as hard to reach -- men who love men, men who love men and women, men who don't identify with the mainstream populations in the so-called gay and lesbian community.

I think it's important to understand that, when it comes to the African American community, the majority of the people who are so-called homosexual are not in those places that are called lesbian and gay. They don't identify with those places. And because of the lack of support of services for so-called gay men or men who love men in the African American community, some choose to go to the white lesbian and gay community, be empowered, for their sexuality and who they are. Often some of them just totally separate from the community because they feel a sense of ownership and acceptance there, and they are the ones who you see usually. At these hearings, you don't hear from people who are in the community all the time and often.

BMX was developed in 1989. My work history has been in collaboration with Dr. Wilbert Jordan. I've done work with him, with the Watts Health Foundation, with Dr. Maisonnet, and Cynthia Davis. I've been working with these people since early 1985. The primary location for the Black Men's Exchange is in Oakland, California. That's where our headquarters are located. Oakland has a major epidemic going on there that's been hardly addressed at all.

One of the problems has been homophobia because San Francisco is right across the bridge, and the city government in Oakland doesn't want to identify itself with that homosexual reputation that San Francisco has; so it doesn't deal with the issues that talk about AIDS at all because we cannot identify with that kind of population. You understand what I'm saying? Is that clear? So there's a lot of political things going on.

In South Central Los Angeles, BMX is ran through Faith United Methodist Church which is in South Central Los Angeles. And in San Francisco, it's ran through the Bayview Hunter Point Foundation. In Sacramento, it's ran through the Project Survival Foundation which is part of Women's Civic Improvement Center. In Oakland, it's ran through an Institute, which is the African American AIDS Support Services Institute in Oakland, California. The Black Men's Exchange serves up to 2,000 men per year statewide. And again, there's a national addendum, so an organization in Denver, Minneapolis, and in Atlanta.

We have found it difficult to acquire funds due to racism, due to politics, and due to hidden agendas. Again, a lot of people who do this work who are men who love men, for example, tend to identify with the mainstream community, trying to

get their foot in the door to get funds so they call themselves lesbians and gay. And some of these programs are, such as the Minority AIDS project, and AIDS Project Los Angeles.

I think it's important to understand that, and I wish the guy from the AIDS Project Los Angeles was still here. AIDS Project Los Angeles provides fine services. They provide very good services. But Black folks are not going to go to APLA and get services, until they're on their last leg and they're so desperate to go anyplace. It's kind of like what we do when we don't take care of our teeth and we wait till it becomes a toothache, and then we don't care if the doctor's a Martian. We just want the tooth out of our head. Well, that's how a lot of people in South Central are dealing with AIDS. And one thing that keeps being said, you see, if we don't look at the barriers, we will not resolve this. The reason we have not resolved this problem is because we keep saying the same thing over and over and over again, and no innovation is implemented.

There's been one thing that keeps being said that disturbs me because it's not true, from my experience. A lot of people keep saying that a lot of people in the Black community think AIDS is a white gay disease. That's not true. A lot of Black people in the community know that AIDS is not a white gay disease. The problem with internalizing these messages is the fact that people in our community are distracted. Like the doctor from Drew said, there's other issues going on. There's other issues such as guilt around being a good Christian, guilt around not being good enough, not making enough money, guilt around not being a good enough wife, not being a good enough man, especially if you're a bisexual or a man who loves men who feels like you failed the Black male litmus test of being man enough. All these issues have a lot to do with why men do not come forward and why people in our community do not come forward.

One thing that might sound overwhelming -- I know you mentioned being cynical, potentially cynical, earlier, Senator Watson, is that -- oh, gosh, so much going on with me; it's hard to concentrate -- is that people of color are set up for distractions and failure from a very young age by not having their culture and anything that validates them in the curriculum of their education.

In collaboration with the distraction such as gang violence, such as institutional racism, all these things together set us up for being distracted from self preservation. So the issue from my point of view, which is going on a ten-year point of view, is not that the Black community thinks that it's a white gay issue. That's not true. It's just that we need excuses not to take care of ourselves because we're so distracted. A lot of women in our community are being served through AIDS programs that are part of WICK clinics, but they go home to men

who are not educated. So they come home with all this knowledge, and the man is offended by being challenged on anything because he has not been educated and he's distracted.

There was a comment made earlier that a lot of the men who go to prison who come out having homosexual behaviors, don't identify with the community, the so-called gay community, please don't think that everybody who doesn't identify as gay, who are men who have sex with men, are people who have been incarcerated. Some people just don't like the terminology. The white gay community tends to be very inclusive -- excuse me -- exclusive. And just as racist is the mainstream community, and so there's not a real attraction to that community, no matter what it offers. I mean if there's a million dollars available to Black people at APLA, many of them won't get that money because they don't want to go to APLA. Though service providership is not the issue, they provide a high quality of service. But a lot of Black people would not wind up there, not unless they're so desperate that they're almost dying anyway. And there's minimal things that can be done to keep them healthy.

I think it's important to understand that a lot of the people who do not come to you in our communities, obviously because you don't see them, they're not being well funded. The Minority AIDS Project is way on the other side of town. And also, I don't want to say anything bad about them because they're doing some excellent work, but they're geographically inaccessible to a large segment of the population in the Black community.

The United Fellowship Church is right on 109th and Western. It's centrally located. But because of politics, hidden agendas, and personalities, it's very difficult for this program to get the monies that it needs. And also somebody made reference to language that's needed to properly create an RFP or a proposal or a grant. Some of that language is very stymie; it stymies people; it's very limited. It's hard to express ourselves fully with the language that the RFPs require because they don't -- they're not appropriate in our community. So again, if a dot is not, you know, dotted, and the "t" is not tied, or whatever the terminology is, many times those RFPs are put aside. And many times agencies would have a larger name, such as APLA and others, will get that money just because they have a big name. But listen to me, the fact they have a big name does not mean they're providing adequate services. Most of these services, including APLA and others which will not be mentioned, are providing a Band-Aid approach to AIDS that does not cause any prevention at all because by the time they get there, as you know, they're already dying. These are not preventive efforts. These are multi-million dollar, crisis-dying institutes for Black people and other people to get their

hands held until they die, until they die.

There needs to be innovative and culturally competent programs funded, that are already working in South Central, such as the Black Men's Exchange, to be advocated for and supported. Again, the over thousand plus men that we deal with in Southern California alone, the work that we do is hardly ever recognized because we're not part of the lesbian and gay clique. We're not part of the high-profile clique because frankly those cliques have turned off a lot of people and don't invite a lot of people who are in the Black community.

So if we really want to do something about the AIDS issue, we have to stop being impressed by glamour and glitz of the million-dollar agencies and find out who's doing things in South Central. And I have some recommendations, believe it or not, or after all this talking.

CHAIRPERSON WATSON: Yeah. Can you get to the...

MR. MANAGO: Yes, I will get...

CHAIRPERSON WATSON: I'm going to give you just a few more minutes because we're over our time limit.

MR. MANAGO: Okay. I'm sorry. Okay. I recommend that there be some advocacy and support provided to programs that are in South Central Los Angeles and that are not necesarily connected to the high-profile agencies but who are individually and independently and innovatively providing some great services in South Central Los Angeles. I think we should include persons who are from the grass-roots and who have ongoing contact with hard-to-reach populations in research and data collection projects.

It was mentioned earlier -- you asked about IV drug use in the Black community and were there any documentation that assess what is going on. Most of the people doing the research do not have a cultural understanding of the community, and they can't even get adequate information because they're not from the community. And people tell -- either they don't see the people at all, or people don't trust them enough to tell the truth. So there's a lot of IV drug users out here who are not even part of the statistics, as well as people with AIDS who die and get other diagnosis because the family doesn't want anybody to know about it, and they do not trust these agencies who have all this glamour.

Also, I think it's important to include persons identified by the community as representing the community to be involved in the consortiums and city-wide and county task force and involved in the language that's developed for RFPs and grants. People from those communities should be in that system to tell you this language is not appropriate; this language is a barrier; it's going to get in the way.

Again, innovative programs that are holistic and effective, like the doctor from Drew said, you cannot go to someone and say AIDS 101 and give them an AIDS 101 education and expect them to take care of themselves. They need to be dealing with the psycho-social issues; they need to have support. You asked should people be tested before marriage. No one should be tested if there's not any appropriate counseling or a psycho-social support system there to help them deal with whatever their diagnosis might be after the test results.

I think, and this is essential. This is my most favorite and important recommendation. Existing services, existing service to a provider should document and prove their ability to attract and serve, underserved, and unserved populations by some kind of tool that must be developed to prove that. And the goal of this recommendation is to not fund or to provide technical assistance to existing organizations who have been incompetent as it relates to minimizing this epidemic in our community, because as you said many times, it has not been minimized; it's getting worse. And it's because of these barriers that I'm addressing. I probably could go on with others, but we don't have time.

I also think that holistic, culturally sensitive health care and AIDS 101 program should be institutionalized in public and civil servant populations, people who serve people who are in public service. I'm a former deputy sheriff. And inside the prison, you were talking about asking the people who work in prisons and in jails to assess homosexuality in the prisons. Now I may get in trouble for saying this. But what's difficult about that is that there's a morale problem going on with law enforcement. You've heard about Rodney King and the dog bites, and I can go on and on and on. Everybody who's in the positions of "power" in legislation are not necessarily culturally sensitive or concerned about the life and death or comfort of people of color. That's why they let dogs bite them and beat them up with canes and stuff.

Inside of the jails, there are people who work for law enforcement who are bringing in IV drug needles who work, who have on a badge. There are people who make sexuality in the prison a joke -- well, let's see who's going to get who tonight. It's like they bet, you know. It's a game, because if you don't respect faggots and homosexual and faggot behavior -- you know how we treat -- you now how there's racial jokes and there's homophobic jokes and there's jokes made on how many Black people get killed. You heard about how the police use the KKK over the radio station to talk about what they're going to do somebody Black. You've heard that. That's been made publicly -- that's been public knowledge based on reports from the news.

CHAIRPERSON WATSON: You said they don't respect faggots. Do you want to

refer to that group as faggots?

MR. MANAGO: Not at all. I'm putting that in -- I'm, paraphrasing. I mean when you're being disrespectful, you don't go, oh, I don't have any respect for homosexuals. You don't have no interest of being respectful. The whole thing is disrespectful. That's why I used the language that's disrespectful, just like when the KKK it's going to kill niggers. They don't say I'm going to kill African Americans. It's a disrespectful process, so the language is disrespectful. I'm just trying to give it to you the way it is so you can see what I'm talking about so we can get rid of these barriers and save lives because people are dying from a disease that's preventable. And there's all of these barriers and all these cliques. Some of these agencies are serving cliques, friends. A lot of the AIDS work for the past ten years, even among so-called people-of-color agencies are serving a clique of people, not the whole community.

CHAIRPERSON WATSON: Right.

MR. MANAGO: And that has to be addressed or else we're not going to publicly serve everyone.

CHAIRPERSON WATSON: Can you finish your recommendations in just another second.

MR. MANAGO: Okay. I really infer with the young man or the man who talked about a mobile unit in the community. What we did when I went down to Atlanta as a consultant was came with an ice-cream truck with the music and everything where people would run out to it, and they would get AIDS information and AIDS education. And, of course, kids were very young. We asked, was your mother home, could she come out here, before we gave them information, because we need parental consent. But, you know, using the social behavior of a community as an educational apparatus works. Try to bring white gay devises and approaches to our work in our community does not work. And that's another reason why the epidemic has increased. We've got to use organic skill and social behavior that's already organic to our community as part of the educational format. And that has not been done.

Again, all these labels and stuff are a barrier -- gay and lesbian and all those other kind of stuff. I believe I'm finished.

CHAIRPERSON WATSON: Now we just heard from a speaker who broke it down into sub-sub-sub-sub-sections, and it gets a little confusing because who on the outside really knows that this is a subset that hasn't been served when you say people who are at high risk?

MR. MANAGO: Well, see, what people tend to do is follow trends. And I'll make this real quick because I know I don't have a lot of time. But the white gay community are the ones who are empowered to do a lot of this work. Then people who

identify with that community as gays and the people-of-color community jump on that bandwagon to do work. So we became this vacuum of lesbians and gays, white, people of color, who are doing all this work and serving each other. And the language now was promoted politically and through the media was lesbian and gay. So that was required in the grant. When people from South Central who referred to themselves by the grant and talked about the fact that our language is not appropriate because the people who provide the funds are not familiar with men who love men, that language, women who love women, that language, the grant is put aside. The Black Men's Exchange has been using that language for several years; it's not new. It's just that we have not been invited. Again, the Black Men's Exchange was not on the list.

CHAIRPERSON WATSON: Well, what you could do to help us is clarify for us how we can identify all these different groups who don't get served because they don't fit the definitions. I mean every time we hold one of these hearings, we get an education.

MR. MANAGO: Right.

CHAIRPERSON WATSON: Because unless you are in the streets every day working with these programs, you know, the vernacular changes. The descriptions change. It's trendy.

MR. MANAGO: Well, you know what? Let me tell you something. The vernacular has not changed, just like someone keeps saying in these meetings that the epidemic has a second wave. That's a misnomer. The epidemic was always in the Black community, always, from the very beginning.

CHAIRPERSON WATSON: Well, what I'm trying to get you to focus on is how can we identify who needs to be served.

MR. MANAGO: Okay. The way you can identify...

CHAIRPERSON WATSON: And I don't want you to tell me now.

MR. MANAGO: Okay.

CHAIRPERSON WATSON: I want you to put it in writing because we really have to bring the hearing to a conclusion. We're way over time for the use of this room. So if you could send it to us, if you just want to send us a memo or a letter describing what the problem is in terms of the way the request for applications and so on goes out, it would help us if we want to broaden the impact --

MR. MANAGO: Right.

CHAIRPERSON WATSON: -- of the funding. And you've got to be sure we know how you're going to ask for it.

MR. MANAGO: Okay. Just one last thing.

CHAIRPERSON WATSON: And conclude because...

MR. MANAGO: I sure will. People tend to use language as a way to get funded too, once they learn the the political terminology.

CHAIRPERSON WATSON: You're going to help us with that by --

MR. MANAGO: Okay.

CHAIRPERSON WATSON: -- broadening out our understanding.

MR. MANAGO: Right. And that's why it's important to target and understand and locate...

CHAIRPERSON WATSON: Well, we can only target if we know what's being used today.

MR. MANAGO: Right. And I'll help all I can with that. Thank you so much.

CHAIRPERSON WATSON: Thank you very much, and I want to thank all of you. We appreciate your attendance; we appreciate you staying with us. And as we -- our attempt was to learn more about what's happening in the streets as it relates to AIDS. And we held a hearing years back. And every time we hold these hearings, we get updated.

Our intention is to go back and put together a package of legislative measures that will address some of the issues that were raised here today. I thank the people from the department and the Office of AIDS for staying with us. I think you learned a lot. And in learning, we're able then better to address the needs out there in the streets.

I thank all of you for coming, and this concludes our hearing.

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BACKGROUND INFORMATION

FACT SHEET

ETHNIC MINORITIES AND AIDS

* A higher proportion of African-American and Hispanic AIDS patients are women, children, and heterosexual men, due to drug-related transmission.

* African-Americans are three times more likely to have contracted AIDS than whites.

* Nearly 90% of American babies born with AIDS are African-American or Hispanic.

* 57% of pediatric cases with AIDS are African-American or Hispanic.

* African-Americans represent 24% of those who have been diagnosed with AIDS, and Hispanics represent 14%, which is greater than their overall proportion in the community (12% and 6% respectively).

* Intravenous drug use is the sole risk factor for 34% of African-Americans and 35% of Hispanics with AIDS, but only account for 5% of whites with AIDS.

* 60% of all women with AIDS are African-Americans.

THE CHANGING COMPOSITION OF AIDS CASES

	1990		1991	
RACE	NO.	PERCENT	NO.	PERCENT
WHITE	3030	71.6	2830	65.1
BLACK	536	12.7	627	14.4
HISPANIC	579	13.7	774	17.8
ASIAN	64	1.5	76	1.8
OTHER	22	0.5	39	0.9

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PATIENT GROUP	NO.	PERCENT	NO.	PERCENT
GAY/BI	3351	79.7	3223	74.7
IDU	280	6.7	392	9.1
GAY/BI IDU	288	6.8	326	7.5
HEMO	21	0.5	17	0.4
HETERO	80	1.9	99	2.3
TRANS	70	1.7	71	1.6
NIR	115	2.7	189	4.4

SOURCE: OFFICE OF AIDS

AUTHOR: Jim Creeger, Chief, IDS Case Registry

AIDS BY ETHNICITY AND TARGET GROUP IN CALIFORNIA

ETHNICITY	PERCENTAGE
White	72%
Hispanic	14%
African-American	12%
Asian	2%
Native American	80 Cases

RISK GROUPS	PERCENTAGE
Homosexuals	82%
I.V. Drug Users	6%
Homosexual I.V. Drug Users	9%
Hemophiliacs	1%
Heterosexuals	2%
Transfusions	2%
None of the Above	3%

CALIFORNIA'S ACCOMPLISHMENTS IN AIDS

1. A COMPUTERIZED AIDS REGISTRY

2. AN AIDS ADVISORY COMMITTEE

3. UNIVERSAL BLOOD-DONOR SCREENING

4. ESTABLISHMENT OF THE ALTERNATIVE TEST-SITE PROGRAM FOR VOLUNTARY, ANONYMOUS HIV TESTING

5. AN AIDS VACCINE RESEARCH AND DEVELOPMENT PROGRAM COMPLETE WITH CLINICAL TRIALS

6. VARIOUS PILOT PROJECTS FOR HOSPICE, HOME HEALTH, AND ATTENDANT CARE FOR PEOPLE WITH AIDS

State of California
Pete Wilson, Governor

Health and Welfare Agency
Russell S. Gould, Secretary

Department of Health Services
Molly Joel Coye, M.D., M.P.H., Director

Office of AIDS
Wayne E. Sauseda, Chief

California HIV/AIDS Update

Office of AIDS

Volume 4, No. 9 | September 1991 | Pages 90-106

DEPARTMENT OF HEALTH SERVICES

In This Issue:

AIDS AMONG CALIFORNIA ASIAN AND PACIFIC ISLANDER SUBGROUPS

INTRODUCTION

The number of new acquired immunodeficiency syndrome (AIDS) cases among Asians and Pacific Islanders in California has been steadily increasing. However, little is known about the impact of the AIDS epidemic among the more than forty ethnic groups within this population. Refinement of AIDS reporting practices can provide valuable new data about Asians and Pacific Islanders who have or may be at risk of developing human immunodeficiency virus (HIV) infection.

Diagnoses of persons with AIDS are reported by physicians and other health professionals to the State Department of Health Services through local health departments. AIDS case information is ascertained using the confidential report form developed by the Centers for Disease Control, which includes data on demographics, risk behaviors, diseases indicative of AIDS, and laboratory results. Currently, the form allows for the reporting of Asians and Pacific Islanders only as a combined racial/ethnic group, making it difficult to plan prevention and treatment services targeted to specific ethnic subgroups within this population. To address this concern, Assembly Member Roos drafted Assembly Bill 3815 which passed during the 1990 legislative session, requiring enumeration of specific population subgroups among Asians and Pacific Islanders with AIDS reported in California. The Office of AIDS designed and administered a survey to obtain this information. Analyses of AIDS case trends among Asian and Pacific Islander subgroups based on the survey are presented in this report.

METHODS

As of February 14, 1991, 24 counties in California had reported a cumulative total of 476 Asian and Pacific Islander AIDS cases. These counties were requested, by a survey, to identify the specific ethnic groups of those cases. A data collection

form listing identifiers for the reported Asian and Pacific Islander cases from each county was developed and tested. The form was mailed to each of the 24 counties on February 22, 1991. All 24 counties responded to the request for information. Survey results were merged with the demographic and risk factor information for each case already collected and stored in the computerized AIDS database, the AIDS Reporting System (ARS). Trends in AIDS cases reported among Asian and Pacific Islander ethnic subgroups were then analyzed. Detailed analyses were not completed for some subgroups due to the small number of reported cases.

RESULTS

Of the 476 reported cases, the specific ethnicity of 22 (4.6%) could not be identified. An additional four newly reported Asian and Pacific Islander cases were included, and 11 cases were coded as Asian and Pacific Islander in error, reducing the actual number of cases to 469. Table 1 shows the cumulative number of Asian and Pacific Islander AIDS cases reported by county. Due to the miscoding of race/ethnicity information, only 22 counties reported Asian and Pacific Islander AIDS cases out of the original 24. Statewide, AIDS incidence among Asians and Pacific Islanders is lower than among other racial/ethnic groups. However, the AIDS incidence rate is much higher in San Francisco than in other counties, among Asians and Pacific Islanders as well as for other racial/ethnic groups.

Table 2 shows the number of cases, deaths, mortality and incidence rates of the 22 identified subgroups in California. Cumulative AIDS incidence rates indicate the impact of the epidemic relative to population size and varied substantially among subgroups. However, these rates should be interpreted cautiously because of the somewhat small numbers of both Asian and Pacific Islander AIDS cases and populations. Also, large population increases occurred in California for some Asian and Pacific Islander subgroups since 1980, so that substantially different rates would be generated using 1980 versus 1990 census data.

Trends in AIDS incidence for Asian and Pacific Islander subgroups are shown in Table 3. The difference in the average number of AIDS cases for three year intervals, which was used to compensate for fluctuations in small numbers of annual diagnosed cases, shows recent increases in incidence for most subgroups. The large increases seen among some subgroups may be due to the small number of AIDS cases within these subgroups. This is most notable among the Southeast Asian ethnic populations.

Exposure Categories

As with all racial/ethnic groups, homosexual/bisexual men constitute the highest proportion of AIDS cases among Asians and Pacific Islanders, making up more than three fourths of the reported cases (Table 4). The second most common mode of transmission among Asian and Pacific Islander men is transfusion with HIV infected blood, which involve almost 8% of the reported Asian and Pacific Islander AIDS cases compared to 1% among other racial/ethnic groups in California. Conversely, the proportion of Asian and Pacific Islander AIDS cases attributed to injection drug use is lower than the proportion among other racial/ethnic groups.

Among Asian and Pacific Islander women, the largest proportion of cases (41%) are associated with heterosexual contact. Of these 14 cases, 6 (43%) reported sexual contact with bisexual men while 3 (21%) reported sexual contact with men who injected drugs, 4 reported sexual contact with an HIV infected person, and 1 reported sexual contact with a hemophiliac. Injection drug use, which is the most common exposure category among female AIDS cases in other racial/ethnic groups, is less prevalent among Asian and Pacific Islander women with AIDS.

Age Categories

Among Asian and Pacific Islander subgroups, as well as other racial/ethnic groups, the most frequently occurring category of age at AIDS diagnosis was 30 to 39 years (Table 5). A higher proportion of AIDS cases among Chinese and Japanese were over age 59, reflecting the higher proportion of transfusion cases in these subgroups. The proportion of AIDS cases diagnosed at 20 to 29 years of age was highest among the 'Other A/PI' subgroup (20.3%), compared to the Chinese (5.9%), Filipino (13.8%), Japanese (13.9%), and races/ethnicities other than

Asians and Pacific Islanders (16.7%).

Regional Trends

Table 6 shows the distribution of AIDS cases among subgroups throughout five regions of the state*. More than one third of all Asian and Pacific Islander AIDS cases are found in San Francisco, which has the highest proportion of cases among the Chinese (50.6%), Filipino (40.2%) and Japanese (41.7%) subgroups. Nearly 40% of the Asian and Pacific Islander AIDS cases from the 'Other A/PI' subgroup were from Los Angeles, with 12 out of those 54 cases (22%) of Thai descent. Half the 40 Asian and Pacific Islander cases from the Southern Metropolitan region were 'Other A/PI' cases, with 11 of the 20 (55%) of Southeast Asian descent. Filipinos make up the largest proportion of Asian and Pacific Islander AIDS cases in the San Francisco, Bay Area, and Remaining regions.

The number of AIDS cases among Asians and Pacific Islanders increased through 1989 in all regions, with a possible plateau or decline in 1990 (Figures 1-4). AIDS incidence increased in San Francisco after 1985 primarily among Chinese and Asians and Pacific Islanders who are other than Chinese, Japanese, or Filipino ('Other A/PI'); in Los Angeles among 'Other A/PI'; and in rest of the state among Filipinos and 'Other A/PI'. Of recently diagnosed (from 1988 through 1990) Asian and Pacific Islander AIDS cases, 34% were from Los Angeles, 31% from San Francisco, and 35% from the remainder of the State.

* Bay Area region (Alameda, Contra Costa, Marin, Napa, San Mateo, Santa Clara, Solano, and Sonoma counties); Los Angeles county; San Francisco county; Southern Metropolitan region (Orange, Riverside, San Bernardino, and San Diego counties); Remaining region (remaining counties in the State).

DISCUSSION

As of March 1, 1991, 469 Asian Pacific Islander AIDS cases were reported in California, comprising less than 2% of the total AIDS cases in the State. Completeness of reporting is thought to be about 85% statewide for all race/ethnic groups and is not known to be different among Asians and Pacific Islanders. Although comprising a small proportion of the total AIDS cases in California, 45% of the nation's Asian and Pacific Islander cases are from California[1]. The detailed breakdown of racial/ethnic subgroup information indicates that the AIDS epidemic has affected nearly all Asian and Pacific Islander populations. This information can be used by health care providers in the development of culturally sensitive treatment and support services for Asian and Pacific Islander AIDS patients.

The number of Asian and Pacific Islander AIDS cases increased through 1989 throughout the State with specific subgroups increasing at higher rates than others. An increase in incidence of AIDS among Asians and Pacific Islanders in San Francisco was noted by Woo, et al[2] in 1988. In Los Angeles and San Francisco counties, the increases are seen predominately in subgroups other than Filipinos, Chinese and Japanese. The apparent plateau or decline in incidence seen in 1990 may be due to inadequate reporting delay adjustments, random variation, or the effect of early drug treatment strategies similar to that seen among white homosexual/bisexual men in San Francisco and Los Angeles.[3]

Currently, there are too few cases to determine accurately trends for each specific subgroup in each region. To continue to monitor these trends, the AIDS Case Registry is implementing methods to collect the subgroup information as each AIDS case is reported. This information can be placed in the comment area of the AIDS Case Report form. Also a local field variable for subgroup information has been created so that the 23 local health jurisdictions which have the AIDS Reporting System (ARS) can then enter specific ethnic information directly into the computer when a new Asian and Pacific Islander AIDS case is added.

In addition to those with AIDS, an estimated 3,000 Asians and Pacific Islanders may be HIV positive[4] and many more are likely to be at risk of HIV infection. To effectively target and plan education and prevention strategies for Asians and Pacific Islanders, AIDS case data must be incorporated with HIV seroprevalence data, behavioral risk data, knowledge, attitude and beliefs data, and the wisdom of the community service providers.

Homosexual/bisexual men, the predominate

patient group among all Asian and Pacific Islander men with AIDS, would benefit from culturally appropriate AIDS intervention programs. Although several studies have found Asian and Pacific Islanders to have the lowest HIV seroprevalence rate compared to other racial/ethnic groups [5,6], the San Francisco Young Men's Study found that 40% of the young Filipino men surveyed engaged in high risk sexual behavior[7]. Since 60% of homosexual/bisexual Asian and Pacific Islander men with AIDS were diagnosed before age 40 and the median incubation period for AIDS diagnosis is approximately ten years[8], programs for preventing HIV transmission targeted to younger men are needed.

HIV seroprevalence among Asian and Pacific Islander childbearing women was found to be two to six times lower than for childbearing women of all other races/ethnicities[9]. Nevertheless, HIV/AIDS education and prevention programs stressing safe sex and the risks of injection drug use are needed for all women of childbearing age.

Among the Asian and Pacific Islander subgroups significant differences exist which relate not only to their diverse cultures, but also to their knowledge, attitudes, beliefs, and behaviors concerning AIDS[10]. Cultural taboos result in the denial of the existence of the disease in their communities. Finding appropriate methods to present information regarding the disease and disseminating the messages must be specific for each subgroup. Multicultural, multilingual service providers are needed to earn the trust of the clients.

Further AIDS case analyses among Asians and Pacific Islanders can examine country of birth to see how the degree of acculturation may be related to the risk of HIV infection. Also, the diseases indicative of AIDS can be examined to determine which diseases occur most frequently among Asians and Pacific Islanders. Additionally, further analyses of several statewide knowledge, attitudes, beliefs, and behavioral surveys can be conducted. These analyses and the additional subgroup information gathered on Asian and Pacific Islander AIDS cases can be used to assist in the development of culturally sensitive services and prevention strategies.

By Sally Jew, Research Analyst I, Office of AIDS

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TABLE 1. Cumulative AIDS Cases Among Asians and Pacific Islanders (A/PI) in California, as of March 1, 1991, by County of Residence when AIDS Diagnosed

COUNTY	Cumulative A/PI AIDS Cases	Cumulative Incidence per 100,000 A/PI population*	Cumulative AIDS Cases all Races/ Ethnicities***	Cumulative Incidence per 100,000 population***
Alameda	30	16.23	1,559	121.87
Contra Costa	7	9.48	579	72.04
Fresno	**	**	202	30.26
Los Angeles	148	16.30	11,416	128.80
Marin	**	**	390	169.49
Merced	**	**	29	16.26
Monterey	4	15.77	164	46.11
Napa	**	**	52	46.95
Orange	10	4.15	1,442	59.82
Riverside	5	13.04	594	50.75
Sacramento	**	**	600	57.62
San Bernardino	**	**	559	39.41
San Diego	23	12.42	2,500	100.08
San Francisco	170	82.65	9,110	1,258.36
San Joaquin	6	10.76	156	32.46
San Mateo	17	16.10	577	88.82
Santa Barbara	**	**	194	52.49
Santa Clara	20	7.95	783	52.28
Solano	8	19.76	248	72.85
Sonoma	**	**	546	140.64
Stanislaus	**	**	107	28.88
Ventura	**	**	164	24.51
TOTAL	469	17.91	31,971	120.57

* Based on Census of Population and Housing, 1990: Summary Tape File 1
** Counties have three or less Asian and Pacific Islander cases
*** Based on California HIV/AIDS Update, February 1991

TABLE 2. Cumulative AIDS Cases Among Asian and Pacific Islander (A/PI) Subgroups in California, as of March 1, 1991

SUBGROUP	Cumulative Number of Total AIDS Cases	Percent of Total	Deaths (No.)	Mortality Rate (%)	Cumulative AIDS Incidence per 100,000 A/PI Subgroup population*
Filipino	174	37	118	68	23.80
Chinese	85	18	59	69	12.10
Japanese	72	15	54	75	23.00
Unknown	22	5	8	36	***
Thai	21	4	11	52	66.50
Vietnamese	18	4	10	56	6.40
Hawaiian	15	3	10	67	43.50
Samoan	12	3	8	67	37.60
Guamanian	10	2	8	80	39.90
Korean	7	1	4	57	2.70
Indonesian	6	1	3	50	***
Cambodian	5	1	4	80	7.30
Laotian	5	1	4	80	8.60
Fijian	4	1	2	50	***
Other**	13	3	11	85	***
TOTAL	469	****100	314	67	16.48

* Based on Census of Population and Housing, 1990: Summary Tape File 1
** Includes 7 other subgroups each with three or fewer AIDS cases
*** Census information not available
**** Totals do not add up to 100% due to rounding

TABLE 3. Percent Change in AIDS Incidence Among Asian and Pacific Islander Subgroups in California

SUBGROUP	Average Annual Incidence 1985-1987	Average Annual Incidence 1988-1990**	Percent Change
Filipino	22.0	33.0	50%
Chinese	8.0	18.7	134%
Japanese	12.3	11.0	-11%
Unknown	2.0	5.3	165%
Thai	1.0	6.3	530%
Vietnamese	2.0	4.0	100%
Hawaiian	2.3	2.7	17%
Samoan	1.7	2.3	35%
Guamanian	1.0	1.0	0%
Korean	0.7	1.7	142%
Indonesian	0.3	1.7	467%
Cambodian	0.3	1.3	333%
Laotian	0.0	1.3	--
Fiji	1.0	0.3	-70%
Other*	1.3	2.7	108%

* Includes 7 subgroups each with 3 or fewer AIDS cases
** Data not adjusted for reporting delay; includes cases reported as of March 1, 1991

TABLE 4. Cumulative AIDS Cases by Exposure Category and Sex for Major Asian and Pacific Islander (A/PI) Subgroups in California, as of March 1, 1991

	RACE/ETHNICITY				
EXPOSURE CATEGORY	Filipino No. (%)	Chinese No. (%)	Japanese No. (%)	Other A/PI No. (%)	All Not A/PI No. (%)
MEN					
Homosexual/Bisexual Men	144 (88)	70 (85)	52 (79)	99 (85)	25,359 (82)
Injection Drug Users (IDU)	2 (1)	0 (0)	0 (0)	2 (2)	1,304 (4)
Homosexual/Bisexual IDU	5 (3)	0 (0)	3 (5)	5 (4)	2,816 (9)
Hemophiliac	1 (1)	0 (0)	2 (3)	2 (2)	165 (1)
Heterosexual Contact	0 (0)	0 (0)	0 (0)	2 (2)	198 (1)
Transfusion	8 (5)	10 (12)	6 (9)	2 (2)	399 (1)
Other	4 (2)	2 (2)	3 (5)	6 (5)	680 (2)
TOTAL MEN	164 (100)	82(100*)	66 (100*)	118(100*)	30,921 (100)
WOMEN					
Injection Drug Users (IDU)	2 (25)	0 (0)	0 (0)	4 (22)	358 (34)
Heterosexual Contact	4 (50)	0 (0)	3 (67)	7 (39)	338 (32)
Transfusion/Blood Prod	2 (25)	2 (67)	2 (33)	4 (22)	273 (26)
Other	0 (0)	1 (33)	0 (0)	3 (17)	92 (9)
TOTAL WOMEN	8 (100)	3 (100)	5 (100)	18 (100)	1,061 (100*)
PEDIATRIC	2 (100)	0 (0)	1 (100)	3 (100)	215 (100)
TOTAL CASES	174	85	72	139	32,197

* Totals do not add up to 100% due to rounding

TABLE 5. Cumulative AIDS Cases by Age Groups for Major Asian and Pacific Islander (A/PI) Subgroups in California, as of March 1, 1991

	RACE/ETHNICITY				
AGE GROUP	Filipino No. (%)	Chinese No. (%)	Japanese No. (%)	Other A/PI No. (%)	All Not A/PI No. (%)
<13 Yrs	2 (1.1)	0 (0)	1 (1.4)	2 (1.5)	215 (0.7)
13-19 Yrs	1 (0.6)	0 (0)	0 (0)	1 (0.7)	59 (0.2)
20-29 Yrs	24 (13.8)	5 (5.9)	10 (13.9)	28 (20.3)	5,377 (16.7)
30-39 Yrs	74 (42.5)	36 (42.3)	24 (33.3)	60 (43.5)	14,493 (45.0)
40-49 Yrs	53 (30.5)	24 (28.2)	22 (30.6)	38 (27.5)	8,127 (25.2)
50-59 Yrs	14 (8.1)	11 (13.0)	6 (8.3)	7 (5.1)	2,831 (8.8)
Over 59 Yrs	6 (3.5)	9 (10.6)	9 (12.5)	2 (1.5)	1,095 (3.4)
TOTAL	174 (100*)	85 (100)	72 (100)	138(100*)	32,197 (100)

* Totals do not add up to 100% due to rounding

TABLE 6. Cumulative AIDS Cases Among Major Asian and Pacific Islander (A/PI) Subgroups by Regions of California, as of March 1, 1991

	RACE/ETHNICITY				
REGION*	Filipino No. (%)	Chinese No. (%)	Japanese No. (%)	Other A/PI No. (%)	All Other No. (%)
Bay Area	33 (19.0)	13 (15.3)	10 (13.9)	30 (21.7)	4,550 (14.1)
San Francisco	70 (40.2)	43 (50.6)	30 (41.7)	27 (19.6)	8,944 (27.8)
Los Angeles	44 (25.3)	24 (28.2)	26 (36.1)	54 (39.1)	11,286 (35.1)
Southern Metro	15 (8.6)	3 (3.5)	2 (2.8)	20 (14.5)	5,042 (15.7)
Remaining	12 (6.9)	2 (2.3)	4 (5.6)	7 (5.1)	2,367 (7.3)
Unknown	0 (0)	0 (0)	0 (0)	0 (0)	8 (0)
TOTAL	174 (100)	85 (100*)	72 (100*)	138 (100)	32,197 (100)

* Bay Area region (Alameda, Contra Costa, Marin, Napa, San Mateo, Santa Clara, Solano, and Sonoma counties); San Francisco county; Los Angeles county; Southern Metropolitan region (Orange, Riverside, San Bernardino, and San Diego counties); Remaining region (remaining counties in the State).

Figure 1. Annual AIDS Incidence Among Asians & Pacific Islanders, San Francisco County, March 1, 1991

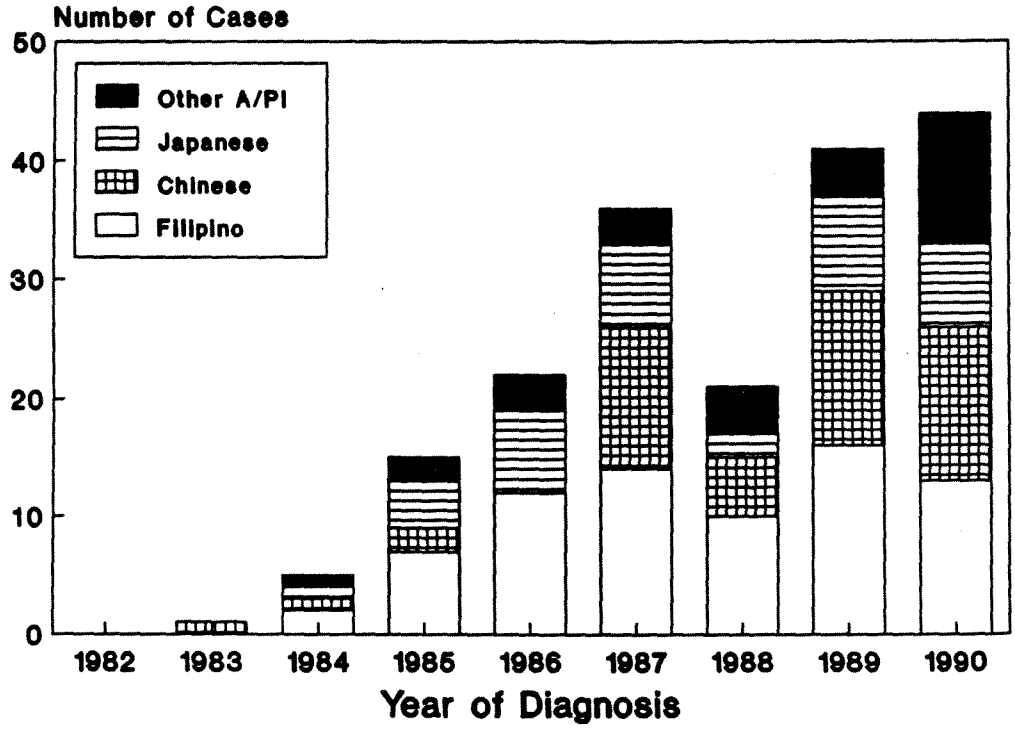
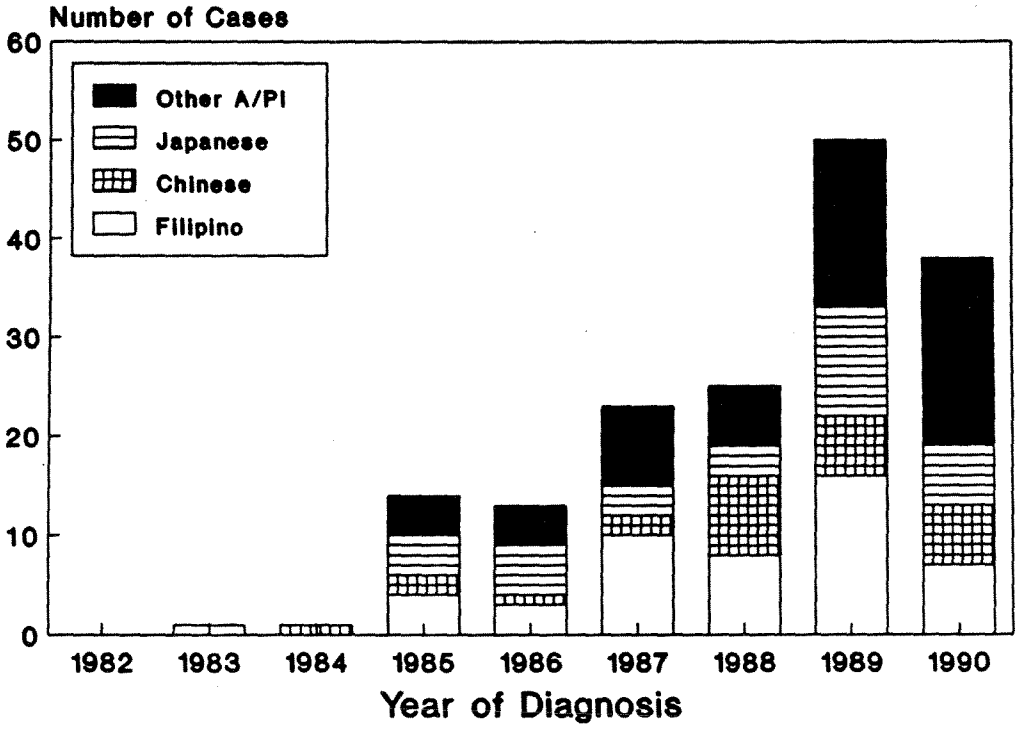


Figure 2. Annual AIDS Incidence Among Asians & Pacific Islanders, Los Angeles County, March 1, 1991



1989-1990 Data Adjusted for Reporting Delays

Figure 3. Annual AIDS Incidence Among Asians & Pacific Islanders, Rest of State, March 1, 1991

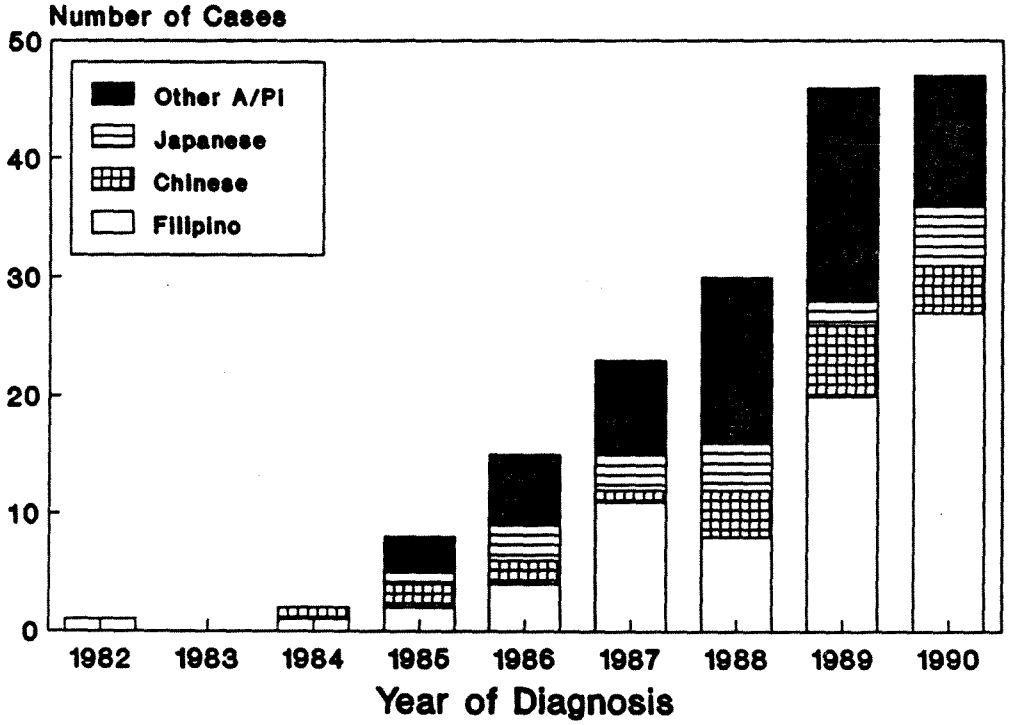
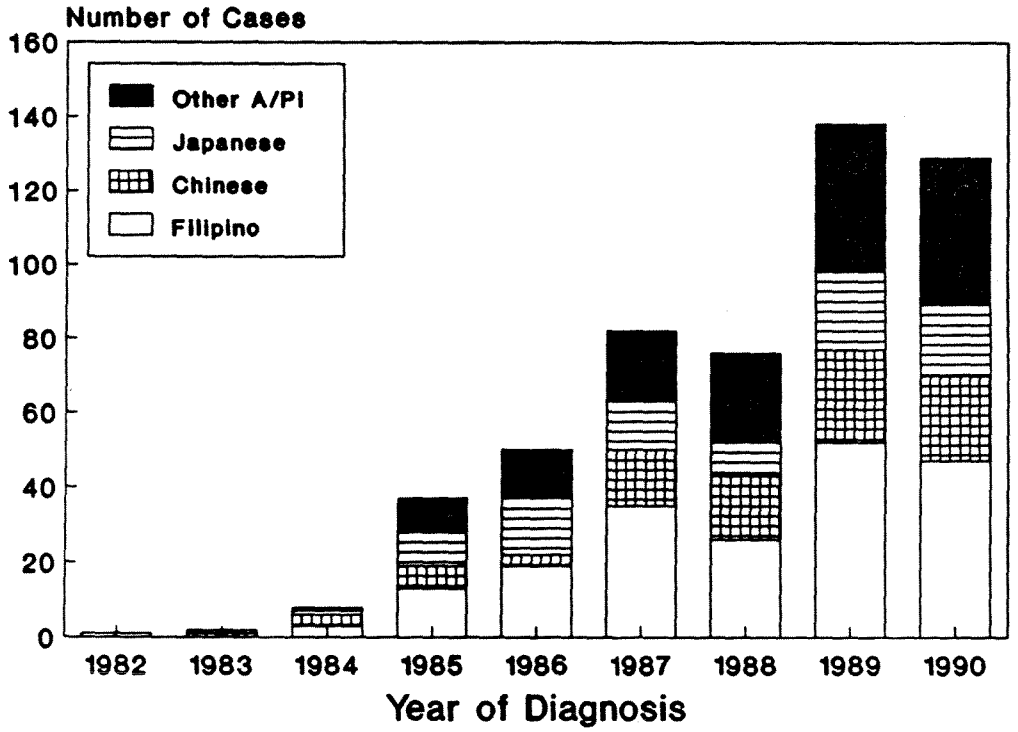


Figure 4. Annual AIDS Incidence Among Asians & Pacific Islanders, All of California, March 1, 1991



1989-1990 Data Adjusted for Reporting Delays

INFLUENZA IMMUNIZATION OF HIV-INFECTED PERSONS AND OF CARE-GIVERS TO PERSONS WITH CLINICAL AIDS

California Department of Health Services
Immunization Unit
August, 1991

The U.S. Public Health Service Immunization Practices Advisory Committee (ACIP) recommends influenza immunization each fall (ideally in November) for certain groups of high-risk persons, as well as for care-givers to these persons. Reproduced below are selected sections from the ACIP's influenza immunization recommendations for the 1991-92 season (MMWR 1991; 40:No. RR-6, 1-15).

Persons Infected With HIV

Little information exists regarding the frequency and severity of influenza illness in human immunodeficiency virus (HIV) infected persons, but recent reports suggest that symptoms may be prolonged and the risk of complications increased for this high-risk group. Because influenza may result in serious illness and complications, vaccination is a prudent precaution and will result in protective antibody levels in many recipients. However, the antibody response to vaccine may be low in persons with advanced HIV related illnesses; a booster dose of vaccine has not improved the immune response of these individuals.

Groups That Can Transmit Influenza to High-Risk Persons

Persons who are clinically or subclinically infected and who attend or live with high-risk persons can transmit influenza virus to them. Some high-risk persons (e.g., the elderly, transplant recipients, or persons with AIDS) can have low antibody responses to influenza vaccine. Efforts to protect these high-risk persons against influenza may be improved by reducing the chances of exposure to influenza from their care providers. Therefore, the following groups should be vaccinated:

1. Physicians, nurses, and other personnel in both hospital and outpatient-care settings who have contact with high-risk persons in all age groups, including infants.
2. Employees of nursing homes and chronic-care facilities who have contact with patients or residents.
3. Providers of home care to high-risk persons (e.g., visiting nurses, volunteer workers).
4. Household members (including children) of high-risk persons.

Influenza Vaccine Dosage

Influenza vaccine[1] dosage, by age of patient - 1991-92 season

Age Group	Product[2]	Dosage[3]	Number of Doses	Route[4]
6 - 35 mos	Split virus only	0.25 mL	1 or 2[5]	IM
3 - 8 yrs	Split virus only	0.50 mL	1 or 2[5]	IM
9 - 12 yrs	Split virus only	0.50 mL	1	IM
≥ 13 yrs	Whole or split virus	0.50 mL	1	IM

[1] Contains 15 µg each of A/Taiwan/1/86 (H1N1), A/Beijing/353/89 (H3N2), and B/Panama/45/90 hemagglutinin antigens in each 0.5 mL. Manufacturers include Connaught (Fluzone® whole or split, distributed by E.R. Squibb & Sons); Evans Medical Ltd.-Lederle Laboratories (Flu-Immune®, distributed by Lederle Laboratories); Parke-Davis (Fluogen® split); and Wyeth-Ayerst Laboratories (Influenza Virus Vaccine, Trivalent® split). For further product information, call Connaught (800) 822-2463, Parke-Davis (800) 223-0432, Wyeth (800) 950-5099, and Lederle (800) 522-3753.

[2] Because of the lower potential for causing febrile reactions, only split virus (subvirion) vaccine should be used in children age 12 years and younger. Immunogenicity and side effects of split and whole virus vaccines are similar in adults

when vaccines are used according to the recommended dosage.

[3] It may be desirable to administer influenza vaccine to high-risk children when they receive routine pediatric vaccines, but in a different site. Although studies have not been conducted, simultaneous administration should not lessen immunogenicity or enhance adverse reactions. Some avoid giving influenza vaccine within 3 days of giving pertussis (DTP) vaccine since both vaccines commonly produce mild local reactions and fever in children.

[4] The recommended site of vaccination is the deltoid muscle for adults and older children. The preferred site for infants and young children (under age 18 months) is the anterolateral aspect of the thigh.

[5] Two doses are recommended for children ≤ 8 years old who are receiving influenza vaccine for the first time.

Sources of Influenza Immunizations

Besides the private medical sector, local health departments in California conduct clinics offering low cost influenza immunizations each fall (late October through November) to persons at increased risk from influenza. Locations and times of these clinics can be determined by calling the local health department (c.f. county or city government listings in the telephone book).

AIDS CLINICAL TRIALS INFORMATION SERVICE

The AIDS Clinical Trials Information Service (ACTIS) provides current information on federally and privately sponsored clinical trails being conducted to evaluate drugs and therapies to treat all stages of human immunodeficiency virus (HIV) infection in adults and children and to treat related opportunistic infections. ACTIS is a Public Health Service project provided collaboratively by CDC, the Food and Drug Administration (FDA), the National Institute of Allergy and Infectious Diseases, and the National Library of Medicine (NLM).

The ACTIS database includes information on more than 300 clinical trails and more than 100 drugs being tested. Information is available on the purpose of the study protocol, the location, the eligibility requirements, the exclusion criteria, and the names and telephone numbers of contact persons. ACTIS provides information on all AIDS clinical trails sponsored by the National Institutes of Health and on studies of all treatments undergoing clinical testing for effectiveness in privately sponsored trials approved by FDA.

The AIDS Clinical Trials Information Service can be reached by calling:

1-800-TRIALS-A (1-800-874-2572)
FAX: 1-300-738-6616
TTY/TDD: 1-800-243-7012
International Line: 1-301-217-0023

AIDS News

NATIONAL CASE SUMMARY:

CDC announced that the cumulative number of individuals diagnosed with AIDS in the United States totaled 191,601 and 122,905 persons have died at the end of August, 1991.

CALIFORNIA CASE SUMMARY:

During August 1991, 784 new AIDS cases and 614 AIDS related deaths were reported to the AIDS Case Registry. However, 154 cases were deleted from the registry leaving a net case increase of 630. From the start of the epidemic through August of 1991, the cumulative case total is 36,620 with 24,938 AIDS related deaths. One year ago, there were 854 new AIDS cases reported with 452 AIDS related deaths. Cases reported in the latest twelve month period (September 1990 - August 1991) are compared with cases reported in the previous twelve month period (September 1989 - August 1990) for both race/ethnicity and mode of transmission in the tables that follow.

	LATEST 12 MONTHS #Reported	% of Total	PREVIOUS 12 MONTHS # Reported	% of Total
Race				
White	5,037	66.0	5,171	70.7
Black	1,113	14.6	955	13.0
Hisp	1,301	17.0	1,027	14.1
Asian	116	1.5	131	1.8
Other	72	0.9	26	0.4
Patient Group				
Gay/Bi	5,793	76.3	5,741	79.1
IVDU	629	8.3	469	6.4
Gay/IVDU	539	7.1	516	7.1
Hemo	27	0.4	32	0.4
Hetero	185	2.4	151	2.1
Trans	123	1.6	137	1.9
NIR	298	3.9	216	3.0
Women	361	4.7	261	3.6
Children	45	0.6	48	0.7

The more significant changes include the increased reporting of black and Hispanic cases, and the higher number of women reported. While fewer cases among homosexual or bisexual men are being received, more IV Drug User, heterosexual transmission, and No Identified Risk (NIR) cases are being reported. Of the 185 heterosexual cases reported in the most recent twelve months, 69 occurred among men and 116 among women.

Overall, the net increase in reported cases for the epidemic was 7,639, in the past twelve months as compared to 7,310 in the previous twelve months. However, 850 cases were deleted during the past year. There were 6,121 AIDS related deaths reported in the most recent period as compared to 5,269 in the previous twelve month period.

By Jim Creeger, Chief, AIDS Case Registry
Office of AIDS

AIDS Cases and Annual Incidence Rates per 100,000 Population by metropolitan area with 500,0000 or more population, reported September 1989 through August 1990, September 1990 through August 1991; and cumulative through August 1991

METROPOLITAN	9/89-8/90		9/90-8/91		Cumulative
Area of Residence	No.	Rate	No.	Rate	Total
San Francisco	1,782	111.1	2,361	146.2	10,845
San Diego	699	28.0	523	20.4	2,657
Los Angeles	2,231	25.2	2,731	30.3	12,714
Oakland	538	25.8	501	23.7	2,328
Anaheim	345	14.3	321	13.1	1,520
Riverside/ San Bernardino	243	9.4	326	12.1	1,241
San Jose	160	10.7	176	11.6	833
Fresno	56	8.4	61	8.9	234
Sacramento	145	9.8	210	13.8	796
Bakersfield	33	6.1	50	9.0	149
Oxnard/ Ventura	37	5.5	42	6.1	175

From the CDC's HIV/AIDS Surveillance Report, September 1991.

Acquired Immune Deficiency Syndrome (AIDS)
AIDS Reporting System
Surveillance Report - 08/31/91

1. Disease Category *	Adult/Adolescent Cases (%)	Adult/Adolescent Deaths (%)	Pediatric Cases (%)	Pediatric Deaths (%)	Total Cases (%)	Total Deaths (%)
PCP	20583 (57)	14766 (72)	108 (44)	67 (62)	20691 (57)	14833 (72)
Other Disease w/o PCP	12108 (33)	7865 (65)	138 (56)	74 (54)	12246 (33)	7939 (65)
KS Alone	3683 (10)	2166 (59)	0 (0)	0 (.)	3683 (10)	2166 (59)
No Diseases Listed	0 (0)	0 (.)	0 (0)	0 (.)	0 (0)	0 (.)
Total	36374 (100)	24797 (68)	246 (100)	141 (57)	36620 (100)	24938 (68)

2. Age	Cases (%)
Under 13	246 (1)
13-19	78 (0)
20-29	6074 (17)
30-39	16418 (45)
40-49	9305 (25)
Over 49	4499 (12)
Unknown	0 (0)
Total	36620 (100)

3. Race/Ethnicity	Adult/Adolescent Cases (%)	Pediatric Cases (%)	Total Cases (%)
White, Not Hispanic	26164 (72)	87 (35)	26251 (72)
Black, Not Hispanic	4477 (12)	72 (29)	4549 (12)
Hispanic	4996 (14)	80 (33)	5076 (14)
Asian	540 (1)	6 (2)	546 (1)
Native American	76 (0)	1 (0)	77 (0)
Unknown	121 (0)	0 (0)	121 (0)
Total	36374 (100)	246 (100)	36620 (100)

4. Patient Groups **	Adult/Adolescent Males (%)	Adult/Adolescent Females (%)	Adult/Adolescent Total (%)
Homosexual or bisexual Men	28691 (82)	0 (0)	28691 (79)
Intravenous (IV) drug User	1567 (4)	438 (35)	2005 (6)
Homo/Bi IV drug User	3136 (9)	0 (0)	3136 (9)
Hemophiliac	185 (1)	9 (1)	194 (1)
Heterosexual contact	240 (1)	399 (32)	639 (2)
Transfusion with blood/products	466 (1)	299 (24)	765 (2)
None of the above/Other	832 (2)	112 (9)	944 (3)
Total	35117 (100)	1257 (100)	36374 (100)

	Pediatric Males (%)	Pediatric Females (%)	Pediatric Total (%)
Hemophiliac	17 (12)	1 (1)	18 (7)
Parent at risk/has AIDS/HIV	64 (47)	85 (78)	149 (61)
Transfusion with blood/products	54 (39)	21 (19)	75 (30)
None of the above/Other	2 (1)	2 (2)	4 (2)
Total	137 (100)	109 (100)	246 (100)

*Disease categories are ordered hierarchically. Cases with more than one disease are tabulated only in the disease category listed first.

**Cases with more than one risk factor other than the combinations listed in the tables are tabulated only in the category listed first.

Case count reflects the deletion of 154 cases.

Acquired Immune Deficiency Syndrome (AIDS)
AIDS Reporting System
Surveillance Report - 08/31/91

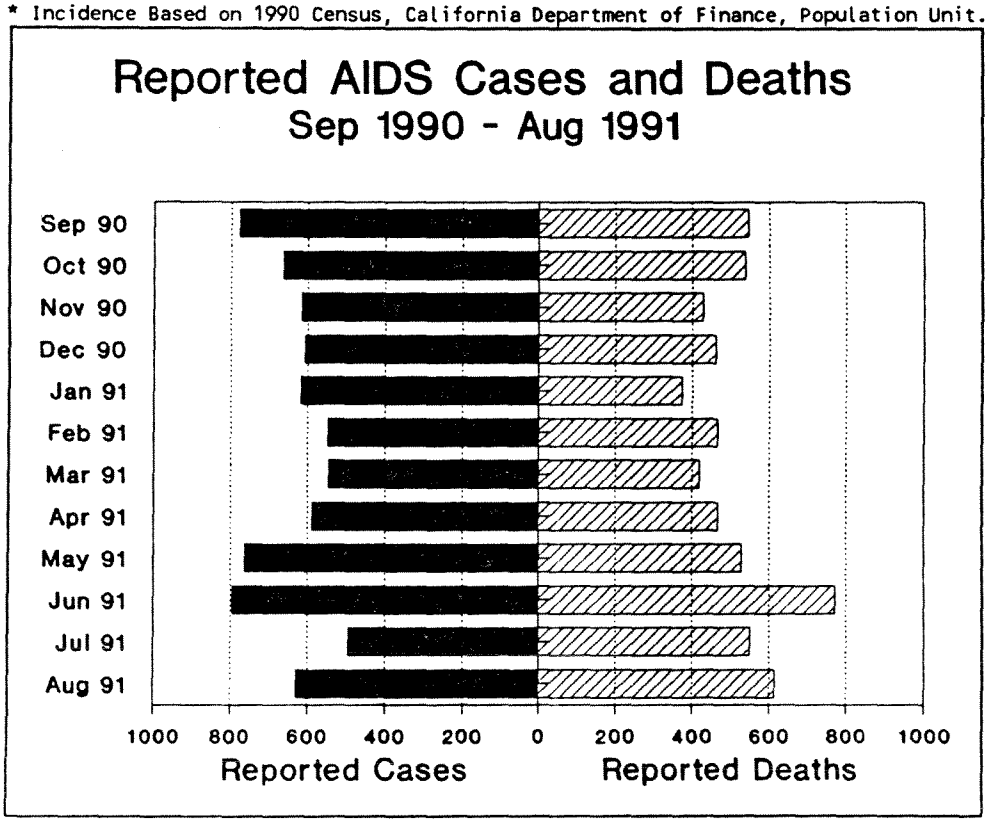
5. Reported Cases of AIDS and Case-Fatality Rates by Half-Year of Diagnosis:

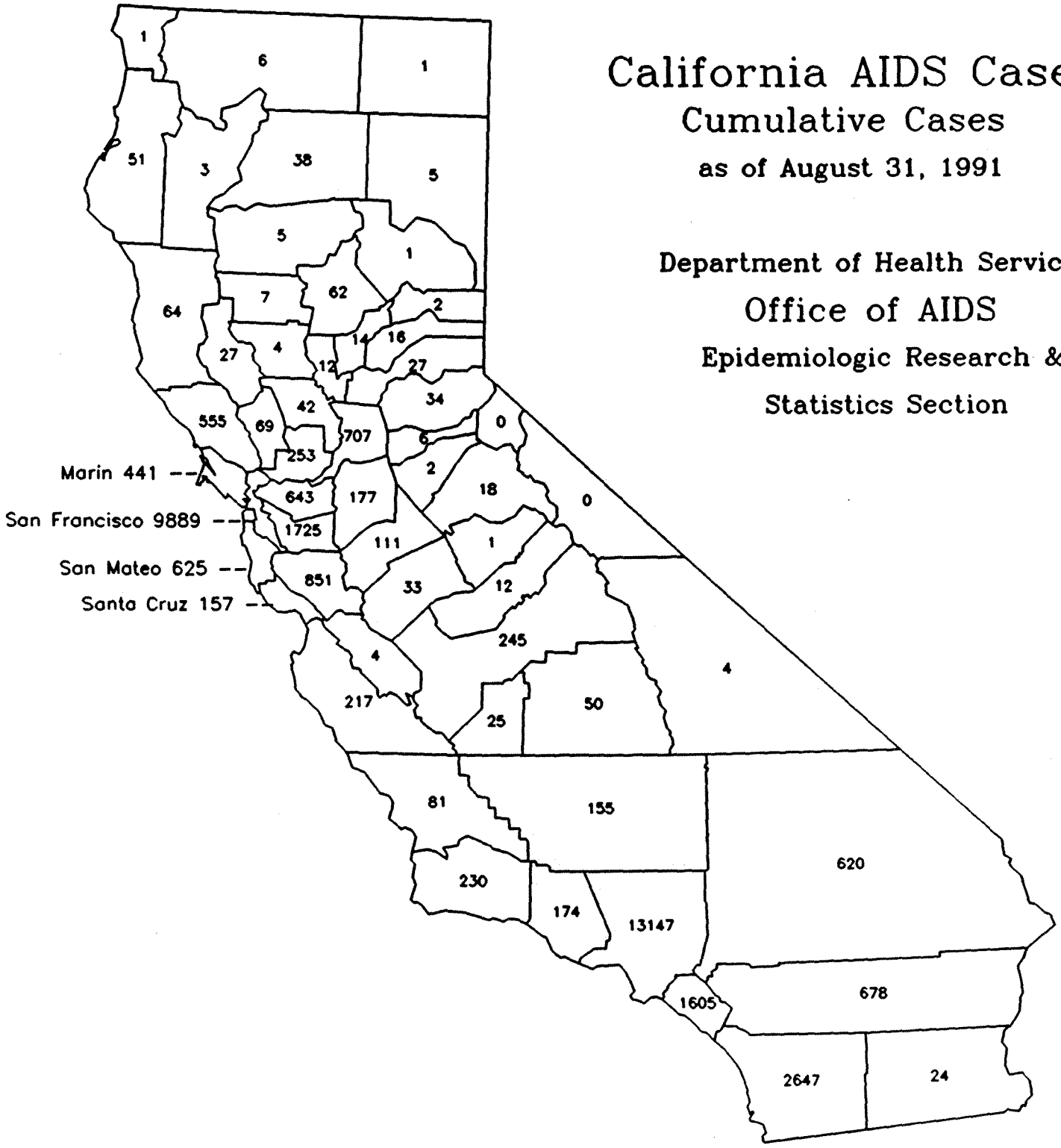
Half-Year of Diagnosis	Number of Cases	Number of Deaths	Case-Fatality Rate
Before 1980	1	0	0%
1980 Jan -June	3	2	67%
July-Dec	7	5	71%
1981 Jan -June	16	15	94%
July-Dec	44	40	91%
1982 Jan -June	70	63	90%
July-Dec	146	135	92%
1983 Jan -June	295	276	94%
July-Dec	402	376	94%
1984 Jan -June	573	543	95%
July-Dec	799	746	93%
1985 Jan -June	1118	1058	95%
July-Dec	1370	1278	93%
1986 Jan -June	1783	1658	93%
July-Dec	2157	1946	90%
1987 Jan -June	2654	2331	88%
July-Dec	2770	2317	84%
1988 Jan -June	3072	2398	78%
July-Dec	3120	2282	73%
1989 Jan -June	3525	2308	65%
July-Dec	3241	1892	58%
1990 Jan -June	3453	1630	47%
July-Dec	3086	1084	35%
1991 Jan -June	2597	539	21%
July-Aug 31	318	16	5%
Totals	36620	24938	68%

CUMULATIVE AIDS CASES and INCIDENCE
1980 through 08/31/91

COUNTY	AIDS Cases	Deaths	Mortality Rate	INCIDENCE per 100,000	COUNTY	AIDS Cases	Deaths	Mortality Rate	INCIDENCE per 100,000
Alameda	1,725	1,054	61.1%	134.85	Orange	1,605	1,055	65.7%	66.58
Berkeley	200	115	57.5%	188.15	Placer	27	13	48.1%	15.63
Alpine	0				Plumas	1	1	100.0%	5.07
Amador	6	4	66.7%	19.97	Riverside	678	495	73.0%	57.93
Butte	62	36	58.1%	34.04	Sacramento	707	472	66.8%	67.90
Calaveras	2	1	50.0%	6.25	San Benito	4	3	75.0%	10.90
Colusa	4	3	75.0%	24.58	San Bernardino	620	422	68.1%	43.71
Contra Costa	643	390	60.7%	80.00	San Diego	2,647	1,750	66.1%	105.96
Del Norte	1	0	0.0%	4.26	San Francisco	9,889	6,965	70.4%	1365.96
El Dorado	34	26	76.5%	26.99	San Joaquin	177	101	57.1%	36.83
Fresno	245	170	69.4%	36.70	San Luis Obispo	81	42	51.9%	37.30
Glenn	7	5	71.4%	28.23	San Mateo	625	382	61.1%	96.21
Humboldt	51	31	60.8%	42.81	Santa Barbara	230	152	66.1%	62.23
Imperial	24	17	70.8%	21.96	Santa Clara	851	592	69.6%	56.83
Inyo	4	3	75.0%	21.88	Santa Cruz	157	94	59.9%	68.34
Kern	155	82	52.9%	28.52	Shasta	38	25	65.8%	25.84
Kings	25	11	44.0%	24.64	Sierra	2	2	100.0%	60.28
Lake	27	22	81.5%	53.33	Siskiyou	6	5	83.3%	13.78
Lassen	5	2	40.0%	18.12	Solano	253	148	58.5%	74.32
Los Angeles	13,147	9,217	70.1%	148.33	Sonoma	555	358	64.5%	142.96
Long Beach	1,080	739	68.4%	257.33	Stanislaus	111	68	61.3%	29.96
Pasadena	170	113	66.5%	126.96	Sutter	12	10	83.3%	18.63
Madera	12	4	33.3%	13.62	Tehama	5	2	40.0%	10.08
Marin	441	221	50.1%	191.66	Trinity	3	2	66.7%	22.97
Mariposa	1	0	0.0%	6.99	Tulare	50	32	64.0%	16.03
Mendocino	64	42	65.6%	79.66	Tuolumne	18	8	44.4%	37.15
Merced	33	18	54.5%	18.50	Ventura	174	123	70.7%	26.01
Modoc	1	1	100.0%	10.33	Yolo	42	23	54.8%	29.77
Mono	0				Yuba	14	9	64.3%	24.04
Monterey	217	145	66.8%	61.01	Unknown	17	13	76.5%	
Napa	69	52	75.4%	62.29					
Nevada	16	14	87.5%	20.38	**Total**	**36,620**	**24,938**	**68.1%**	**123.05**

* Incidence Based on 1990 Census, California Department of Finance, Population Unit.




California AIDS Cases
Cumulative Cases
as of August 31, 1991
Department of Health Services
Office of AIDS
Epidemiologic Research &
Statistics Section
Marin 441
San Francisco 9889
San Mateo 625
Santa Cruz 157
1
6
1
51
3
38
5
5
1
64
7
62
2
27
4
14
16
12
27
34
555
69
42
707
6
0
253
2
Marin 441
643
177
18
0
San Francisco 9889
1725
111
1
San Mateo 625
851
33
12
Santa Cruz 157
245
4
4
217
25
50
81
155
620
230
174
13147
1605
678
2647
24

MEETINGS/ANNOUNCEMENTS

- **November 7:** "HIV Disease in Women and Children", a conference at Chico Community Hospital which will provide current medical information on HIV disease symptoms, diagnosis, treatment and care for women and children living with HIV disease. For more information call: **(916) 265-1450.**

- **November 14-16:** "Taking Charge: Communities of Color in Solidarity Against the HIV/AIDS Epidemic", a conference sponsored by the U. S. Public Health Service, Regions IX and X. It will be coordinated by the Office of Minority Health and held in Seattle. For more information, call **(206) 728-8911.**

- **November 19-22:** "Planning and Evaluating HIV Prevention Programs". The conference will be held in San Francisco. For information contact the STD Prevention/Training Center, 1372 Mission Street, S.F. 94103 or call **(415) 554-9620.**

- **December 3:** "HIV Disease and the Social Security System". For information on this conference, contact: AIDS Project Los Angeles, 6721 Romaine St., L.A. 90038 or call **(213) 962-1600, ext 355.**

- **December 9-10:** "Clinical Care of the AIDS Patient". Presented by the University of California, San Francisco. Please write UCSF Postgraduate Programs, 521 Parnassus Avenue, C405, S.F. 94143-0656, or call **(415) 476-5808.**

California HIV/AIDS Update is published on a monthly basis by the California Department of Health Services, Office of AIDS, 714/744 P Street, Sacramento, CA 94234-7320, Phone: (916) 445-0553, FAX Phone: (916) 323-4642.

Editor: Aleck B. Darr, M.A., M.P.A. *Circulation Manager*: James Creeger.

Department of Health Services
Office of AIDS
714/744 "P" Street
Sacramento, CA 94234-7320

Pediatr Infect Dis J. 1991;10:322–8
0891-3668/91/$03.00/0

Vol. 10, No. 4
Printed in U.S.A.

PERSPECTIVES ON PEDIATRIC HUMAN IMMUNODEFICIENCY VIRUS INFECTIONS.
EDITED BY PHILIP A. PIZZO, M.D., AND CATHERINE M. WILFERT, M.D.

Epidemiology of acquired immunodeficiency syndrome and human immunodeficiency virus infection in adolescents

HELENE D. GAYLE, MD, MPH AND LAWRENCE J. D'ANGELO, MD, MPH

Attention has increasingly been focused on human immunodeficiency virus (HIV) infection and acquired immunodeficiency syndrome (AIDS) among adolescents. In the early years of the HIV/AIDS epidemic, adolescents received less attention than younger children and adults. This was due at least in part to the fact that most of the early knowledge of the AIDS epidemic came from AIDS case reporting. Since adolescents 13 to 19 years old comprise less than 1% of all people with AIDS, the risk of HIV infection in this group appeared minimal relative to the pediatric (less than 13 years) and adult populations. However, for purposes of prevention and care, adolescents are a unique and important group to highlight. Adolescence is a time when sexual behavior and drug use patterns are developing: clearly it is a critical time to have an impact on those behavior patterns. Also, there is a growing recognition that adolescents may be a group at considerable risk for HIV infection.[1–4] However, information about this group is still limited. Many gaps in our knowledge remain, limiting our ability to provide appropriate health and social services and prevention efforts for the adolescent population. We will review the epidemiology of HIV infection and AIDS among adolescents and examine factors that place adolescents at risk and the current research needs related to these areas.

EPIDEMIOLOGY OF AIDS IN ADOLESCENTS

As of October 31, 1990, 604 cases of AIDS among adolescents 13 to 19 years of age had been reported to the Centers for Disease Control (CDC) AIDS surveillance system. This represents 0.4% of the 152 231 total reported AIDS cases. Another 6472 cases (4.3%) have been reported among young adults 20 to 24 years of age, many of whom were presumably infected with HIV as adolescents. Since 1982, the number of cases of AIDS among adolescents has increased steadily, at a rate of increase similar to that for adults and children (Fig. 1). This suggests that, as with the other age groups, AIDS in adolescents will be an increasingly important cause of morbidity and mortality.

AIDS cases in adolescents have been reported from 41 states, Puerto Rico, and the District of Columbia. Fifty-three percent of all adolescent cases have been reported from New York, Florida, California, Texas, Puerto Rico, and New Jersey, with 14% from New York alone. This geographic distribution has remained fairly stable over time with 46 to 59% of the cases being reported from these areas each year since 1984. Additionally, most (72%) of those for whom residence information was available were from Metropolitan Statistical Areas with populations of 1 million or more. By contrast, only 42% of the total 1980 United States population lived in metropolitan areas of this size. The proportion of cases reported from these large metropolitan areas has decreased from 78% in 1986 to 69% in 1988. Since the number of adolescent AIDS cases reported per year is still small, interpreting these trends is difficult. These data suggest, however, that HIV infection among adolescents is an issue for concern regardless of place of residence.

Overall, older adolescents, males, and racial and ethnic minorities predominate among adolescents with AIDS. Reported cases steadily increase with patient's age. Relatively few cases have been reported among adolescents younger than 17 years, with 75% of the reported cases occurring in those 17 to 19 years old.

Eighty percent of the total number of adolescents with AIDS are male. The cumulative male to female ratio is 4:1 compared with a male to female ratio of 10:1 among adults 20 years of age and older. The male

Accepted for publication Dec. 19, 1990.
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Key words: Acquired immunodeficiency virus, human immunodeficiency virus, adolescents.

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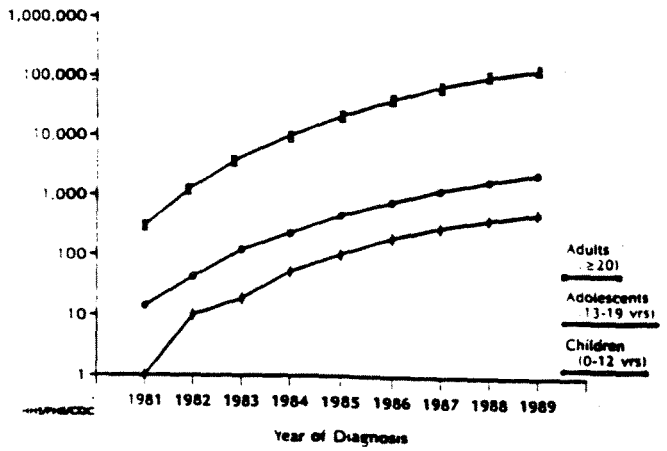

FIG. 1. Cumulative incidence of AIDS cases in children, adolescents and adults: United States, 1981 to 1988. Reported through October 31, 1990.

to female ratio remained stable from 1985 to 1987 (4.5:1 to 5:1), but in 1988, it dropped to 3:1, reflecting an 80% increase in the number of female cases reported between 1987 and 1988.

As for AIDS cases overall, minority adolescents are disproportionately represented among persons with AIDS. African-Americans and Hispanics make up 36 and 18% of adolescents with AIDS, respectively, but represent only 14 and 8%, respectively, of the 1980 U.S. population 13 to 19 years old. The cumulative incidence is highest for all other racial and ethnic groups compared with whites.

MODES OF TRANSMISSION

To date all reported AIDS cases among adolescents have resulted from transmission of HIV infection by the same routes as for adults, although in somewhat different proportions. By individual transmission category, the largest proportion of reported adolescent AIDS cases were those resulting from transfusion of blood products for coagulation disorders. The second largest category is transmission by homosexual or bisexual contact, comprising approximately 30% of cases. However, when behavior-related exposures are combined, sexual contact and intravenous drug use account for the majority (57%) of cases.

Within the adolescent age group, there are distinct differences in modes of transmission by age, sex, and race or ethnicity. Among young adolescents 13 to 14 years old, exposure to HIV through the transfusion of blood products for hemophilia accounts for 70% of cases, and blood transfusions another 21%. Understandably, in this age subset, 87% of AIDS cases are mong males. The proportion of cases attributable to exposure to blood or blood products decreases markedly with age to 72% of cases among 15- and 16-year-olds and 25% in older adolescents 17 to 19 years old. Correspondingly, the proportion of cases due to behavior-related exposure increases with age from 9% among 13- and 14-year-olds to 24% among 15- and 16-year-olds and 69% of cases among older adolescents 17 to 19 years old. The largest single exposure category for older adolescents is sexual contact between males, accounting for 36% of cases in this group. The importance of this progression is emphasized by the fact that over 90% of all cases among young adults 20 to 24 years old are attributed to behavior-related exposures.

Modes of transmission also differ by gender. Overall among males, blood product exposure accounts for the largest proportion (38%) of cases, closely followed by sexual contact between males (37%). However, by adding the overlapping categories of male homosexual or bisexual contact and IV drug use, up to 43% of cases among males could be due to male-to-male sexual contact. Among females, the most frequent exposure category was heterosexual contact, accounting for 44% of cases, followed by IV drug use (28%). Male IV drug users were reported as partners in 60% of female heterosexual-acquired cases or 28% of all female cases. Therefore, in total, 56% of reported female cases were related to IV drug use. The male to female ratio is highest for cases due to blood product exposure and lowest for heterosexual contact.

The mode of acquiring HIV infection among adolescents also vary by race and ethnicity. More than half (53%) of cases among white adolescents are attributed to transfusion of blood products for hemophilia; another 23% are due to homosexual or bisexual contact. By contrast, the two largest transmission categories are homosexual or bisexual contact (39%) and heterosexual contact (24%) for African-Americans, and IV drug use (29%) and homosexual or bisexual contact (28%) for Hispanics. The higher proportion of cases due to heterosexual contact and IV drug use among the African-American and Hispanic cases account for the higher proportion of females and lower male to female ratios in these groups compared with whites.

INDICATOR DISEASES AND MORTALITY

Clinically, adolescents with AIDS are more similar to adults than to children. Adolescents with AIDS have been diagnosed with a wide spectrum of opportunistic diseases, conditions, and cancers. *Pneumocystis carinii* pneumonia was the most frequently diagnosed infectious disease, reported in 43.5% of cases. Wasting was the next most common condition (15%), followed by *Candida* esophagitis (7%), cryptococcosis (6.5%), and toxoplasmosis (5%). Kaposi's sarcoma was not diagnosed frequently among adolescents.

Fifty-seven percent of adolescents with AIDS reported to the CDC surveillance system are known to have died. Additionally, AIDS mortality data are available from the National Center for Health Statis-

tics. Based on these data, AIDS accounts for less than 1% of deaths among adolescents 13 to 19 years old. However, for young adults 20 to 24 years of age, AIDS accounts for 2% of all deaths and is now the fourth leading cause of death.[5]

HIV SEROPREVALENCE DATA

Although AIDS case reporting is very useful for assessing serious morbidity and mortality due to HIV infection, it does not provide as much information on the current, ongoing situation. Given the long incubation period between HIV infection and the development of AIDS, the number of AIDS cases alone is probably much too low to serve as an estimate of the prevalence of HIV infection among adolescents. Adults aged 20 to 29 years represent 20% ($N = 21\,834$) of the total reported AIDS cases. Many of these adults were most likely infected as adolescents. Back-calculation is one method of estimating the number of persons previously infected with HIV by using reported AIDS cases and the estimated incubation period between infection and development of AIDS.[6] Applying this method, the probability of being infected with HIV as adolescents for people 13 to 29 years old can be calculated.[7] Based on these probabilities, it is estimated that from 1981 through 1987, approximately 17 000 persons aged 13 to 19 years were infected with HIV.[7] Current knowledge about the incubation period and natural history of HIV infection is limited, however, and the number of adolescents with AIDS is small. These factors can affect the precision of estimates derived from back-calculation. However, this estimate serves as a more useful indicator of the probable impact of HIV infection among adolescents than can be provided by AIDS cases alone.

Estimates of HIV seroprevalence in adolescents and young adults exist from multiple sources. As part of the CDC Comprehensive Family of Serosurveys, seroprevalence data have been collected for adolescents in different health-care settings.[8] All of these surveys were conducted in a blinded manner by testing discarded blood specimens that were collected for other routine medical purposes. Test results are linked only to limited, nonidentifying demographic information. This method is used to provide an unbiased estimation of seroprevalence while preserving anonymity.[8] Seroprevalence data are also available to CDC from HIV screening of applicants for military service (U.S. Department of Defense) and from applicants for residential Job Corps programs (U.S. Department of Labor). Since all applicants for both of these programs are screened for HIV, seroprevalence data are available for the entire applicant pool.

From 1988 to 1989, more than 108 000 specimens and demographic data from adolescents (15 to 19 years old) and young adults (20 to 24 years old) attending sexually transmitted disease (STD) clinics and women's health centers across the country were collected (9). In these surveys, the median seroprevalence was highest in the STD clinics for adolescents (0.5%, range 0 to 4.6%) and young adults (1.8%, range 0 to 30.4%). Median seroprevalence in the women's health centers was 0% (range 0 to 1.7%) for adolescents and 0% (range 0 to 3.1%) for young adults. The median rates for adolescent males and females in STD clinics were 1.3 and 0.6%, respectively.[9]

From October 1985 to September 1989, the overall HIV seroprevalence for applicants for military service was 0.03% (range 0 to 0.6%) among adolescents aged 17 to 19 years and 0.19% (range 0 to 1.1%) for adults aged 20 to 24 years.[10] Among 17- to 19-year-olds, the seroprevalence was equal for men and women (0.03%); among 20- to 24-year-olds, the proportion of HIV-infected males (0.19%) was approximately twice as high as that for females (0.09%). The seroprevalences for 17- to 19-year-old African-Americans and Hispanics were 5 and 1.5 times that of white recruits of this age, respectively. A similar trend was seen in the 20- to 24-year-old age group. These data are an important source of national seroprevalence estimates for the adolescent population but may underestimate the severity of the problem in this age group since homosexual and bisexual males, IV drug users, and persons with coagulation disorders are discouraged from applying for military service.

The Job Corps, the major federal job training program for socioeconomically and educationally disadvantaged youth, began screening all applicants to their residential training program for HIV infection in 1987.[11] Almost all (97%) of Job Corps entrants are aged 16 to 21 years. The overall seroprevalence in this group is 0.39%. The seroprevalence varied by age, sex, race or ethnicity, and geography. The highest seroprevalence occurred in African-Americans and Hispanic males (0.99 and 0.83%, respectively) and African-American females 19 to 21 years old (0.66%). The male to female ratio was 1:1 for 16- to 18-year-olds and approximately 2:1 for 19- to 21-year olds. Seroprevalence was highest in the Northeast (0.63%) and the South (0.42%). These data indicate that this population is at higher risk for HIV infection than those applying for military service. Since the Job Corps does not accept known IV drug users, this population may not necessarily represent the total spectrum of adolescents at high risk for HIV infection.

Other blinded seroprevalence surveys have been done in adolescent populations in several areas between 1987 and 1989. In a study of runaway homeless youth 16 to 20 years old, a seroprevalence rate of 7% was found.[12] Data from an STD clinic in Baltimore showed a 2.2% seroprevalence among 15- to 19-year-old adolescents.[13] In a study conducted among adoles-

cents aged 13 to 19 years attending an adolescent outpatient clinic in Washington, DC, the seroprevalence was 0.37%, with the highest prevalences occurring in females (0.47%) and in patients 18 to 19 years old (0.56%).[14] Another study was done among individuals who had blood drawn for syphilis screening in the general medical or pediatric clinic or emergency room of a municipal hospital in the Bronx, New York.[15] The seroprevalence was 1.2% among adolescents and young adults aged 15 to 24 years. Also in the Bronx, a seroprevalence survey among young women attending a family planning clinic for first-trimester abortions revealed a seroprevalence of 2.5% among young women aged 20 to 24 years.[16] Although methods for these different surveys vary, they indicate that there is a heterogeneity in the seroprevalence among the adolescent and young adult population and that certain adolescents are at very high risk of HIV infection. These data suggest that adolescent females may be at higher risk for HIV infection than males of the same age and that African-American and Hispanic adolescents also appeared to be at an increased risk relative to white adolescents.

RISK OF HIV TRANSMISSION IN ADOLESCENTS

Data from AIDS case reports and selected seroprevalence surveys indicate that behavior is a major factor for placing adolescents at risk for HIV infection. Since the risk of transmission of HIV through exposure to infected blood or blood products has been drastically reduced with the advent of blood screening, blood donor self-deferral, and heat treatment of clotting factors, virtually all new infections among adolescents will result from sexual or drug-use exposures. Information on risk behavior among adolescents will be important for developing prevention efforts in this population.

Studies indicate that many adolescents may be at risk for HIV infection through sexual exposure. There has been an increase in adolescent sexual activity over the last 2 to 3 decades with both a declining age at first intercourse and increasing number of partners over time.[17-20] The median age at first intercourse is 16 years old in this country, but it varies substantially by gender, race or ethnicity, and geographic location.[19, 21] In a 1982 study of never-married females living in metropolitan areas, the proportion reporting ever having had intercourse ranged from 17% for 15-year-olds to 70% for 19-year-olds reporting having had intercourse.[22] The impact of the increasing proportion of males and females who have had intercourse during adolescence is heightened by the relatively small number who constantly use contraceptive methods that could also prevent HIV infection and other STDs.[17, 18, 23] The presence of STDs indicates behavior that places one at risk for exposure to HIV infection. STD rates in adolescents are high and have increased over time. Since the early 1960s, the annual number of reported cases of gonorrhea in teenagers (aged 10 to 19 years) has increased dramatically from a total of 56 907 cases reported in 1960 to 256 112 in 1980.[24] Females had higher rates of gonorrhea and a faster rate increase than same-aged males. From 1960 through 1970, 15- to 19-year-old males had a higher rate of infection than same-aged females. By 1973, the gonorrhea rate among females in this age group exceeded that of males and has remained consistently higher. In 1987, gonorrhea was reported in 43 of 100 000 persons 10 to 14 years old, in 1028 of 100 000 persons 15 to 19 years old, and in 1527 of 100 000 persons 20 to 24 years old, compared with ≤749 of 100 000 persons aged 25 years or older.[25] However, when adjusting for rates of sexual activity among the different age groups, 15- to 19-year-olds actually have the highest gonorrhea rates of any age group.[26]

Other features of adolescent sexual behavior may influence the risk of HIV transmission in this population. Receptive anal intercourse has been demonstrated to be an important risk factor for transmission of HIV infection. Anecdotal evidence suggests that anal intercourse may be practiced frequently among some groups of adolescents as a method of avoiding pregnancy and of "maintaining virginity." In a recent study among African-American and Hispanic inner-city adolescent females, 25% acknowledged having had anal intercourse.[27] Because homosexual and bisexual activity has been the major mode of HIV transmission, adolescent males engaging in sex with other males may place themselves at considerable risk of exposure to HIV infection. This may be particularly true since homosexual adolescent males who have intercourse tend to have older male partners.[28] Based on the Kinsey data from the 1970s, approximately 10% of the male population is predominantly homosexual.[29] However, studies have described 17 to 35% of males having had homosexual experiences during their lifetimes. Regardless of eventual sexual orientation, the earliest sexual experiences of many adolescent males are homosexual in nature.[18, 30]

Less information is available about IV drug use among adolescents; however, this is clearly an important risk factor. In a national survey conducted in 1986 of approximately 15 200 high school seniors attending 129 schools, 1% reported ever having used heroin and 16.9% reported ever having used cocaine. The proportion of students injecting these drugs is not known. Drug use can begin very early. Of eventual users of these drugs, 10% reported first using heroin and 1% reported first using cocaine in the sixth grade.[31] A 1987 national survey of HIV-related knowledge, beliefs, and behavior provided information on

drug use from four of the participating sites. The proportion of students reporting ever having injected cocain, heroin, or other illegal drugs ranged from 2.8 to 6.3%.[32] Since only students enrolled in school were included in these surveys, these figures probably underestimate drug use among adolescents. The crack epidemic will very likely have an effect on HIV transmission. Although crack use by itself has not been directly linked to the spread of HIV, increased high-risk sexual behavior that often accompanies crack use has been associated with an increase in STD rates and will undoubtedly have a similar effect on HIV transmission.[33, 34] Additionally, injectable forms of cocaine and heroin may accompany crack use and increase the risk of HIV transmission.[35] It is also important to keep in mind that alcohol and marijuana use, which are more prevalent than use of opiates among adolescents, can lead to impaired judgment about sexual choices and increased risky sexual behavior.[36, 37]

KNOWLEDGE, ATTITTUDES, BELIEFS AND BEHAVIOR

Although adolescents are at risk of becoming infected with and transmitting HIV, many of them are misinformed about their risk of transmission. Information on adolescents' HIV-related knowledge, attitude, beliefs, and behavior is available from several studies.[37-43] Although these studies vary considerably in their methodologies and populations surveyed, certain common results were found. Overall, most adolescents knew that sexual intercourse and sharing needles for IV drug use are the main modes of HIV transmission. Adolescents were somewhat more likely to associate HIV transmission with homosexual as opposed to heterosexual contact. The most common misconceptions were about acquisition of HIV through casual contact and blood donation and believing that one could tell if a person was infected with HIV. Even with adequate knowledge, many adolescents fail to translate this knowledge into appropriate behavior.[27, 37-40] Although some adolescents report changing their behavior because of fear of AIDS, few reported changes in kinds of behavior that would decrease the risk of exposure to HIV (i.e., abstinence or condom use). Perceived risk was found to be associated with decrease in risky behavior. Most adolescents expressed an interest in learning more about HIV infection and AIDS; schools and health professionals were preferred sources of information for many.[37, 42, 44]

RESEARCH NEEDS

Knowledge related to AIDS and HIV infection in adolescents has definitely grown rapidly. Our knowledge in this area, however, still lags behind what is known about the disease and infection in young children and adults. Further information is needed about the clinical, epidemiologic, behavioral, and prevention aspects of HIV infection among adolescents. For example, very little is known about the natural history of HIV infection in adolescents. Evidence from studies of HIV infection in people with hemophilia suggests that infected adolescents may have a lower rate of progression to AIDS or a longer incubation period and may tolerate severe immunodeficiency better than adults.[45] More data from a wider range of patients are needed to better understand the natural history and to determine whether factors unique to adolescence, such as the hormonal changes accompanying puberty, influence the clinical course of infection and progression to AIDS.[1]

Further work should be done to evaluate health-care models for adolescents, particularly since many of those at highest risk may have limited access to health-care facilities. For many adolescents, their status as legal minors may act as a barrier to obtaining needed services, such as drug treatment, HIV testing, and, in some states, STD treatment.[46] HIV-infected adolescents have had very limited access to clinical trials, since research protocols for adults often exclude minors and pediatric protocols are generally designed for children younger than 13 years of age.

Epidemiologically more data are needed about distribution of risky behavior among all adolescents and about which subpopulations of adolescents are at highest risk. Of particular interest is the impact of the crack cocaine epidemic on HIV transmission through increasing sexual and other risk-taking behavior. As more data are gathered from seroprevalence surveys and AIDS case reporting, models are needed to provide better estimates of the number of HIV-infected adolescents and to monitor the trends. Data on the antecedents of high-risk behavior in adolescents are critically needed to prevent these kinds of behavior from developing. Evaluation of ongoing intervention efforts will provide information to improve our ability to prevent HIV infection.

PREVENTION

Preventing HIV infection among adolescents will require new, creative approaches. AIDS education combined with appropriate HIV counseling and testing[47] are critical elements for preventing new HIV infections in adolescents. AIDS case data indicate that educational messages should cover all risky behavior, be targeted to males and females of all racial and ethnic groups and sexual orientation, and begin as early as the preteen years. Public and private schools have a strategic role in educating young people about AIDS and specific actions they can take to prevent infection. CDC recently published guidelines for comprehensive school health education to prevent the spread of HIV infection.[48] However, many adolescents will not be reached by school-based education programs. In 1984, about 615 000 adolescents ages 14 to

17 years and 1.1 million 18- and 19-year-olds were not enrolled in school and had not completed high school.[49] These adolescents will need to receive their educational messages from other sources.

Additionally, prevention efforts must go beyond imparting information and must help adolescents develop the motivation, attitudes, and skills to avoid behavior that places them at risk for HIV infection. Clearly, adequate knowledge alone does not always translate into behavior change. Innovative prevention models that reach adolescents in an acceptable and appropriate way must be developed.

Preventing further transmission of HIV infection and AIDS in adolescents will depend on the combined efforts of persons who have contact with adolescents. Pediatricians and other health professionals who understand and deliver care to adolescents can play a critical role by providing appropriate counseling and prevention messages. Counseling and ascertainment of potential risks for HIV infection should be approached in a straightforward, nonjudgmental manner (see Chapter 38). Understanding the epidemiology of AIDS in adolescents may help identify those adolescents at highest risk for HIV infection. However, clinicians should remember that any adolescent, particularly one who is sexually active, can be at risk now or in the near future. Counseling should include information about risk reduction and ways of protecting oneself from HIV infection and, if infected, of reducing the risk of possible transmission to one's sexual or needle-sharing partners. This second component of counseling is often overlooked and may be particularly important for adolescents who acquired HIV infection from blood or blood products.[50] These adolescents were not infected as a result of their behavior but may place current or future sexual or needle-sharing partners at risk of exposure to HIV.

Targeting adolescents whose behavior places them at high risk of HIV infection is important. However, providing information and helping to build skills that will prevent other adolescents from beginning such behavior is also crucial. Information about appropriate prevention education and approaches for youth is emerging but still limited.[51-54] Helping preadolescents and adolescents to develop safe sexual behavior and to avoid drug use will have a major impact on the future of the HIV-AIDS epidemic. Hopefully, efforts to decrease the transmission of HIV will also have a major impact on other important problems in this age group, including teenage pregnancy, sexually transmitted diseases, and drug use.

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Epidemiology of Women With AIDS in the United States, 1981 Through 1990

A Comparison With Heterosexual Men With AIDS

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In the United States, women account for an increasing number and percentage of adults with the acquired immunodeficiency syndrome (AIDS). Overall, 51% of women with AIDS were infected through intravenous drug use and 29% through heterosexual contact; the proportion of intravenous drug users decreased, while the proportion attributed to heterosexual contact increased, between 1986 and 1990. Most women with AIDS were black or Hispanic (72%); residents of large metropolitan areas (73%), especially cities along the Atlantic coast; and of productive age (15 to 44 years) (85%). However, the proportion of women with AIDS reported by smaller cities and rural areas has increased from 22% in 1986 to 28% in 1990. The male-to-female ratio of heterosexuals with AIDS has remained about 2.4:1 since 1987. A comparison of women with AIDS to heterosexual men with AIDS showed that these two groups were similar by age, race, and geographic distribution. Also, survival times from AIDS diagnosis to death for women and heterosexual men with AIDS were not significantly different.

(*JAMA*. 1991;265:2971-2975)

SINCE 1981, when the first cases of the acquired immunodeficiency syndrome (AIDS) in women were reported in the United States, the number of women with human immunodeficiency virus (HIV) infection has increased rapidly.[1] In 1988 more than 1800 (0.7%) women who gave birth in New York State were HIV seropositive, and in some areas of New York City more than 2% of childbearing women were infected with the virus.[2] As a result of this increase, HIV has had a major impact on morbidity and mortality among young women. By 1987, AIDS had become the eighth leading cause of death in women of reproductive age (15 to 44 years) in the United States and the leading cause of death in black women of the same age group in New York and New Jersey.[3] In addition, since HIV-infected women transmit the virus to about 25% to 35% of their children during pregnancy or at delivery, increasing HIV seroprevalence rates in childbearing women has resulted in a growing number of children with HIV infection and AIDS.[4-7] In 1989, an estimated 6000 infants were born to HIV-infected women in the United States, and probably about 1500 to 2000 of these infants were infected perinatally.[8]

Understanding the epidemiology of HIV infection and AIDS in women is essential for developing better public health strategies and allocating resources more effectively to prevent the spread of HIV to women and children. National AIDS surveillance provides information on current HIV-related morbidity and mortality and continues to be essential in accurately predicting national trends and patterns of HIV infection in the United States.[9] In this article, we analyze surveillance data for women with AIDS in the United States and compare the epidemiology of AIDS in women with that in heterosexual men.

METHODS

This descriptive analysis reviews AIDS cases in women reported to the Centers for Disease Control (CDC) through December 31, 1990. The CDC AIDS surveillance system includes all 50 states, US territories, and the District of Columbia. Cases of AIDS are initially reported to local and state health departments, which in turn forward reports without personal identifiers to the CDC.[10-12] Reports are updated to record date of death for persons who have died. The CDC defines a case of AIDS as an instance of a disease, at least moderately predictive of a defect in cell-mediated immunity, occurring with HIV infection or no known cause for diminished resistance to that disease.[13] Increased use of the HIV antibody test and greater understanding of the spectrum of HIV-related diseases led to a revision of the case definition in 1987 that expanded the list of diseases indicative of AIDS and included some diseases diagnosed presumptively (ie, without histological or laboratory confirmation). Each case of AIDS reported

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in women and heterosexual men was placed in only one exposure category, by using the following hierarchical order: (1) intravenous drug use, (2) hemophilia or other coagulation disorder, (3) heterosexual contact with a person at risk for AIDS, (4) transfusion with blood or blood products, and (5) undetermined risk. Women with more than one reported mode of exposure to HIV are classified in the exposure category listed first in the hierarchy. Women with AIDS were compared with heterosexual men with AIDS, who were defined for this analysis as men whose reported risk behavior did not include sexual contact with other men. Adult AIDS patients were 13 years of age and older, and pediatric AIDS patients were less than 13 years of age.

Data were analyzed by year of report. Since only 1020 AIDS cases in women were reported during 1981 through 1985, trend analyses of exposure categories were performed on cases reported prior to 1986 and then for each subsequent year.

Geographic analyses were based on place of residence at the time of AIDS diagnosis. The denominators for rates were calculated from 1989 population estimates by age, sex, and race. The 1989 estimates are an extension and modification of white/nonwhite age estimates for 1982 and 1984 produced by the US Bureau of the Census from 1980 census data. The denominators for rates of heterosexual men are estimates of the adult male population, including homosexual and bisexual men. Metropolitan areas are defined as the Metropolitan Statistical Areas for all areas except the six New England states. For these states, the New England County Metropolitan Areas are used. Metropolitan areas are named for a central city in the Metropolitan Statistical Area or New England County Metropolitan Area, and they may include several counties and cross state boundaries. Kaplan-Meyer survival analysis was calculated by using AIDS cases and deaths reported through December 31, 1989. Persons with no date of death on the report as of December 31, 1989, were presumed to be alive. Statistical testing included analysis by χ^2 tests for associations and linear trends. Unless otherwise stated, all trends or comparisons were significant at $P<.001$.

RESULTS

As of December 31, 1990, a total of 15 493 (10%) of the 158 279 adults reported with AIDS in the United States were women. Between 1985 and 1990, the percentage of adult AIDS cases that occurred in women increased from 6.6% to 11.5% (Table 1). During the same period, the percentage of cases in heterosexual men also increased. Since 1985, the largest percent increase of AIDS cases in both women and heterosexual men occurred between 1987 and 1988. Of the AIDS cases reported in 1988, 1322 (41%) cases in women and 3269 (41%) cases in heterosexual men met only the 1987 case definition, suggesting that at least part of the increase in AIDS cases in these two groups in 1988 was due to the change of the AIDS case definition. Thus, while the proportion of cases in heterosexuals increased from 28% in 1987 to 39% in 1990, the male-to-female ratio for heterosexuals with AIDS remained relatively constant at about 2.4:1.

Overall, slightly more than half of the women with AIDS were black, while about one fourth were white and one fifth Hispanic (Table 2). As a result, Hispanic and black women had cumulative incidence rates 8 and 13 times, respectively, that for whites. Between 1986 and 1990, the absolute number of women with AIDS increased in all racial and/or ethnic groups; however, the proportion of women with AIDS who were black did not change significantly, while the proportion who were Hispanic increased from 18% to 22% and the proportion who were white decreased from 28% to 25%. Although women with AIDS had a larger proportion of blacks and a smaller proportion of Hispanics than heterosexual men with AIDS, overall these two groups had similar racial distributions. Heterosexual men who were Hispanic or black had cumulative incidence rates 9 and 12 times, respectively, that for whites.

At the time of diagnosis of AIDS, the mean and median ages for women were 36 years and 34 years, respectively, compared with 38 years and 36 years for heterosexual men. About 1% of both women and heterosexual men with AIDS were 13 to 19 years of age at the time of diagnosis (Table 3). A larger proportion of women compared with heterosexual men were in their 20s when diagnosed (27% vs 16%), and many of these women were likely infected as adolescents. Overall, 85% of wo

Table 1.—Number and Percentage of Reported Cases and Male-to-Female Ratio for Women and Heterosexual Men With AIDS in the United States, by Year, 1981 Through 1990*

Year	No. (%) of Cases†		Ratio of Heterosexual Men to Women
	Women	Heterosexual Men	
1981‡	6 (3.2)	24 (12.7)	4.0
1982	47 (7.4)	151 (23.6)	3.2
1983	144 (7.0)	435 (21.0)	3.0
1984	285 (6.4)	866 (19.4)	3.0
1985	538 (6.6)	1553 (19.0)	2.9
1986	980 (7.5)	2523 (19.3)	2.6
1987§	1701 (8.1)	4127 (19.7)	2.4
1988	3263 (10.4)	7956 (25.3)	2.4
1989	3639 (10.5)	8836 (25.6)	2.4
1990	4890 (11.5)	11 632 (27.3)	2.4
Total	15 493 (9.8)	38 103 (24.1)	2.5

*AIDS indicates the acquired immunodeficiency syndrome.
†The denominator for the percentage of cases is all reported AIDS cases, including homosexual and bisexual men, for the respective year.
‡Reporting began in mid-1981.
§The case definition changed in September 1987.

Table 2.—Number and Percentage of Reported Cases and Cumulative Incidence Rates for Women and Heterosexual Men With AIDS in the United States, by Racial/Ethnic Group, Through December 31, 1990*

Racial/ Ethnic Group	Women		Heterosexual Men	
	No. (%) of Cases	Cumulative Incidence Rate†	No. (%) of Cases	Cumulative Incidence Rate‡
Black	8037 (52)	67	17 171 (45)§	164
White	4121 (27)	5	10 456 (27)‖	14
Hispanic	3184 (21)	39	10 169 (27)§	127
Other/unknown	151 (1)	...	307 (1)	...
Total	15 493 (100)¶	...	38 103 (100)	...

*AIDS indicates the acquired immunodeficiency syndrome.
†Per 100 000 women (1989 intercensal population estimate).
‡Per 100 000 men, including homosexuals and bisexuals (1989 intercensal population estimate).
§Women vs heterosexual men, $P<.001$.
‖Women vs heterosexual men, $P<.05$.
¶Percentages have been rounded to the nearest whole numbers.

rith AIDS were of reproductive age
.o 44 years) at the time of diagnosis.
ases of AIDS in women have been
nosed in residents of all 50 states.
10 reporting areas with the highest
ulative incidence rates of AIDS
es in women included Puerto Rico,
nt states located on the Atlantic
st, and the District of Columbia (Fig-
). These 10 areas reported almost
ee fourths (72%) of the AIDS cases in
men. The geographic distribution of
terosexual men with AIDS by num-
r of cases and cumulative incidence
te was similar to that in women. As of
ecember 31, 1990, 26 657 (70%) of
103 heterosexual men with AIDS
ere reported from the same 10 report-
g areas. Puerto Rico had the highest
mulative incidence rate of AIDS
ses in heterosexual men (224 per
00 000 adult male population), followed
y New York (179 per 100 000), New
ersey (158 per 100 000), Washington,
)C (154 per 100 000), and Florida (75
er 100 000). New York had the largest
umber of both women (4830) and het-
rosexual men (12 427) with AIDS. In
ddition, New Jersey had the second
argest number of AIDS cases for these
wo groups (2120 women and 4782 het-
erosexual men), followed by Florida
(1923 women and 3802 heterosexual
men).

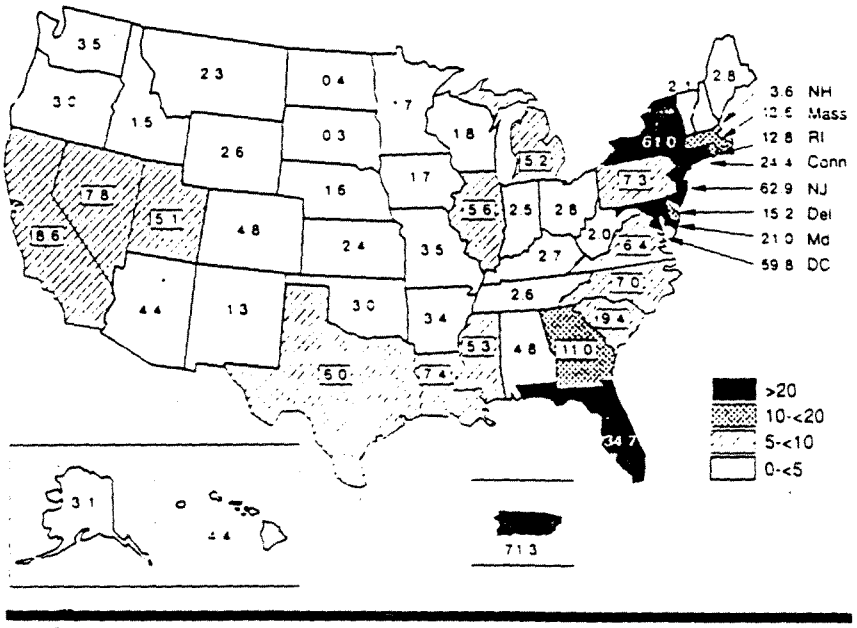
At the time of diagnosis, about 73% of women with AIDS were residents of large metropolitan areas with populations over 1 million. Another 21% were from small-to-medium metropolitan areas (population 50 000 to 1 million), and the remaining 5% were from nonmetropolitan areas (population <50 000). Large metropolitan areas also had the highest cumulative incidence rate of women with AIDS (25 per 100 000 women), followed by small-to-medium metropolitan areas (nine per 100 000) and nonmetropolitan areas (four per 100 000). However, between 1986 and 1990, the proportion of women with AIDS from small-to-medium metropolitan and nonmetropolitan areas increased from 22% to 28%. For heterosexual men with AIDS, both the percentage of cases and the cumulative incidence rate were highest (71% and 62 per 100 000 men, respectively) in large metropolitan areas and lowest (7% and 12 per 100 000) in nonmetropolitan areas. Since 1986, the proportion of heterosexual men with AIDS reported by small-to-medium metropolitan and nonmetropolitan areas increased from 24% to 29%.

Slightly more than half of women with AIDS were intravenous drug users (Table 3). In addition, almost one third

Table 3.—Number and Percentage of Reported Cases for Women and Heterosexual Men With AIDS in the United States, by Age and Risk Groups, as of December 31, 1990*

Group	No. (%) of Cases		Ratio of Heterosexual Men to Women
	Women	Heterosexual Men	
Age group, y			
13-19	157 (1)	280 (1)	1.8
20-29	4171 (27)	6090 (16)	1.5
30-39	7245 (47)	18 541 (49)	2.6
40-49	2298 (15)	8536 (22)	3.7
≥50	1622 (11)	4656 (12)	2.9
Risk group			
IVDU	7858 (51)	26 537 (70)†	3.4
Sex partner of IVDU	3183 (21)	1287 (3)†	0.4
High-risk, non-IVDU sex partner	1337 (9)‡	597 (2)†	0.4
Born in pattern II country§	553 (4)	1483 (4)‖	2.7
Transfusion¶	1466 (9)	3604 (9)	2.5
Undetermined	1096 (7)	4595 (12)†	4.2
Total	15 493 (100)#	38 103 (100)	2.5

*AIDS indicates the acquired immunodeficiency syndrome; and IVDU, intravenous drug user.
†Women vs heterosexual men, $P<.001$.
‡The sex partners of these women included 498 (37%) bisexual men, 175 (13%) men who received transfusions since 1977, 53 (4%) men who were born in a pattern II country, and 611 (46%) men infected with human immunodeficiency virus with no reported risk factor.
§In these countries, most of the reported AIDS cases occur in heterosexuals, and the male-to-female ratio is approximately 1:1.
‖Women vs heterosexual men, $P<.01$.
¶Includes adult hemophiliacs.
#Percentages have been rounded to the nearest whole numbers.



Cumulative incidence rates of cases of the acquired immunodeficiency syndrome in women by state of residence per 100 000 women, United States, through December 31, 1990.

were sex partners of intravenous (IV) drug users and 9% were sex partners of men with other risk factors. In comparison, heterosexual men with AIDS had a larger proportion of IV drug users than women with AIDS (70% vs 51%), while a smaller proportion of heterosexual men with AIDS reported sexual contact with high-risk partners (5% vs 29%). More than two times as many women [illegible] with men with AIDS, reported heterosexual contact with high-risk partners. The proportions of both groups were not significantly different for those who received transfusions of blood or blood components or were born in a country with a high rate of heterosexual transmission.

From 1986 to 1990, the number of women with AIDS who were IV drug users increased, but the proportion of women with AIDS who were IV drug

Table 4.—Percentage of Reported Cases for Women and Heterosexual Men With AIDS in the United States, by Risk Group and Year, as of December 31, 1990*

Risk Group	≤1985	1986	1987	1988	1989	1990
IVDU						
Women	56	50	50	54	52	48
Heterosexual men	72	72	68	74	70	66
Sex partner of IVDU						
Women	14	20	20	21	21	22
Heterosexual men	1	2	3	3	4	4
High-risk, non-IVDU sex partner						
Women	5	8	9	7	9	10
Heterosexual men	<1	1	1	1	2	2
Born in pattern II country						
Women	7	6	4	3	4	2
Heterosexual men	11	6	5	3	3	2
Transfusion recipient						
Women	10	11	13	10	9	8
Heterosexual men	9	13	15	10	9	7
Undetermined						
Women	8	5	4	5	6	7
Heterosexual men	6	7	5	5	7	10

*AIDS indicates the acquired immunodeficiency syndrome; and IVDU, intravenous drug user.

users decreased ($P = .01$) (Table 4). During the same period, the proportions of women with both IV drug–using and other high-risk sex partners increased ($P = .05$ and $P = .02$, respectively). Similarly, the proportion of heterosexual men with AIDS who were IV drug users decreased from 72% in 1986 to 66% in 1990, while the proportion with high-risk sex partners increased from 3% to 6%. In addition, during the same period the proportions of both women and heterosexual men with AIDS who were transfusion recipients or who were born in countries with high rates of heterosexual transmission decreased.

Survival times from AIDS diagnosis to death for 10 558 women and 26 362 heterosexual men, reported to the CDC as of December 31, 1989, were not statistically different. The median survival time from AIDS diagnosis to death for women was 9.8 months, compared with 9.3 months for heterosexual men. After a diagnosis of AIDS, the 3-year survival rate was 20% for women and 19% for heterosexual men.

COMMENT

In the United States, women account for an increasing number and percentage of adults with AIDS. About 51% of women with AIDS were infected through IV drug use and 29% through heterosexual contact. Most women with AIDS were young, black or Hispanic, and residents of urban areas on the Atlantic coast. Although most women with AIDS were reported as residents of large metropolitan areas, the proportion reported by smaller cities and rural areas has increased since 1986. Additionally, a comparison of women with AIDS to heterosexual men with AIDS showed that these two groups were similar by age, race, geographic distribution, and survival time from AIDS diagnosis to death.

Since severe, clinical manifestations of HIV disease are required for the diagnosis of AIDS and the median time for progression from HIV infection to AIDS may be as long as 10 years, patients with AIDS represent only part of the HIV epidemic.[14] Persons infected with HIV who are asymptomatic or have HIV-related symptoms not included in the AIDS case definition represent the other, much larger part of the epidemic. In 1989, an estimated 1 million persons were infected with HIV in the United States.[3] Although the number of HIV-infected women at present is not known, HIV seroprevalence surveys and studies suggest that the epidemiology of women who are HIV-infected but do not have AIDS is similar to that of women with AIDS. For example, the highest rates of HIV infection in women have been found in IV drug users, with rates greater than 10% reported primarily from states in the Northeast.[15,16] Statewide screening programs of neonates for passively acquired maternal HIV antibody found much higher rates in states located along the Atlantic coast, where seroprevalence was highest in inner-city areas and lowest in rural areas.[15,16,18] Routine HIV antibody testing of female applicants for military service found the highest rates in New Jersey, Puerto Rico, New York, Washington, DC, and Maryland; the rates in Hispanic and black women, respectively, were four and seven times that of white women in this group.[19]

Male IV drug users with AIDS accounted for about 80% of the absolute difference between the number of AIDS cases in women and the number of cases in heterosexual men. This difference is probably not the result of distinctive drug-use behaviors by either group, because HIV seroprevalence rates among heterosexual IV drug users do not differ significantly by gender.[20] Thus, the greater number of AIDS cases in heterosexual men, as compared with women, is most likely the result of the larger number of men who are estimated to use IV drugs.[21]

The higher number of women with heterosexually transmitted AIDS was probably the result of several factors. Since most IV drug users and virtually all hemophiliacs are men and some men with HIV infection acquired through sexual contact with other men are bisexual, women in the United States are currently at higher risk than men of encountering an HIV-infected heterosexual partner. In addition, several studies of couples with one infected partner suggest that the relative efficiency of sexual transmission of HIV from male to female may be greater than from female to male.[22,23]

Several case histories of possible female-to-male sexual transmission of HIV have been reported.[24,25] Women with AIDS who reported sexual relations only with a female partner since 1977 represented about 0.8% of AIDS cases in women reported to the CDC through September 30, 1989.[26] Ninety-five percent of these women with AIDS were IV drug users, while the remaining 5% were recipients of blood or blood products. No cases in the AIDS surveillance database have documented male-to-female transmission.

More knowledge about the natural history of HIV infection in women is needed. A previous study suggested

he median sur... from diagnosis to deat... shorter men than in ... ays for n and 357 days ... However- s study of 583... n AIDS osed in New ... prior to compared men ... g homo- als and bisexua... women. ival in homose... bisexual is longer than ... ther risk ips. In part, th... ed to the er percentage ... sexual men with ... sexual and ch has a longer ... sarcoma, er opportunisti... time than lyses based o... Survival ould be interpr... iance data ce the reportin... n caution, ses is known to ... s for AIDS th the proportio... plete. Also, death and th... s diagnosed eaths may vary ... reporting In the United ... groups.[5] urveillance is a... ational AIDS nd state health ... ystem. Local AIDS cases prim... ments identify contact with hos... ough frequent care providers; ... d other health ods, such as rev... other meth- sions and deat... ospital admis- used. Overall, ... ates, are also threatening sy... % to 90% of life- tic HIV infec- tions have been ascertained through AIDS surveillance.[5] At present, few data are available that quantify underdiagnosis or underreporting in different groups, including women and heterosexual men with AIDS. Differential completeness of AIDS case reporting for women and heterosexual men with different demographic characteristics and risk behaviors could potentially bias data obtained through AIDS surveillance, thus affecting the validity and generalizability of the conclusions of this report.

To improve surveillance, the AIDS case definition was revised in September 1987 to include several additional AIDS-indicative diseases, such as HIV encephalopathy and HIV wasting syndrome, and some presumptively diagnosed diseases, such as *Pneumocystis carinii* pneumonia. A higher proportion of persons who met only the 1987 case definition were female, black or Hispanic, or IV drug users compared with those meeting the earlier case definition.[30] However, many of these persons probably would have developed conditions included in the pre-1987 case definition and been reported at a later date. Although additional AIDS cases were reported because the case definition was revised in 1987, the epidemiologic trends for AIDS cases in women and heterosexual men that were significant prior to the revision continued after the revision.

Mortality statistics, AIDS case surveillance, and HIV seroprevalence surveys all document the increasing impact of HIV on the health of women in the United States. Through education and counseling, uninfected women can learn to protect themselves from HIV infection, and those with high risk behaviors can be referred for treatment of drug addiction and/or sexually transmitted diseases that contribute to transmission of HIV. For women already infected with HIV, recent advances in therapy, including zidovudine and other antiretroviral agents, as well as prophylactic measures such as pentamidine isethionate to prevent *P carinii* pneumonia, suggest that early recognition of HIV infection with medical interventions for persons showing evidence of immunodeficiency can delay HIV-related morbidity. Clearly, providing all persons at risk for HIV infection ready access to education, counseling, and HIV testing and appropriate medical follow-up must be health care priorities.

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Researchers waking up to needs of women with HIV

Women and HIV: Facing the Epidemic, a conference on women and HIV, will be held from 8:30 a.m. to 6:30 p.m. on Saturday, Nov. 9, at the Faculty Center of UCLA.

The conference, co-sponsored by AIDS Project Los Angeles, is designed for women with HIV and anyone interested or involved with the issue. Morning presentations on topics such as epidemiology, medical issues and prevention will be followed by an afternoon of workshops on topics such as activism, safer sex, living healthy, legal issues, pregnancy and substance use. Guest speakers will include Eunice Diaz, M.S., M.P.H., of the National Commission on AIDS and Mark Katz, M.D. of Kaiser Permanente Medical Center.

Presentations will be made in English and Spanish. Donations of $15 or more will be appreciated but not required.

For information, call Lori Levine at Being Alive/ People with HIV/AIDS Action Coalition, (213) 667-3262 or Jeffrey Fricke at (213) 825-3596. Callers who want information in Spanish may call Angie Martinez at AIDS Project Los Angeles, (213) 962-1600, Ext. 198.

By STEPHAN KORSIA

Women with AIDS are finally beginning to be heard.

At this year's 7th International AIDS Conference in Florence, Italy, several studies focused on health issues specifically encountered by women with HIV disease. These studies confirm what AIDS activists have been insisting for years: Women with HIV suffer from frequent gynecological manifestations with symptoms that are often worse than those observed in HIV-negative women.

Common symptoms

The two most common manifestations seem to be genital warts, due to the infection by the Human Papilloma Virus (HPV) and cervical cancers. Both these infections benefit from patient's diminished immune status, and seem to help each other's development.

A study presented in Florence by Dr. Katherine LaGuardia from New York Hospital shows that 61 percent of female patients with no AIDS symptoms and fewer than 200 T4 cells per mm3 (cubic millimeters) suffer from cervical cancer, versus 38 percent of patients with more than 200 T4 cells per mm3. In 92 percent of the patients studied, these cancers are associated with genital warts.

An analysis of 21 studies shows that HIV-positive women are five times more at risk to develop cervical cancers. These results clearly indicate the need for Pap Smears and gynecological examinations every six months for women with no AIDS symptoms and every three months for women who experience symptoms.

Genital warts seem to appear mainly in women with fewer than 250 T4 cells per mm3, and cervical cancers are more frequent in patients with fewer than 150 T4 cells per mm3.

HIV-positive women also seem to suffer from a higher susceptibility to sexually transmittable disease, especially genital ulcers and Pelvic Inflammatory Disease (PID). The cervical inflammation that develops during these infections is responsible for an increase in the secretion of HIV particles in vaginal fluids.

Interestingly, no study was presented in Florence regarding the incidence of recurrent yeast infections in women with HIV.

This topic is particularly important because clotrimazole vaginal creams, the standard treatment for vaginal yeast infections, are now being sold over the counter. If vaginal yeast infections are an early symptom of HIV disease, repeated use by the patient would delay diagnosis and initiation of helpful therapy.

A study conducted in Georgia shows that women with HIV are prone to develop oesophageal thrush, Mycobacterium Avium infection, wasting syndrome as well as urinary and neurological infections. Irregularities in the menstrual cycle, as well as loss of sexual drive, have also been reported.

Despite earlier diagnosis and antiviral therapy, women with AIDS still have a shorter survival time. A study conducted in San Francisco, reported that an average of 11 months passes from diagnosis to death in women AIDS patients, versus an average of 15 months for male patients.

Impact of pregnancy

The effects of pregnancy on the progression of HIV disease are better known.

In patients with no AIDS symptoms, pregnancy does not seem to have any negative consequences, except for a possible increased susceptibility to bacterial lung infections, which disappear a few months after delivery.

For women with HIV symptoms, consequences seem to vary greatly, depending on the T4 cell counts and plasma levels of p24 antigen, a viral protein. Women with HIV symptoms seem to give birth to a larger percentage of infected children.

Research on the manifestations of HIV disease on women remains limited. Especially needed is a preventive treatment plan against opportunistic infections geared toward women. In terms of new HIV infection, women are the fastest-growing group. But still very little is known about the natural history of HIV infection in female patients.

WOMEN AND HIV

Women's Treatment and Research Agenda

prepared by:

ACT UP

Work in progress

11/9/91

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Women's Treatment and Research Agenda

The U.S. government's negligence towards women in the AIDS crisis has prompted this attempt to create a Women's Treatment Agenda. For the past four years, AIDS activists in different countries have been raising issues about women's exclusion from research, treatment and educational programs engaged in by various government agencies. This past year the focus intensified. In May 1990, ACT UP and other AIDS activists "Stormed the NIH" to demand changes in the way drugs were being researched by the federal government. There were many affinity groups at that action, all with different foci, hoping to bring attention to the many levels of bureaucratic blundering, blatant discrimination and unnecessary deaths in the AIDS crisis. One affinity group took over the office of Dr. Daniel Hoth, Director of AIDS at NIAID. They demanded that the ACTG (AIDS Clinical Trials Group) form a Women's Committee. One month later Hoth was confronted by AIDS activists at the VI International Conference on AIDS where, again, the same message was repeated in the form of a banner reading "NIAID: FORM A WOMEN'S COMMITTEE NOW." Under continued pressure and with the threat of another sit-in, Dr. Hoth and Dr. Tony Fauci agreed to meet with women from ACT UP/NY and ACT UP/DC to discuss women's issues. At that meeting we were met with a great deal of professed ignorance about women's health and HIV as well as with sexist belligerence. We demanded that NIAID have a Women and HIV conference within 6 weeks. ACT UP initially participated in planning that conference and in submitting names of women with HIV and women working with HIV+ women in clinics and other settings on a day-to-day basis to be on the Steering Committee and to be presenters at that conference. ACT UP's representative on the Steering Committee formed to plan the conference, had to resign rather than have ACT UP's name attached to a process in which the government wrenched control of the conference from the planning group. In short, NIAID revised the initial structure and content for the conference. Meanwhile, meetings at the Centers for Disease Control (CDC) with Drs. Noble, Berkelman et al, revealed their intransigence towards changing the CDC definition to include women specific opportunistic infections, despite available research evidence. We heard no one solid scientific reason for their refusal. Their perspective was sexist and revealed the double standard pervasive in this pandemic.

The first draft of this document was handed out at the First National Conference on Women and HIV Infection (December 13-14, 1990) in Washington D.C.. However limited, we believe it provided more information than the government bureaucrats who were given the opportunity to address the 1500 participants during plenary sessions. Instead of hearing from women with HIV about their symptoms and issues or from practitioners seeing hundreds of HIV+ women daily in their clinics, we were subjected to an "AIDS 101" lecture from Dr. Fauci, a presentation on clinical treatments by Dr. Daniel Hoth who began by saying he had no information about possible clinical treatments for women since NIAID had not researched any, and a presentation by Dr. James Curan of the CDC in which he once again refused to admit any problems with the CDC AIDS surveillance definition, although it does not contain one single woman specific opportunistic infection.

Since the conference NIAID has formed a Women's Health Committee, but it remains to be seen what will be accomplished for women through that system.

In December 1990 we did another action at the CDC and have begun a campaign to obtain 1,000 endorsements for a call to change the CDC definition of AIDS. We have also continued to work on this agenda.

We still consider it a work in progress though it certainly presents far more directions for research, education and treatment than what has come out of government agencies in the past ten and a half years. This agenda is part of our commitment to pressure the U.S. government until there is a concerted effort to actually save the lives of women with HIV/AIDS.

ACT UP! FIGHT BACK! FIGHT AIDS!
The ACT UP Network Women's Issues Committee
May 1991

HIV/AIDS: An International Crisis For Women

The global AIDS crisis has had a devastating impact on women. While this research and treatment agenda focuses primarily on issues specific to the United States, we recognize the international dimensions of the AIDS pandemic and are committed to advocating for expanded resources and treatment options for women worldwide.

Globally, according to the most conservative estimates, eight to ten million adults are HIV positive. Three million, or one-third, are women. The fastest growing number of cases is among women. The World Health Organization predicts that by the year 2000 the number of HIV positive women will exceed the number of HIV positive men. Already in sub-Saharan Africa, HIV positive women outnumber HIV positive men.[2] In some countries of Central and East Africa, women and men have been affected by HIV/AIDS in roughly equal numbers since the beginning of the epidemic. **The number of women expected to be diagnosed with AIDS worldwide during the next two years will exceed the cumulative total of all the AIDS cases reported to the World Health Organization during the first decade of the pandemic.**[3]

The Myths

Unfortunately, the response of economically powerful Western nations to the international scope of the crisis has been deplorable. The United States has scapegoated Third World countries, particularly Haiti and the countries of central Africa, rather than providing adequate medical resources and financial assistance. By the mid 1980's, many Western scientists and researchers were claiming that the HIV virus originated in Africa. None of these claims have ever been scientifically substantiated. Fueled by racism and ignorance of local cultural practices, arguments promoting either the African or Haitian "origins" of AIDS were printed in widely read newsmagazines such as Newsweek, Time, and U.S. News & World Report. **In short, the presence of high rates of HIV infection in certain Third World nations was not treated as a vexing international health issue. Instead, affected cities and countries were blamed by the U.S. for 'spreading disease' through prostitution and sexual promiscuity.**[4] **Thus, women in these nations have been treated as vectors of disease rather than as individuals with legitimate health concerns.**

The Facts

In fact, the rapid spread of HIV/AIDS in many of the poorer nations of the world can be directly linked to lack of access to basic healthcare, culturally relevant educational information, and sterile medical supplies. All of which can, in turn, be linked to the extraction and exploitation of local resources by politically powerful Western nations. The deteriorating economic situation in many Third World countries has adversely affected the health status of entire populations. The high prevalence of HIV/AIDS in many nations is only one life-threatening epidemic among many others such as malaria, malnutrition, and dehydration. All of these life-threatening conditions disproportionately impact women and their children.

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[1] "WHO Notes & News," World Health Forum, Volume 11, 1990, p. 341.

[2] The Futurist, November-December, 1990.

[3] Netter, Thomas. "World AIDS Day 1990," World Health, November-December, 1990.

[4] Sabatier, Renee. Blaming Others: Prejudice, Race, and Worldwide AIDS. Panos, 1988.

In every known society worldwide, women are the primary caregivers to children and the elderly. Women with HIV/AIDS typically tend to the needs of partners, children, and dependent elderly family members before addressing their own healthcare needs. As the epidemic continues, more and more women in every country will find themselves caring for sick children and partners and neglecting their own needs. The burden of care-giving must be more effectively shared throughout families and communities in order to allow women with HIV/AIDS the time, energy, and resources to care for themselves.

International Scope of HIV/AIDS Crisis

The impact of AIDS varies tremendously from one country to the next. It would be impossible in this short piece to document the impact of the pandemic in every country in the world.

Because there has been so much mythology and misinformation about African AIDS promoted by the mainstream media in the United States, it is necessary to present a more accurate account of the pandemic on the African continent.

In Nigeria, for example, there have been relatively few cases thus far. More recently, however, testing in urban areas suggests that approximately 4% of urban dwellers in Nigeria may be HIV positive.

In Uganda, on the other hand, approximately 23% of the population has tested positive for the human immunodeficiency virus (HIV).[5] Some villages in Uganda are comprised of only small children and the elderly; the vast majority of people between the ages of 20 and 50 have died of AIDS. There are 200,000 orphans in Uganda, and the number is rapidly growing.

The hardest hit African countries thusfar have been, in descending order, Uganda, Kenya, Malawi, Congo, Ivory Coast, Zaire, Burundi, Rwanda, Zimbabwe, and Zambia.[6]

The following countries on the African continent have reported a case rate of less than one case per one hundred thousand residents: Algeria, Angola, Cameroon, Cape Verde, Central African Republic, Comors, Equatorial Guinea, Ethiopia, Guinea, Lesotho, Liberia, Madagascar, Mauritania, Mauritius, Mozambique, Niger, Nigeria, Sao Tome & Principe, Seychelles, Sierra Leone, South Africa, Swaziland, and Togo.

Every region and every continent has reported AIDS cases to the World Health Organization. Less than 15 countries worldwide have reported zero cases of HIV/AIDS thusfar. Countries reporting high case rates in Latin America and the Caribbean include: Bahamas, Barbados, Bermuda, Brazil, Dominican Republic, Haiti, Mexico, and Trinidad & Tobago. In Southeast Asia, India and Thailand are experiencing small but growing caseloads which should be of concern to the international AIDS community. In Europe, Romania, the United Kingdom, Italy, the Netherlands, Spain, and Switzerland are coping with relatively large and growing caseloads.

There is some evidence to suggest that many countries are underreporting AIDS cases. The CDC in the U.S. admits to a 40% undercount. Underreporting can be the combined result of three factors. First, there may be a reluctance on the part of government officials to acknowledge the growing epidemic. Second, many countries still have neither adequate resources to provide accurate testing nor health professionals trained to diagnose and treat people with HIV/AIDS. Finally, because of the

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[5] "Louis Sullivan's Health Mission to Africa," Focus, Volume 19, #3, March 1991.

[6] All Statistics in this section have been drawn from the World Health Organization's Global AIDS Statistics as reported in AIDSCARE, Vol. 2, #4, 1990. They can be taken, at this date, as a rough approximation of the international statistics.

stigma of AIDS internationally, many people are naturally reluctant to be tested. This is particularly true for women.

Treatment And Research Issues

Currently, there are approximately 600 AIDS-related studies under way in Africa. Over half of them are being directed by researchers from outside the continent.[7] The reality is that the vast majority of Africans will not benefit from most Western medical advances for two primary reasons. First, there is no profit in the African market for Western drug companies (and these companies are not known for their generosity to the poor). Secondly, many drug treatments and trials are designed to address opportunistic infections and HIV-related conditions more common in the industrial world.[8]

It is no secret that the clinical manifestations of HIV/AIDS in women and people of color have been inadequately addressed in the Western industrialized nations. Therefore, many of the research models being implemented by Western researchers in Africa reflect the same narrow understanding of the parameters of HIV infection that has plagued research in the West.

Unfortunately, there has been very little debate concerning the ethics of research in Africa. Many Western researchers see certain countries in Africa and other parts of the Third World, with their large AIDS caseloads and high rates of transmission, as ideal "laboratory settings" for biomedical research. A draft report of the World Health Organization indicates that many AIDS-related research activities "have been directed solely by the sponsoring country, with little or no input from local investigators."[9] In fact, only about half the AIDS-related studies now being undertaken in Africa were ever known to national AIDS officials when they were begun! Moreover, local investigators are often exploited by Western researchers who use them to gain access to a population group and then never make the research results available to the host investigator.

Regardless of societal and cultural differences, no researcher should ever be excused from the ethical obligation to provide clear, accurate, and culturally relevant informed consent. However, some U.S. researchers have argued that "it makes no cultural sense to have somebody give informed consent the way we often go about informed consent." Warren Johnson, a tropical disease researcher at Cornell Medical Center claims "it's a little naive for us to expect the same procedures we utilize in Manhattan in an urban, educated population to be meaningful and relevant to a rural, largely illiterate population...it's not very meaningful to have a thousand sheets of paper with an 'X' on them."[10] This type of view speaks volumes as to the dangers of Western researchers conducting HIV/AIDS research in Third World countries.

Unfortunately, few researchers have educated themselves regarding the cultural values, customs, and languages of the populations from which they are drawing their research subjects. Too many Western researchers have naively "confused illiteracy with lack of intelligence and even education. You can always translate technical terms to levels that people will understand and encourage potential subjects to make an informed choice."[11]

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[7] Palca, Joseph. "African AIDS: Whose Research Rules?" News & Comment. Oct. 12, 1990, p. 199.

[8] Patton, Cindy. Inventing AIDS. p. 85.

[9] Palca, p. 199.

[10] Palca, p. 201.

[11] Peter Lamptey, Director of Family Health International, as quoted in Joseph Palca's "African AIDS: Whose Research Rules." p. 201.

Finally, there is the issue of compensation for participation in research studies. In one study of maternal HIV infection they offered a photograph of a child to women who participated in their study, and in another it was a bottle of milk.[12] The rationale used to justify this exploitation of women and their communities is that "cash compensation would prove too tempting."[13] More needs to be done to insure that women are adequately compensated for their participation in trials which, after all, are more likely to benefit the researchers than the actual trial participants in the long run.

The growing international research interest in Africa finally prompted the World Health Organization and the U.S. Public Health Service to convene a group of researchers and health officials to discuss the ethical issues. This process began in Annapolis, Maryland in 1990. The idea behind the discussion was to take a "first step" towards drafting rules that will apply to all PHS-funded research in Africa and other regions in the Third World.[14]

These discussions, not surprisingly, have failed to be inclusive of Third World researchers, health officials, and people living with HIV/AIDS. As activists we must demand that any agenda setting of ethical guidelines for Western research in the Third World be open to the participation of researchers, social workers, and people with HIV/AIDS from the countries in question.

Activist Agenda: United States

There are many actions those of us in the U.S. can take to support and advance the efforts of women with HIV/AIDS in the Third World.

o Interrogate the research of North American scientists who rely primarily on African women, men and children as research subjects. What measures are they taking to insure the safety and well-being of the populations being researched? Are they working collectively with local doctors and social workers? What cultural assumptions are they making about their research population?

o We often confront researchers here in the U.S. with ethical concerns about HIV/AIDS trials designed for U.S. based populations of women. When doing so, we must make it clear that our ethical concerns are internationally focused--they extend to all women with HIV/AIDS. Let them know that our objections should never be construed as an invitation to pack up their trial and "export" it to another country.

o Demand that local researchers and people with HIV/AIDS be involved in every stage of U.S. sponsored research projects in Third World countries, from concept through design and implementation.

o Researchers, government officials, and drug companies must guarantee that any beneficial treatments resulting from U.S. sponsored trials in the Third World be made available and realistically affordable to ALL people with HIV/AIDS regardless of gender, race, or country of residence. Demand worldwide access to treatment for women with HIV/AIDS!

o Demand that the U.S. Congress increase the amount of humanitarian aid provided to countries with high infection rates. Demand a shift from military aid to humanitarian aid.

o Vigorously challenge any individual who claims that AIDS originated on the African continent or in

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[12] Palca, p. 201.

[13] Palca, p. 201.

[14] Palca, p. 199.

Haiti. Demand that they present scientific and sociological evidence to support their misinformed claim.

o Demand that the United Nations/World Health Organization convene and fully fund an international conference on women and HIV/AIDS. Demand that conference participation accurately represent the demographics of the global pandemic. The majority of women attending such a conference should be women with HIV/AIDS from countries where women are disproportionately impacted. Other participants should include activists, educators, and healthcare providers from around the world whose work is focused on women.

Women and HIV/AIDS in the United States:
Introduction and Overview

It is estimated that over 1 million[15] people in the United States are infected with HIV[16] and that at least 100,000 of these persons are women. Because of the long incubation period of the disease, the number of CDC defined AIDS cases is expected to rise dramatically over the next few years[17]. From 1980 through 1990, there have been 100,000 AIDS deaths in the United States. In 1 991 alone, there will be over 50,000 AIDS deaths in the US. In New York City and other major US cities, AIDS is the leading cause of death for women ages 15-44. Nationwide, AIDS is among the top five leading causes of death in women of "childbearing" age.

Epidemiologists have been charting the demographic shift of the pandemic toward women, Hispanics and blacks for several years. Women are among the fastest growing groups of newly infected persons with HIV. There has been a 31% increase in the number of new AIDS cases in women in 1990, versus a 22% increase in AIDS cases among men.[18]

Women are the most misdiagnosed, underdiagnosed, and underserved population in the AIDS pandemic. Statistics on life expectancy evidences the shortcomings of the health care delivery system in respect to women, especially minority women, who are most effected by AIDS. The life expectancy for men, from day of diagnosis, currently ranges from between 24 to 36 months. Life expectancy for women from day of diagnosis averages between 15 weeks and 6 months. The average life expectancy for a black woman in New York City, is approximately 15 days. In San Francisco, survival time for women after diagnosis is less than 8 weeks[19].

The reasons for the vast discrepancy in survival statistics are varied. Issues of access to proper medical care, treatment, information on early diagnosis and intervention, insufficient funding for women and the programs that assist women with HIV disease, the Department of Health and Human Services' criteria for disability insurance and the Center for Disease Control's classification system, are some co-factors for low survival rates for women with AIDS. Access to health care, treatment, and education for women is a broad social problem that is not limited to the AIDS pandemic. When these problems meet the AIDS pandemic however, the result is fatal.

Recent seroprevalance data from New York indicate that in younger age groups (13-19; 20-24) an

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[15] All of these figures come from the Centers for Disease Control (CDC) and other government agencies which admit at least a 40% undercount. We believe the undercounting of women is even greater since neither the CDC surveillance definition of AIDS nor their classification system include a single woman specific opportunistic infection.

[16] It is estimated that one million people in the U.S. are infected with HIV. There may be along prodromal period before the development of symptomatic AIDS, and fulminant AIDS may develop in 30% or more of infected persons within a 3-5 year period. Even if the spread of infection slows, the number of AIDS cases will continue to increase, unless effective early intervention strategies are developed.

[17] Broder, Samuel. "Pharmacodynamics of 2',3'-Dideoxycytidine: An Inhibitor of Human Immunodeficiency Virus," The American Journal of Medicine. Vol. 88, Suppl 5B, 1990.

[18] HIV/AIDS Surveillance Report: August 1990.

[19] Current results of the Project AWARE natural history study being conducted at San Francisco General Hospital, Judith Cohen, PhD

equal or higher percentage of women, compared to heterosexual men, are seropositive[20]. And, for reported AIDS cases, the second highest percentage of cases of women within an age group are women 65 years of age and older -23% of the cases at this age are reported among women[21]. Of the women diagnosed with AIDS, 52% are black, 27% are white, 20% are Latina, and Asians and Native Americans comprise a little less than 1%, though their numbers are increasing dramatically. Currently, the majority of women with HIV illness are low-income and rely on Medicaid and public health care facilities for their primary health care needs. The AIDS pandemic has exposed the serious failures of the public health care system in meeting the needs of women.

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[20] New York City Department of Health, Division of AIDS Program Services, HIV Serosurvey Unit. AIDS and HIV Infection in New York City--Men and Women. Vol. 1, #3, 1990.

[21] CDC, DOH, HIV/AIDS Surveillance. U.S. AIDS Cases Reported through Nov., 1990.

AIDS is a Crisis for Women. What is the U.S. Government's Response?

Education

The government has cut $30,000,000 out of the AIDS budget which would have gone for education and prevention specifically for women and children with HIV. Women are among the fastest growing groups of newly infected persons with HIV and therefore are among the most needy in terms of materials for education and prevention. It is not merely government inaction which is responsible for the spread of AIDS, the government it would seem is actually taking steps to insure the spread of AIDS among women by cutting back on preventative and educational services.

Classification/Surveillance

The Center for Disease Control's (CDC) classification of AIDS does not recognize HIV-related opportunistic infections which are specific to women. Pelvic Inflammatory Disease (PID), chronic vaginal candidiasis, chlamydia and Human Papillomavirus (HPV) are a few of the manifestations of HIV which are specific to women. Because the CDC does not recognize women specific opportunistic infections, women are not accurately represented in national statistics on AIDS. If a woman dies of PID or HPV, even though she is HIV positive, her death is not registered as an AIDS death.

The CDC is a government agency and other government agencies, such as the AIDS Clinical Trial Group (ACTG) and the Social Security Administration, use the CDC's information to form policies and set agendas for research. The CDC is not making responsible decisions in terms of women with HIV infection and their bias in policy making is responsible for the deaths of hundreds of women with HIV. In a study of the death certificates of women for whom HIV/AIDS was listed anywhere, recently conducted by the CDC, it was found that 48% of women died of conditions not listed in the CDC definition for AIDS[22]. This clearly illustrates that the CDC is not accurately representing how HIV is impacting women. Other institutions which in turn base decision making on the information provided by the CDC are excluding women's interest in their policy-making process.

Furthermore, the CDC must make an all out effort to conduct responsible studies which establish the natural history of HIV in women. Physicians who treat women must be provided with materials which outline early symptoms and strategies for care. Physicians, especially in rural areas, rely on CDC guidelines for diagnostic information. Researchers set priorities based on natural history studies. Effective treatment for women with AIDS cannot be fully established until the CDC acknowledges and reports on how women are being affected by HIV.

Research

It comes as no surprise that opportunistic infections and indicator diseases related to HIV will be and are different in women. Possibly, the power of this document lies in its departure from continuously establishing that gynecological infections, for example, or metabolic consumption of pharmaceuticals are different in women. In this document, we attempt to begin to suggest a treatment agenda that gives direction to research, both in terms of drugs/treatments and basic science for women with HIV infection.

Very little research has been done on women with HIV infection. Women are both technically and functionally excluded from AIDS clinical research. Because there are very few FDA approved

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[22] Chu, S et al. "Impact of the Human Immunodeficiency Virus Epidemic on Mortality in Women of Reproductive Age, United States," JAMA, July 11, 1990, 254(4):225-229.

drugs/therapies to treat AIDS and its associated opportunistic infections, clinical trials are for many the only mechanism for access to therapeutics.

Many AIDS Clinical Trial Group (ACTG) trials require a CDC defined AIDS diagnosis as entry criteria. As women are not represented in the CDC's definition, they are barred entry into these trials. Most clinical trial participants find out about trials through primary care physicians. The majority of women affected by the AIDS pandemic are low-income and depend on public health facilities for their primary health care needs and often are not provided with information on how to gain access to experimental therapeutics. While the institution of parallel track programs are commendable, because of the vast amount of paper work required for these protocols, public health physicians are reluctant to enroll patients. The ACTG has been negligent in the recruitment of women into trials.

Women are often excluded from clinical trials because of their "child-bearing potential". Almost all ACTG trials require women to be on some type of contraceptive rather than having trial arms for pregnant women. Those with a contraceptive requirement do not offer specific criteria for acceptable forms of birth control, some of which could be dangerous for women with HIV (for example pills or IUDs). Researchers interpret the requirement as stringently as they see fit. Adequate birth control for some researchers may be word of mouth confirmation, others require measures as drastic as sterilization. Women's "reproductive potential" should not be held as trade for access to possible life-saving therapies. This is immoral.

There are no women specific questions in protocol guidelines for case reports. Women experience many gynecological manifestations of HIV, yet pap smears and pelvic examinations are not part of standard research protocols. Routine pap smears and pelvic exams as a standard of practice in clinical research could provide a mechanism for gathering data on the progression of HIV in women. Women specific case questions would also provide a mechanism for more thorough and accurate drug evaluation. What effect, for instance, does ddI have on menstruation, pregnancy, or the development of cervical cancer? A drug's toxicity is not adequately established until these questions are answered. Toxicity is supposedly established in phase I clinical trials and therefore women must be included from day one of phase one testing of drugs to treat life-threatening illnesses.

The scope of AIDS in women is unknown because accurate means of tracking the pandemic in women do not exist. Statistics are showing a rapid rise of AIDS cases in women, despite poor diagnostic measures. Transmission risks and education are severely under-researched. Virtually nothing is known about woman to woman transmission of the virus, although there are increasing numbers of documented cases. Risk assessment procedures do not address or represent the real world of the AIDS pandemic.

The government has not responded to the AIDS crisis in women, therefore we, women with AIDS, their lovers and advocates are. In this document we will outline a strategy for a treatment and research agenda for women with HIV. We will address the following:

- **Description of Clinical Manifestations**
- **Standard of Care Recommendations**
- **Critique of Research**
- **Transmission**
- **Centers for Disease Control's (CDC's) Policy**
- **Additional References**

Description of Some Clinical Manifestations of HIV in Women*

- o Pelvic Inflammatory Disease
- o Bacterial Pneumonias
- o Menstrual Irregularities
- o Vaginal Candidiasis
- o Tuberculosis
- o Sexually Transmitted Diseases

* This section is still in progress. It is not inclusive of all clinical manifestations of HIV disease in women.

Pelvic Inflammatory Disease

Pelvic Inflammatory Disease or PID is probably the most under-researched and life-threatening gynecological complication of HIV infection. Little is known about the pathogen most commonly causing this infection in HIV positive women. In fact, most of the scant AIDS literature published on PID still remains in the realm of epidemiology. Nonetheless, infectious disease specialists and gynecologists seeing women with HIV infection anecdotally report an alarming rate of PID that is resistant to traditional treatment resulting in tubo-ovarian abscesses and radical hysterectomy.

On October 10th, Phillip J. Illits' article, "Growing Concern Over Pelvic Infection in Women" was published in the New York Times. According to the article, PID "must be counted as the most important sexually transmitted disease affecting women, excepting only AIDS." Probably it is unnecessary to sever the tie between the two seemingly separate illnesses. And the rates of PID have alarmingly sky-rocketed in the past twenty years, especially among young women. If we look at the increase in the number of cases of ectopic pregnancies (half of which are caused by PID) we see something more than a ripple effect. In 1970 there were 18,000 tubal pregnancies. Alarmingly, 16 years later, the new number of cases hovers at 84,000. Dr. Patricia Kloser, director of the AIDS Program at the University of Medicine and Dentistry of New Jersey, reports that "seven percent (of her patients) have PID that is often so severe it is more likely to require hospitalization than some AIDS-defined infections."[23]

Although much anecdotal information abounds, and epidemiologically few studies have been completed, Dr. Howard Minkoff at SUNY Downstate Medical Center in Brooklyn suggests that further investigation of PID and HIV is needed[24]. In New York City-in 1989-1990-there were two reported deaths due to PID. A single death from this disease was reported to the New York City Department of Health in the ten years prior. Could these women have died from a refractory PID complicated by HIV-infection?

Unfortunately, PID diagnosis is difficult. According to Illits' article, "It takes place in a part of the body that is inaccessible to doctors." Furthermore, while PID diagnosis can be made by examining the abdomen with a surgically inserted instrument called a laparoscope, Mary Beth Caschella writes that, "HIV-infected women may be unable to mount an immune response, causing the inflammation and pain by which professionals are able to make a diagnosis."[25] This means that traditional modes of PID diagnosis must be re-evaluated for women with HIV-infection, as is the case with cervical neoplasia and HIV.

Some clinicians have suggested that PID can present itself as a form of disseminated tuberculosis. This comes as no surprise. According to Dr. Kloser, chlamydia and gonorrhea, common cause pathogens in PID, are easily treatable in the HIV infected woman[26]. Thus, the cause of PID infection is quite possibly not related to GC or Chlamydia. If there were that relationship, presumably more traditional modes of treatment for PID would be effective in the HIV-infected

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[23] Ms. July 1988, p. 67.

[24] Hoegsberg et al. "Sexually Transmitted Diseases and Human Immunodeficiency Virus Infection Among Women with Pelvic Inflammatory Disease," American Journal Obstetrics and Gynecology, 1990; 163:1135-9, vol4, part 1.

[25] Treatment Issues, Vol. 5 no. 1, p.5.

[26] Based on a conversation in April 1990, at UMDNJ and her oral report at the Women and HIV Conference (Dec. 1990).

woman, but they are not. Lab analysis of pathogens responsible for PID is crucial if we are to begin to research treatment modalities for HIV-infected women. Also, to unravel the mystery as to why so many HIV-infected women regularly experience amenorrhea we might look to PID and its resultant tubo-ovarian abscess as a cause.

There are many unanswered questions about the relationship between HIV and PID. In the immediate future, certain pieces of information must be ascertained if treatments for HIV-complicated PID are to be further researched. What follows is a list of recommendations for research in this area:

- Determine the pathogens responsible for refractory PID.
  It comes as no surprise that HIV-related PID appears to be untreatable if the assumed pathogen is, for example, C. trichomatous, when in fact it is Tuberculosis.

- Develop new methods for diagnosis. Make laparoscopy more readily available.

- When PID is suspected in the HIV-infected client, immediate referrals for accurate diagnosis and possible hospitalization should be made.

Bacterial Pneumonias

Primary respiratory illnesses account for the largest proportion of life-threatening opportunistic infections occurring in people with HIV disease, AIDS and AIDS-Related Complex (ARC)[27]. Pneumocystis Carinii Pneumonia (PCP) is still the leading cause of death in people with Acquired Immune Deficiency Syndrome (AIDS), despite the availability of prophylaxis such as aerosolized pentamidine, Bactrim and Dapsone. Moreover, PCP is the most common AIDS defining opportunistic infection reported to the CDC. Currently, reported incidences of PCP presenting as an initial AIDS defining opportunistic infection are higher for women than men[28]. Similarly, of the major AIDS defining opportunistic infections, women present more frequently with Mycobacterium avium-intracellulare (MAI) than do men[29]. The respiratory tract is the most common portal of entry, though entry through the gastrointestinal tract may occur[30]. Virtually no research has been done to examine why women present more frequently with PCP and MAI. Clearly there is a lack of research on the affects of therapeutic agents for these opportunistic infections in relation to women's physiologies. That women with HIV infection present more frequently with PCP and MAI begs the question: Do women have a greater susceptibility to pulmonary incidence of HIV related complications than do men?

In the last ten years in the U.S. there has been an increase in the death rate of women from bacterial pneumonias[31]. Whether these women presented with HIV infection is unknown. Clearly it is possible as HIV infected persons are more susceptible to bacterial pneumonia and other non-pneumocystis carinii pneumonias, including fungal pneumonias, than the general population[32]. Additionally, in a CDC study of the death certificates of women who had HIV/AIDS listed anywhere, pneumonias other than PCP were listed as the cause of death for 14% of the cases[33]. It is estimated that 10-20% of pneumonias manifesting in people with HIV are community-acquired bacterial pneumonias, Hemophilus influenzae, Streptococcus pneumoniae and Branhamella catarrhalis being among the most common. When examining the non-AIDS fatal outcomes of HIV infection in women, bacterial pneumonias warrant much further study.

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[27] Hadley WK, NG I, "Organization of Microbiology Laboratory Services for the Diagnosis of Pulmonary Infection in Patients with Human Immunodeficiency Virus Infection," Seminars in Respiratory Infections, Vol 4, N2(June), 1989; 85-92.

[28] C Wofsy; data from a study at San Francisco General; presented at the National Conference on Women and HIV Infection, Washington DC, Dec. 13-14, 1990.

[29] G Friedlander; data from a 1987 study presented at the National Conference on Women and HIV Infection, Washington, DC, Dec. 13-14, 1990.

[30] Hadley, pp 85-92.

[31] "Women's Unexplained Deaths Cited," Newsday, 14 June 1988.

[32] Polsky B, et al, "Bacterial Pneumonias in Patients with Acquired Immunodeficiency Syndrome," Annals of Internal Medicine, 1986; 104:38-41.

[33] Chu SY. et al, "Impact of the Human Immunodeficiency Virus Epidemic on Mortality in Women of Reproductive Age, United States.

Pathophysiology

The true scope of bacterial pneumonias presenting in people with HIV infection has not been adequately researched. It is clear, however, that pyogenic bacteria are the cause of a substantial number of respiratory infections in patients infected with HIV. This is not as surprising as HIV infects macrophages, B Lymphocytes and alters B lymphocyte function- -increasing a patients risk for bacterial infection[34]. Incidences of H. Influenzae, S. Pneumoniae and Branhamella catarrhalis seem to be associated with underlying B-cell defects described in people with AIDS[35]. Incidences of serious pneumococcal infection are inversely relational to CD4 counts and in persons with HIV there is a high rate of recurrence, evidencing the need for ongoing therapy after initial presentation. Neutropenia seems to be related to increased susceptibility to bacterial infection. Neutropenia is not, at present, considered to be a symptom of HIV disease but has been seen directly associated with drugs used for the treatment of HIV infection such as ZDV, gancyclovir, and pentamidine. Absolute neutropenia is associated with bacterial infections in patients with HIV disease[36].

Epidemiology

Bacterial infections have been recognized as a cause of pulmonary disease in AIDS patients since early in the pandemic. Health workers have been reporting increases in the rates of community-acquired pneumonias in patients with HIV disease, AIDS and ARC[37]. Similarly the incidence of nosocomial or hospital-related pneumonias are increasing in patients with HIV disease. In some sites, Methicillin-resistant Staphylococcus aureus (MRSA) is presenting in epidemic proportions. MRSA strains often spread quickly among the most seriously ill, antibiotic-treated patients[38]. MRSA strains are, of course, very serious as they are resistant to most therapies. Injection drug users (IDUs) are at increased risk for bacterial pneumonias[39] This is extremely important to acknowledge when giving women information on treatment options as over 50% of women with reported AIDS are reported with injection drug use as a risk factor[40].

Clinical Features

Signs and symptoms of bacterial pneumonias in seropositive individuals are similar to the typical clinical finding of community-acquired pneumonias in non-HIV infected patients, though infections are often more severe and occur more frequently. Fever, a productive cough, dyspnea, chest pain, and focal consolidation are typical manifestations. HIV seropositive adults usually present with encapsulated H. Influenzae. Typically, though not always, patients presenting with bacterial

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[34] Polsky B, et al, "Bacterial Pneumonias in Patients with Acquired Immunodeficiency Syndrome".

[35] Chaisson RE, "Bacterial Pneumonia in Patients with Human Immunodeficiency Virus Infection," Seminars in Respiratory Infections, Vol 4, No 2 (June). 1989; pp133-138.

[36] Ibid.

[37] Ibid.

[38] [Letter], "Methicillin-Resistant Staphylococcus aureus: Do We Just Have to Live with It?," Annals of Internal Medicine, Vol 114, #2, 15 January 1991; p 162.

[39] Des Jariais DC, Friedman SR, Stoneburner RL, "HIV Infection and Intravenous Drug Use: Critical Issues in Transmission Dynamics, Infection Outcomes, and Prevention," Reviews of Infectious Diseases, Vol 10, Mo 1, Jan-Feb 1988: 151-164.

[40] HIV/AIDS Surveillance Report, 1991. U.S. Centers for Disease Control January 1991.

pneumonias have a higher white blood count (WBC) than baseline WBCs for patients presenting with PCP. The majority of patients with respiratory illness will have abnormal chest radiographs.

Diagnosis

Chest Radiograph. The chest radiograph (chest x-ray) is considered the best initial screening tests. HIV+ patients with bacterial pneumonias most often have focal infiltrates characteristic of community-acquired organisms. Many patients have single segmental or patchy lobar infiltrates. Acute diffuse infiltrates are reported common in patients with H. Influenzae. Dense lobar consolidation is seen frequently in patients with S. Pneumoniae[41].

Gram-Stain. Patients with abnormal radiographs should have sputum collected for gram-stain and culture. The presence of polymorphonuclear leukocytes (PMN) is not common in patients with PCP or mycobacterial pneumonias and is commonly seen with bacterial pneumonia. A predominance of gram-positive diplococci or pleomorphic gram-negative coccobacilli may be seen with pneumococcal and H. Influenzae pneumonias, respectively. Cultures of sputum and blood offer more definitive diagnosis of a bacterial infection. Bacteria causing pneumonias in patients with HIV infection are, gram-positive: Streptococcus pneumoniae, Group B Streptococci, Staphylococcus aureus and gram-negative: Hemophilus influenzae, Hemophilus sp, Branhamella catarrhalis, enterobacteriaceae and, less frequently, Legionella pneumophilia[42]. Gram-stain is **not** conclusive in determining PCP infection.

Open Lung Biopsy is not recommended as part of routine evaluation. Though it may be the most complete diagnostic technique, it is very painful and costly. Other diagnostic methods, such as bronchoscopic procedures should precede open lung biopsy[43]. If sputum does not provide a diagnosis, **bronchoscopy** has been highly successful in detecting pathogens. **Needle aspiration** should be used as a last resort as pneumothorax can easily occur. Less invasive techniques should be employed first.

Therapy and Response

Because of the large number of potential pathogens, an aggressive diagnostic approach to establish etiologic diagnosis and to help direct therapy is warranted[44]. Antibiotic therapy should be carefully monitored because of possible kidney and hearing problems resulting from toxicities. Women beginning antibiotic regimens should be made aware of possible side effects. If a yeast infection appears or worsens, it could be indicative of overly high dosages. Antibiotic therapy, if managed properly, does not cause yeast infections. Antifungal regimens to prophylax against yeast infections could only further disrupt the bodies natural flora.

Empirical treatment of patients with strong clinical indications of bacterial pneumonias with cefuroxime or ampicillin may be warranted. H. Influenzae seems to be highly responsive to

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[41] Polsky B, et al, "Bacterial Pneumonias in Patients with Acquired Immunodeficiency Syndrome."

[42] Chaisson RE, "Bacterial Pneumonia in Patients with Human Immunodeficiency Virus Infection."

[43] Luce JM, Clement MJ, "Pulmonary Diagnostic Evaluation in Patients Suspected of Having an HIV-Related Disease," Seminars in Respiratory Infections, Vol 4, No 2(June), 1989:pp93-101.

[44] Polsky B, et al, "Bacterial Pneumonias in Patients with Acquired Immunodeficiency Syndrome."

ampicillin. In areas where beta-lactamase-producing H. Influenzae is high, amoxacillin-clavulanic acid should be used instead of penicillin. Penicillin resistant stains of Hemophilus are not uncommon. Antimicrobial treatments should be employed to see what the bacteria is sensitive to. Injection drug users who may have bacterial endocarditis or pneumonia should be treated with an anti-staphylococcal agent such as nafcillin, as well. Specific therapy for bacterial pneumonias should be tailored to the in vitro susceptibility of the organism. Resistant strains of H. Influenzae have been detected in western Europe, indicating the necessity for geographical monitoring for resistant strains.

Response is prompt in patients with HIV infection. Improvement of symptoms and clearing of infiltrates usually occur in several days in adult patients. Patients with gram negative pneumonias other than H. Influenzae, the most common bacterial pneumonia presenting in people with HIV infection, have a poor prognosis of short term survival time. Patients with HIV-related bacterial infections have a 25-50% rate of recurrence. Continued antibiotic therapy is recommended.

Prevention

Because of the high incidence of bacterial pneumonias, bacteremia and recurrence of HIV-related pulmonary complications, prophylaxis and prevention methods should be utilized. Both prophylactic antibiotics and immunotherapy are proving to be useful in controlling and preventing bacterial complications.

Trimethoprim-sulfamethoxazole (TMP-SMX) has been used for prophylaxis against encapsulated bacteria and is advantageous as a PCP prophylaxis as well. It is not recommended, however, because of the increasing incidences of adverse reactions in people with AIDS to sulfa drugs. Adding ampicillin to pentamidine may be effective in prophylaxing against both PCP and bacterial infections. Bactrim may be useful in prophylaxing against bacterial lung infections as well. Immunotherapy such as PATH or HIVIG, to prevent bacterial pneumonias has been recommended in some settings. The efficacy of vaccines in patients with HIV infection is doubtful as protective antibody responses do not typically occur[45].

Preventative therapies should be examined and considered in light of the context of each woman's life. Women should be informed of their risk for bacterial infection and their treatment options and then be let to make an informed choice on the specific course of prophylaxis. For instance, a woman who is an injection drug user should be informed that HIV seropositive IVUs experience a seven-fold increase in the rate of bacterial complications compared to seronegative IVUs, community-acquired bacterial pneumonias and hospital-acquired pneumonias should be adequately addressed and treatment options and risks should be outlined.[46]

The following is a list of guidelines for research:

o As women seem to be disproportionately affected by PCP than are men, women need to be actively recruited into BW566 trials. While PCP is presumably caused by a protozoan, it is

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[45] Ibid.

[46] Other resources include
Witt DJ, Craven DE, McCabe W, "Bacterial Infections in Adult patients with Acquired Immune Deficiency Syndrome and AIDS-Related Complex," The American Journal of Medicine, Vol 82, May 1987; pp990-906.
ed Devita VT, et al., AIDS Etiology Diagnosis, Treatment and Prevention, second edition. J.B. Lippincott Company, NY, 1988.

essential to address PCP when considering pulmonary incidences of HIV infection in women.

- o Abbott Laboratories must immediately establish a compassionate use protocol for Clarithromycin for the prophylaxis of MAI. Women, who are disproportionately affected by MAI, should be actively recruited into existing trials.
- o Trials must be conducted to examine the efficacy and toxicity of Clarithromycin in combination with drug detox therapies such as Methadone, a similar approach must be employed with BW566. Additionally, arms of these trials must be designed to examine the efficacy and toxicity of these pharmaceuticals in combination with street drugs. This information is essential towards obtaining a clear profile of these therapies in the real world of the AIDS pandemic.
- o Gender relational research must be done to examine the susceptibility of pulmonary incidences in people with HIV infection.
- o Research must be conducted to determine gender relational responses to current therapies for bacterial pneumonias.
- o Clinical trials of pneumococcal and other vaccines in patients with HIV infection must begin immediately. **Women specific questions must appear on all case reports for all trials** and pap smears, colposcopy and cervical examines must be conducted routinely. Women should be actively recruited into these trials. All trials should be located in centers that serve large numbers of women and child care must be provided during visits.

Menstrual Irregularities

MEDLINE searches reveal that the handful of studies which mention women with HIV do not address women's reproductive health--specifically menstrual irregularities. As this Treatment Agenda describes in other sections, the few medical reports which do exist largely treat women in terms of their capacity to transmit HIV to men and children.

The lack of attention to women's health results in many unanswered questions. How does HIV affect women's menstrual cycles? How do HIV and drug treatments like AZT and ddI affect levels of progesterone and estrogen? When HIV infected women suffer from secondary amenorrhea (cessation of menstrual periods) or dysmenorrhea (difficulty with menstrual periods) what are the causative factor(s)? The lack of gynecological care at clinical trials means that it is unknown which, if any, sexually transmitted diseases (STD's) or gynecological infections are present.

Women's complaints about amenorrhea or dysmenorrhea are generally not recorded in medical records of HIV clinical trials. Because of this and because women are not usually asked about menstrual difficulties, it is difficult to draw conclusions. It is also impossible to conduct retrospective studies.

Dysmenorrhea

HIV infected women frequently complain about painful periods and bleeding which lasts for weeks, as well as a lack of bleeding.

Women suffering from all chronic fatigue syndromes report an increase in pre-menstrual syndrome (PMS) problems (breast tenderness, bloating, more cramps, longer periods, mood changes). It is also known that sub-acute, chronic Pelvic Inflammatory Disease (PID) and bacterial infections can cause longer periods, which are exacerbated for immunocompromised women.

Some HIV infected women report that it is common knowledge among themselves that AZT is connected to worsening cramps, painful blood clotting, and menstrual periods which last 10 to 15 days. Many women take themselves off AZT because of dysmenorrhea. Women on ddI and in other experimental trials often report common knowledge about similar menstrual problems.

During which part of the menstrual cycle is the extended bleeding taking place? Is it related to ovulation bleeding?

Do AZT or other drugs increase estrogen? Do they increase progesterone (which causes glands in the endometrium to secrete nourishing substances and which increases uterine blood supply)? Would these cause longer and heavier periods? Or are the arteries and veins in the uterus pinched off too slowly? later than they should be?

Dysmenorrhea researcher Katherina Dalton theorizes that one type of dysmenorrhea (spasmodic) results from too much progesterone in relation to estrogen, and the other (congestive) as well as PMS result from too much estrogen for the amount of progesterone--from a progesterone deficiency.

Amenorrhea

Amenorrhea is associated with stress, weight loss, and street drugs, particularly heroin. How does HIV-related wasting fit in? Or poor intake of food because of poverty or drug use? At a New York Community Health Project or Bronx-Lebanon Medical Center, where women frequently complain of amenorrhea, roughly 60% of the women are present or former drug users.

Research and Treatment Goals

It is imperative that researchers and care providers begin to record women's complaints and begin to ask women about their reproductive health. Women who do complain of dysmenorrhea or amenorrhea should be taken seriously and diagnosed--menstrual problems should not be merely taken for granted. Women should receive a pelvic exam, pap smear, ultra sound, etc. Anemia should also be monitored in women who suffer extended bleeding.

If HIV infected women share common knowledge about how AZT, ddI, or infections affect their reproductive health, why do researchers and care providers remain ignorant and unwilling to record women's complaints? Until clinicians become involved in the health of women they are treating, HIV infected women are likely to continue prescribing their own relief from menstrual pain (such as taking themselves off AZT -- sometimes without informing their clinicians) Clearly this benefits no one.

Vaginal Candidiasis

Vaginal candidiasis also known as vaginal thrush or yeast infection, is a fungal infection generally caused by Candida albicans. Its most common symptoms are severe vaginal itching and a thick, often white discharge with the consistency of cottage cheese. It is a common problem which most women will develop at least once. It is often caused by antibiotic therapy, use of corticosteroids, birth control pills or immune suppression associated with pregnancy. Vaginal candidiasis is usually treatable by the use of common antifungal agents such as Gyne-Lotrimin (a trade name for the generic drug clotrimazole).

When a woman with HIV/AIDS develops vaginal candidiasis however, much of this picture is altered. Although the initial symptoms remain the same, the infection is no longer easily resolved, is painful and sometimes results in lesions. Women with HIV/AIDS find that their vaginal candidiasis recurs within a short period of time after they stop using their medication. Frequently they will have this infection almost nonstop for a year or more. Some HIV positive women have reported that although they have symptoms of Candida albicans and initial microscopic evidence of such, confirmatory cultures fail to grow the organism--possibly indicating another organism as a cause of these symptoms.

The infection is usually seen in conjunction with a decreased CD4 cell count, often below 200, and a decreased T4/T8 cell ratio. Vaginal candidiasis will often predate the appearance of esophageal and/or oral thrush (also caused by Candida albicans) by at least a year. Resistance to treatment also develops with the persistent, recurring infection; which often leads to the use of more potent drugs such as Amphotericin B. Drugs such as these present their own problems for women with HIV/AIDS.

Researchers at Walter Reed Hospital believe that at least 24% of women with AIDS will have recurrent vaginal candidiasis as their presenting symptom. They also believe that it is often the only clinical indication of the severe underlying immunodeficiency and may present a serious risk for the onset of other AIDS-defining illnesses.

Does this mean that the appearance of vaginal candidiasis may be an indication of advanced disease in women? Unfortunately, the research has not been done to answer this question.

The persistent, recurrent vaginal candidiasis that women with HIV/AIDS contract may be a form of Candidiasis Hypersensitivity Syndrome (CHS). However, the medical profession has not been able to agree whether this type of syndrome really exists, and if it does exist, how it should be defined. As a result, there are no studies being done on the best ways to treat it. What knowledge we do have, derives from the problems with oral thrush that cancer patients have been faced with, especially since the advent of chemotherapy. Common antifungal agents such as clotrimazole (now available over the counter as Gyne-Lotrimin) or Nystatin are most frequently used. If these drugs are not effective, usually a drug such as Amphotericin B will be used. Amphotericin B is usually given through an IV and has many side effects. It is an antibiotic, and antibiotics can increase yeast production unless acidophilus is taken with it. It can cause anemia, which often is caused by other medications taken by women with HIV/AIDS. It is also dangerous to the kidneys, creates sensitivity to light and also often causes high fevers and chills. Fluconazole is a new drug approved last year for the treatment of oral candidiasis, can be taken as a pill or through IV, and may be a safer and more effective treatment. However, it has never been tested for vaginal thrush.

Vaginal candidiasis complicates the treatment of women with HIV/AIDS. It is known that it can be caused in healthy women by taking antibiotics; women with AIDS frequently have to take antibiotics due to other opportunistic infections. It can also be caused by taking birth control pills; women with AIDS who want to participate in ACTG trials are often required to use contraception as defined by the researchers, and birth control pills are often the method required. It often appears during pregnancy; most of these drugs will have an unknown effect on pregnant women and fetuses.

Since a drug such as Amphotericin B can cause anemia, does this mean that it can't be used by a woman taking AZT, which also causes anemia? Will the development of recurrent vaginal candidiasis inevitably lead to the development of esophageal or oral thrush? Do women develop this infection more frequently when their CD4 cell count falls below 200, or are we just not seeing these women sooner because they can't afford the medical costs? Will recurrent vaginal candidiasis which is resistant to treatment cause a more rapid progression of immunosuppression and therefore death?

Since women in general, and HIV positive women in particular, are more likely to get a variety of fungal infections, can some type of broad spectrum anti-fungal prophylaxis be developed which is similar in treatment regimen to Bactrim or Pentamidine (for PCP)? Will taking such a regimen allow women to remain healthy for longer periods of time?

Why is it that the CDC recognizes Candida albicans as an AIDS defining illness in esophageal thrush, but not in vaginal thrush? Why can't the medical profession decide whether Candidiasis Hypersensitivity Syndrome really exists and define it, so that research will begin on effective treatments? Why is the medical profession ignoring an illness that is believed to be the presenting symptom in one quarter of all women with HIV/AIDS?

These questions remain unanswered more than ten years into the epidemic. Researchers need to establish priorities to examine these issues immediately in order to save women's lives.

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Cytolytic Vaginosis

Cytolytic Vaginosis, previously known as Doderlein Cytolysis, is an easily diagnosed and treated condition that is frequently missed since symptoms are often similar to those associated with vaginal candidiasis. Cytolytic Vaginosis should be ruled out, especially in women with apprent chronic or recurrent candidiasis. A wet smear (microscopic examination) negative for trichomonas, Gardnerella, or Candida with fewer white blood cells (than normally associated with infection), increased evidence of lactobacilli, and evidence of destruction of living cells (cytolysis) are all indications of Cytolytic Vaginosis. A hallmark of this condition is low vaginal pH, usually between 3.5 and 4.5. Discomfort is usually most severe during a phase of the menstrual cycle known as the luteal phase. Suggested treatment is sodium bicarbonate douches, which increase vaginal pH.

Practitioners who see women, especially HIV positive women, with vaginal yeast infections that do not respond to usual treatment should be alert to the possibility of Cytolytic Vaginosis. Although there is no evidence to suggest that HIV positive women have an increased likelihood of developing Cytolytic Vaginosis, the difficulty in treating some vaginal infections in HIV positive women makes it imperative that this condition be investigated and that an accurate diagnosis be made.*

* Source: International Society for the Study of Vulvar Disease (ISSVD Tutorial Reporter, March, 1991). Leonard J. Cibley, MD, Harvard Medical School, Clinical Professor, OB/GYN. ISSVD Tutorial Reporter, Gardiner-Caldwell SynerMed, PO Box 458, Califon, NJ 07830

HIV And STD'S In Women

More than 20 organisms have been identified as causing sexually transmitted diseases (STD)[47] Here we will focus only on those which at this time appear to have a particular impact on women who are seropositive or have been diagnosed with AIDS. These include syphilis, chancroid and herpes simplex virus (HSV)[48]. Others, such as gonorrhea, chlamydia and trichomonas will be mentioned briefly. Human papilloma virus will be discussed in a later version of this treatment and research agenda.

Syphilis, HSV and chancroid are the most common causes of genital ulcer disease. Since 1980 the U.S. has seen rates of primary and secondary syphilis increase by more than 200%.[49] The incidence of genital herpes in the U.S. is up 16 fold as reflected by visits to practitioners[50]. Five thousand and one (5001) cases of chancroid were reported in 1988 in the U.S. Approximately 2/3 of these cases were localized in New York City[51].

Lymphogranuloma venereum (a disorder of the lymph tissues caused by chlamydia) and granuloma inguinale (a chronic bacterial infection of the genitals) are comparatively rare. Other causes of genital ulcer disease include cuts or open skin surfaces, gonorrhea and infectious mononucleosis.[52]

Genital ulcer disease is important in discussions of HIV infection in women for a number of reasons. Genital ulcers and some cervical infections, notably chlamydia and trichomoniasis, are suspected of increasing the risk of HIV transmission (see Transmission Issues section). Whether HIV actually increases a woman's risk of genital ulcer disease is a question which remains unanswered by current research.

Reports from healthcare providers treating HIV positive persons for syphilis, HSV and chancroid suggests that the typical course of illness and/or treatment may be different than for HIV negative individuals. For example, some studies indicate that treatment failure for chancroid can be an important predictor of HIV seropositivity[53].

HSV infection is more common and recurs with more frequency in HIV positive women than in seronegative women[54]. HSV 1 and HSV 2 gene products in a laboratory test (*in vitro*) may increase the replication of HIV. Further study is needed to determine whether HSV actually accelerates the

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[47] Lichtman R, Duran P, "Sexually transmitted diseases," Gynecology: Well-woman Care. 1990.

[48] New Jersey Women and AIDS Network. "Me First! Medical Manifestations of HIV in Women," 1990. (Available from NJWAN, 5 Elm Row, New Brunswick, NJ 08901.)

[49] Ibid.

[50] Mertz CJ, "Genital herpes simplex virus infections," Medical Clinics of North America, 1990 74(6):1443-1454.

[51] Schmid GP, "Approach to the patient with genital ulcer disease," Medical Clinics of North America, 1990;75(6):3-9.

[52] Ibid.

[53] Jessamine PG, Ronald AR, "Chancroid and the role of genital ulcer disease in the spread of human retroviruses," Medical Clinics of North America, 1990;74(6):1417-1431.

[54] "Me First!..." (NJWAN).

progression of disease in HIV positive women[55].

Secondary syphilis in HIV seropositive individuals is frequently undetectable by standard testing. Whether HIV positive women are more affected in this way is a question which should be answered, especially since research indicates that primary syphilis in women is more likely to be undetected that in men[56]. In HIV positive individuals infected with secondary syphilis, tests for syphilis have been negative. Failure of standard treatments for syphilis and rapid progression to neurosyphilis have been demonstrated[57].

Although little research exists about the relationship between gonorrhea and HIV and, in fact, what does exist describes gonorrhea as easily treatable in women who are HIV positive, some questions remain. We know that the gram stain test still used in some places is useless for detecting gonorrhea in women. Cultures, though more accurate, must be taken from appropriate sites. Yet we also know that gonorrhea can show up as endocarditis, pneumonias and adult respiratory distress, unusual or abnormal sites for the infection (disseminated gonorrhea)[58]. Though these symptoms of disseminated gonorrhea are rare in people who are not HIV positive, women who are HIV positive (as well as intravenous drug users) have a high incidence of bacterial pneumonias, endocarditis and other respiratory diseases. Is it possible that the relationship between HIV and gonorrhea (undiagnosed or seemingly treatable but really not cured) is at the base of this symptom picture?

Early and accurate diagnosis and treatment of STDs is important for all women, but especially for women who are HIV positive since some infections may be more difficult to treat. Additionally clinical evidence exists to suggest that pelvic inflammatory disease (PID) is not only more common among seropositive women but also more severe and refractory to treatment[59]. In fact, investigators Moss and Kreiss report that, "... HIV infection itself appears to increase the severity of certain STDs once they are acquired[60]." Educational materials, clearly describing symptoms, must be developed since knowledge about the course of illness is an important source of information for diagnosis.

Clinical misdiagnosis of genital ulcers occurs as often as 40% of the time. Inappropriate use of testing, unavailability of tests, advanced condition of ulcers, and patient self treatments can all contribute to making diagnosis difficult. False negative results of cultures and blood tests may account for many of the high number of cases (25-50%) where no cause for symptoms is identified[61]. More sensitive diagnostic testing should be a research priority.

The demographic and geographic distribution of particular infections such as syphilis, HSV and chancroid, as well as the distribution of drug resistant strains, may be useful tools in diagnosing and treating illness. These should, however, never be used as a substitute for thorough examination, history taking and diagnostic testing.

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[55] Moss GB, Kreiss JK, "The interrelationship between human immunodeficiency virus infection and other sexually transmitted diseases," Medical Clinics of North America. 1990;74(6):1647-1660.

[56] Schmid GP, "Approach to the patient with genital ulcer disease."

[57] Ibid.

[58] Lichtman R, Duran P, Gynecology: Well-woman Care.

[59] NJWAN, "Me First!...".

[60] Moss GB, Kreiss JK, Medical Clinics of North America, 1990; 74(6):647-1660.

[61] Schmid GP, Medical Clinics of North America, 1190;74(6):1559-1572.

Generalizations about disease prevalence are subject to socioeconomic factors. For example, it may be that African-Americans living in urban areas in the U.S. have a higher recorded incidence of syphilis because many rely on public clinics for treatment where case reporting is more likely to occur than with private physicians[62]. Consequently, women suspected of having any STD should be tested for a full range of possible pathogens.

Practitioners should also bear in mind that secondary infections and coinfections are always possible. It is important that clinicians understand and be able to use blood (serologic) and other diagnostic tests appropriately. The critical need for timely diagnosis and treatment for HIV positive women justifies any added expense of direct testing for pathogens using the latest and most accurate technology.

It is of major important that the practitioner be able to discuss sexual histories and practices in a frank, culturally sensitive and non-judgmental manner. Assuming that all women sleep with men and self-identify as heterosexual renders lesbians invisible and provides inaccurate information which may impact on treatment decisions. Clinicians must not rely on assumptions and concepts such as risk group categories which are impediments to assessment, treatment and patient education.

Since there is evidence of standard therapy failure for women with some STDs (syphilis, chancroid) and HIV coinfection, it is imperative for there to be close follow-up after treatment. Routine initial culture and sensitivity testing to detect drug resistant organisms may reduce treatment failure. Clinicians will do well to "think" HIV coinfection when treating genital ulcer disease, especially when confronted with treatment failure, virulent and/or refractory PID or test results inconsistent with clinical evidence.

Recommendations for Research

o Improved diagnostic testing for Sexually Transmitted Diseases and access to necessary tests should be a priority.

o Questions regarding the rate of false negative diagnostic tests among HIV positive women should be researched.

o Research should be conducted on the course of STDs in seropositive women. These should include, but not be limited to syphilis, chancroid, HSV, HPV, trichomoniasis, chlamydia, gonorrhea, granuloma inguinale and lymphogranuloma venereum. Special attention should be paid to all questions regarding the spread of these infections beyond their original sites (disseminated disease).

o Questions regarding the relationship of HIV infection to genital ulcer disease need to be addressed, as do questions remaining about the increased risk of HIV transmission in the presence of genital ulcer disease.

o The possible link between HSV 2 and genital cancer as well as questions about a possible partnership between HSV 2 and HPV in causing cancer must be researched with special attention paid to the potential consequences to HIV seropositive women.

o HIV positive women should be intentionally included in all AIDS research and drug trials.

o Researchers and practitioners must acknowledge the existence of lesbians and address the reality that lesbians can and do become infected with STDs and HIV through sex with one another.

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[62] Lichtman R, Duran P, Gynecology: Well-woman Care, 1990.

Tuberculosis

It is estimated that half of the world's population is infected with the tuberculin bacilli (a rod shaped organism identified as causing tuberculosis). TB prevalence worldwide has doubled in the last decade; it is the world's major infectious killer. Half of the 6-8 million people in the world believed to be infected with HIV actually have TB, and TB is the most prevalent opportunistic infection to be reported in conjunction with HIV worldwide.

In subSaharan Africa TB has doubled in the past 5 years; 40-70% of people with TB are HIV antibody positive--yet many have a negative test for TB on analysis of sputum samples[63].

From 1984 to 1986, the incidence of TB increased in the U.S. by 2%, and by 36% in New York City. In New York City today, active TB occurs at a rate 10 times that which was reported in 1980. When cases of TB increased during this period, a public health correlation with HIV should have been made.

In 1987, the CDC added extrapulmonary TB to the list of AIDS-defining opportunistic infections even though it was only in 1988 that systematic information regarding the presence of extrapulmonary TB among HIV antibody positive individuals was collected. Pulmonary TB has yet to be added to the CDC's list of AIDS defining infections[64].

In 1989 and 1990, in the U.S., the incidence of TB rose 5% and 8% respectively. The largest increases were seen in children under the age of 5 (15% in 1989) and in individuals between the ages of 25 and 44. Since 4-5% of cases are not diagnosed until death, this would indicate approximately 10 million people who are infected with tuberculosis without a diagnosis of infection[65].

Prior to World War II, TB was the major killer of all African Americans; black women were 4-5 times more likely to be infected than were white women. In the U.S., it is predicted that the downward trend in TB in whites will continue. Today, the incidence of TB in persons of color is twice that of whites[66].

TB occurs at a rate 30% higher in people who are institutionalized (nursing homes, prisons, shelters and refugee encampments) than in people in more ventilated noncongregate housing. For people without any housing, there is a greater danger of exposure to drug resistant strains, the prevalence of these strains being 300% higher than in all other populations.

As of May, 1991, 84% of newly diagnosed cases of TB in New York state were reported in New York City; with reactivation infection highest in older men and new infection highest in younger women[67]. Deaths due to TB in HIV positive women are double that reported in AIDS case surveillance, and the presence of HIV and TB together is almost entirely due to IV drug use, the largest transmission category for women in the U.S. (It is estimated that in IVDUs and women AIDS is underestimated

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[63] Marain M, WHO Global Programme on AIDS, personal conversation.

[64] "Guidelines for Preventing the Transmission of Tuberculosis in Health-Care Settings, with Special Focus on HIV-Related Issues," MMWR. 39:RR17, Dec 7, 1990.

[65] McMurray D, "Micronutrients May Affect Resistance to Tuberculosis," The New York Academy of Sciences, press release, June 1, 1989.

[66] Marain M, WHO Global Programme on AIDS.

[67] Stoneburner RL, NYC Department of Health, personal conversation.

by 100%.) There are virtually no reports of TB in women who are HIV antibody negative.

Transmission and Presentation of TB

TB is a chronic bacterial infection which usually goes unrecognized, even though some bacilli remain alive in the systems of individuals infected who have healthy immune systems. TB is spread from person to person via particles which can be airborne and which contain TB. These particles can be coughed or sneezed by a person with clinically active pulmonary TB.

In immune competent individuals the TB bacillus remains dormant, contained in an envelope called a granuloma. In immune compromised individuals, the envelope is lost. Immune suppression increases the likelihood for dormant TB to become activated, resulting in clinical symptoms. HIV infection appears to be one of the highest risk factors associated with the progression from inactive to active TB infection; in HIV antibody positive individuals, the risk of activation of dormant TB is almost 100%[68]. In addition to HIV as an agent of immune compromise, lack of proper nutrition, absence of specific nutrients, inadequate ventilation, incomplete health care provision and injection of immune suppressive drugs all contribute to decreasing immune competence.

Pulmonary TB usually shows up in the upper portion of the lungs, however, in HIV antibody positive individuals, the involvement is in the middle or lower portion of the lung. TB emphysema involves infection throughout and around the lungs and has been misdiagnosed as lymphoma.

Extrapulmonary and atypical TB are often not recognized as TB, and other diagnoses are first reported. In the U.S., 5-10% of people with TB have both pulmonary and extrapulmonary manifestations. Extrapulmonary TB can involve any organ or system, including sites not observed in people who are HIV antibody negative. These include the gastrointestinal tract, brain, blood, genitals, pericardium, wrists, lymphatic and other presentations. Unrecognized TB diagnoses include oral or vaginal candidiasis, meningitis, peritonitis and lymphoma[69]. Central nervous system mass lesions caused by TB are relatively common in IVDUs with AIDS and precede other OIs by months.

Symptoms of active TB include fever, night sweats, weight loss and sputum production--symptoms which are often overlooked in institutionalized and older individuals. In the absence of specific treatment, death occurs from chronic wasting, respiratory failure and meningitis.

Both MAI (Mycobacterium avium intracellulare) and TB are of the same family of mycobacterial species. MAI is the most common species seen in persons with AIDS in general, while in IVDUs TB is more common. In the U.S., where greater than 50% of women with CDC-defined AIDS are reported to have been infected through IVDU, MAI shows up more frequently than in men[70]. However, TB is not being reported unless extrapulmonary in nature. Since both MAI and TB can present with the same clinical picture the current CDC statistics are questionable. While TB is infectious, it is also generally curable if treatment is begun early in the infectious process. At present there is no treatment for MAI and it could be the progression of untreated tuberculosis.

Testing

Initial screening for TB is based on skin test reactions. However, when someone is immune suppressed, these types of tests are meaningless, often nonreactive in the face of active infection. In a

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[68] "TB/HIV the Connection: What Health Care Workers Should Know," CDC, July 1989.

[69] Bishburg E, Annals of Internal Medicine, 105:2,Aug 1986:pp210-212.

[70] Farer LS, et al., "TB Today: Don't Count it Out," Patient Care, November 15, 1987, pp141-150.

receive a dose too high to be effective as an immune modulator. Some practitioners have raised the concern that these high doses of naltrexone might be immunosuppressive, and should be avoided in drug users with HIV disease.

AZT Treatment

The question of interactions of AZT with other drugs has been a major concern since the drug's approval. Drugs that share the same mechanism of elimination as AZT (hepatic glucuronidation) are likely to increase AZT toxicity, as well as to see their own toxicity increased. In addition, drug users tend to have abnormal hepatic functions, due to the lasting toxic effects of opioids on their liver. Some of the drugs that increase AZT toxicity have been identified. Non-steroidal anti-inflammatory drugs such as paracetemol and acetaminophen (Tylenol) have been suspected to increase toxic effects of AZT, i.e., to be responsible for an increased incidence of anemia[92]; aspirin and ibuprofen do not seem to produce similar effects.

Anti-infectious drugs such as sulfadoxine and sulfamethoxazole (a component of Bactrim/Septra) also compete with AZT for glucuronidation and might increase AZT toxicity. In addition, these two drugs, as well as pyrimethamine, gancyclovir (DHPG) and Amphotericin B, may potentiate AZT toxicity on the bone marrow.

AZT has been used in individuals receiving methadone, as well as in individuals injecting opioids, with satisfying results[93]. However, opioids such as morphine or codeine compete with AZT for hepatic glucuronidation, and might increase AZT toxicity.

Unofficial reports have mentioned that AZT treatment might interfere with lithium administration in drug use treatment, i.e., that patients taking AZT might be more likely to become addicted to lithium. This information has not been confirmed since.

Probencid is a drug used to treat gout, but also to increase the duration of action of antibiotics by competing for glucuronidation. Proper use of probenecid with AZT could reduce the amount of AZT needed every day, thus dramatically cutting the cost of AZT treatment.

The question of interaction of AZT with sexual hormones is still an open one. A Burroughs-Wellcome study of female mice chronically receiving large doses of AZT showed an increased incidence of cancers of the reproductive organs. To this date, no data collection has been made on the effects of chronic administration of AZT in women. Interactions of AZT with birth control pills and use of steroids by transsexuals have been completely ignored. Since female drug users often suffer from reproductive dysfunction, and hormonal cycle seems to have an influence on the effects of drugs on women's physiology,[94] the safety of AZT and other antiretrovirals on the health of women with HIV who are drug users should be investigated in priority.

AZT use in pregnant women is under studied, and there does not seem to be any incompatibility so far. However, more studies are needed regarding the specific toxicity of AZT in pregnant drug users with HIV disease.

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[92] Morse GD, et al., "Zidovudine update:1990," DICP, 1990;24:754-760.

[93] Cowan FM, et al., "Use of zidovudine for drug misusers infected with human immunodeficiency virus," J. Infection, 1989;18 Suppl.:59-66.

[94] Naegle M, "Substance abuse among women: prevalence, patterns, and treatment issues," Issues Ment. Health Nurs., 1988; 9:127-137.

study done by Selwyn and coworkers, 3% of people who were not HIV antibody positive were anergic (unable to produce a skin test reaction because of immune suppression). 27% of HIV antibody positive patients were anergic to multiple antigen skin testing.

Tests used to establish a definitive diagnosis of extrapulmonary TB include collection of a variety of specimens for culture including respiratory secretions, bronchial washings, gastric lavage, lung tissue, pleural fluid, lymph node tissue, bone marrow, blood, urine, stool, brain and cerebrospinal fluid[71]. The current microbiological lab procedure to culture TB takes 6 weeks to grow. There is a need for the development of tests for the rapid diagnosis of both extrapulmonary and pulmonary TB.

While skin tests (used to detect TB infection regardless of its site) are often uninformative, samples collected for diagnosis are invasive and often do not provide results. Given the incidence of nonreactive skin tests, there is a need for the development of more sensitive tests for both extrapulmonary and pulmonary TB. Less invasive tests, and research into appropriate body fluids from which to collect samples in cases of extrapulmonary TB, which will yield accurate and definitive results must be developed.

In New York state doctors are currently being denied Medicaid reimbursement for TB (and syphilis) testing. In the absence of signs or symptoms on an individual chart, payment is denied. This applies to screening tests of any kind, including blood chemistry profiles where appropriateness of tests ordered must be specifically indicated[72]. Community health physicians are being audited and some are being required to subject themselves to administrative hearings. According to Peter Wyer, M.D., there is "no precedent in the history of medicine" for this type of scrutiny in patient care[73].

Treatment

According to the World Health Organization (WHO) people who are HIV antibody positive have an almost 100% risk of reactivating dormant TB. TB is one of the first OIs presenting, and once diagnosed is treatable[74]. Untreated it is fatal to HIV positive individuals. Standard treatment is chemotherapy over a course of 6-18 months. However, poor nutritional status, malnutrition and famine threaten complete healing and the stability of healed lesions. In the U.S., 95% of primary TB lesions completely heal with treatment.

Inadequate treatment is as fatal as lack of treatment--a poorly implemented program may worsen the condition. Underdosing can lead to drug resistant disease. There are estimates that 25% of infected individuals in California and 15% in New York are drug resistant to one of the 3-5 drugs which are part of a treatment regimen. People who stop treatment on their own prior to the completion of a regimen, can also develop drug resistance. If the strain of TB was originally drug susceptible, the bacteria mutate and a secondary resistance is created. For people who do not respond to prescribed treatment, a more difficult and extended course is administered.

If someone is resistant to TB chemotherapy, the resistant strain of TB can be spread. More than 30% of adults with TB at Kings County Hospital, a public hospital in Brooklyn, were resistant to at least

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[71] Tuberculosis At-A-Glance. Department of Health, New York City, April, 1991.

[72] Perales CA, Commissioner, NYS Dept. of Social Services, Administrative Hearings, May 7, 1991.

[73] Wyer P, PACT for Equal Health Services, Bronx NY, Personal Conversation.

[74] Marain M, WHO Global Programme on AIDS.

one drug[75]. In a study at Grady Memorial Hospital (a public hospital in Atlanta, GA.), gay men who were HIV antibody positive had contracted drug resistant TB within the hospital setting[76].

Isoniazid is inappropriate for people who are active alcoholics or in those with clinically significant liver disease. Resistance to this therapy is widespread in industrialized countries.

If on methadone, and given rifampin, individuals may require increased methadone dosage to avoid withdrawal symptoms caused by the interaction between methadone and rifampin[77]. While this data was published in 1976 and therefore certainly not a new finding, individuals continue to have these drugs prescribed at inappropriate levels. This results in methadone failure leading to "noncompliance" for the rifampin regimen.

The Following Is a List Of Guidelines For Research:

o Develop rapid, predictable diagnostic tests for the presence of TB which are unaffected by an individual's immune status and which include testing appropriate for infection in women.

o Develop acute and prophylactic treatment regimens which are more efficacious and unaffected by compliance (which often results in the development of resistant strains).

o Study was to boost defense mechanisms prior to infection as well as risk factors (such as living conditions) and their effect on TB infection.

o Develop treatment regimens which do not contribute to immune suppression. Some examples may be: diet, beta blockers, air, rest and phototherapy.

o Investigate the usefulness of vaccines which are currently in use in non-industrialized countries.

o Fully investigate the clinical and pathological course of extrapulmonary TB in women.

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[75] Steiner P, "Steep rise in drug-resistant cases alarms NY's doctors," The New York Post, p.4.

[76] Castro KG, Centers for Disease Control, Personal Conversation.

[77] Kreek MJ, et al, "Rifampin-induced methadone withdrawal," NEJM, 1976;294:pp1104-1106.

Standard of Care Recommendations

- **Alternative Therapies**
- **Drug Detoxification**
- **Prison Issues**

Women, AIDS, and Alternative Therapies

Introduction

A recent survey by the Physicians Association for AIDS Care found that over half of PWAs use an "alternative" or "complementary" therapy and feel that it is beneficial. Despite this opinion -from people living with HIV -the traditional medical establishment, the FDA, NIH, and health insurance industry (among others) are actively antagonistic towards non-traditional, non-pharmaceutical, nontoxic treatments for HIV infection and opportunistic infections (OIs). Physicians criticize alternative and holistic treatments, the NIH refuses to research them through its ACTG system, the FDA won't license them, and the health insurance industry refuses to pay for them--even when they are widely used in other countries. Their resistance is all the more outrageous when we remember that the distinction between "traditional" and "alternative" therapies is largely artificial, since today's alternative treatment may be tomorrow's conservative medical approach. After all, where would you put Compound Q or NAC? Both started out in the AIDS underground and are now being investigated by government- and AmFAR-backed trials.

We must demand that people with life-threatening illnesses have the freedom to make informed choices about the full range of treatment options. The right to choose an alternative course of therapy is especially needed by those segments of the AIDS-affected community to whom the traditional medical establishment offers the least--notably, women and people of color. We demand that participants in the health care delivery system in this country recognize and support this right and respond accordingly.

The reasons for the exclusion of alternative and holistic AIDS treatments are many, but essentially it comes down to the same problems we face in other areas of AIDS policy--professional chauvinism, careerism, financial interest, racism, sexism, and xenophobia. Because of this exclusion, numerous barriers exist to use of alternative treatments by the communities that need them most. Generally, information about alternatives is available only to people who are well-educated, English-speaking, and motivated to seek out that information. It is not available at the agencies that provide healthcare services to lower-income people. Second, because of lack of research, alternative therapies are not approved by the FDA. Non-FDA-approved therapies are not covered by public or private health insurance; they are excluded from the Medicaid formally, and not available to low-income women who comprise a big chunk of the HIV+ female population. Consequently, all cost for alternative or holistic therapies must be paid by the user. There is no such thing as insurance reimbursement for Vitamin C.

Alternative treatments for women-specific opportunistic infections

In addition to offering greater potential access, alternative treatment regimens may also offer effective therapies for women-specific OIs or OIs that occur with greater frequency in women.

Anal and cervical cancer. As more becomes known about women and HIV, it is clear that various forms of cancer are more common in HIV+ women. Research by Chinese scientists suggests that garlic may have an anti-tumoral effect, by killing cancerous cells and protecting against carcinogens.

Pelvic Inflammatory Disease. A potential treatment for PID may be ozone, which many believe to be helpful against various bacterial and viral infections, including hepatitis-B and abscesses. Ozone needs more research in the United States, since it is currently available only in Germany.

Vaginal and cervical candidiasis. This is one OI that may be entirely treatable with natural therapies. One of the most effective ways of controlling many kinds of yeast infections is by altering one's diet. Most nutritionists tell candida-sensitive people to stay away from refined sugar, fruit, dairy, and foods like beer that contain yeast. Chinese herbs, such as astragalus, have shown anti-candida ability in addition to inhibiting HIV and Epstein-Barr virus. Ascorbate may slow the growth of yeast and acidophilus may prevent areas from becoming colonized. Some physicians prescribe pau d'arco tea or tablets for candidiasis. Most holistic practitioners try to avoid using the allopathic standard--nystatin--because a long term program may be necessary. The objectives of treatment should be to restrain the growth of yeast long enough for sensitivities to lessen and to restore the ability of the immune system to suppress the yeast on its own.

Chlamydia. This parasitic infection may be treatable by a number of natural substances. Hypericin (St. John's wort extract), for example, has been found to be a broad-spectrum antimicrobial. Other supplements, such as alkylglycerols, may increase white blood cell counts, enabling the body to defend itself better.

Human papilloma virus infection. Once again, hypericin may be a possible treatment since we know it is effective against herpes viruses. Chinese studies of garlic showed anti-CMV, anti-herpes effect; it should be investigated for HPV infection, too. We could also benefit from additional research on the use of bioflavinoids such as Quercitin as an antiviral.

Pneumocystis pneumonia. This OI is the highest reported killer of women with AIDS; in fact, HIV+ women generally have more pneumonias and respiratory problems than men. Garlic should be researched further for its anti-protozoal effect, especially since standard treatment with a broader-spectrum drug like Bactrim can cause yeast growth--a bad idea in a population that is already disproportionately affected by candidiasis. Vitamin C may also offer some promise.

Other benefits of alternative therapies

Nutritional supplements can help PWAs deal better with the side effects of traditional therapies. For example, metabolization of many standard HIV treatments depletes the body of nutrients necessary for proper immune functioning. In addition to causing anemia, AZT depletes B vitamins, and B-12 deficiency may be responsible for some of the CFIDS symptoms associated with AIDS. ddI and ddC can decrease trace minerals, and vitamin therapy may reduce these side effects. Therapies like acupuncture and colonics may help the body to detoxify from overuse of pharmaceuticals or illegal drugs. Acupuncture could be part of a treatment program for injection drug users, to help them reduce the risk of re-infection by sharing needles. Acupuncture is covered by Medi-Cal in California but not by Medicaid or Medicare. Many states do not even have a mechanism for licensing practitioners of acupuncture.

Strategies for the future

In addition to overall reform of the drug development, testing, and approval process, and the current medical research paradigm, there are a few steps the activists can take to make the benefits of alternative therapies available to more women.

Activists must stress the importance of enrolling women in community-based trials. These studies, run by physicians in their offices, constitute the only access to some non-pharmaceutical experimental drugs. Community-based research organizations must have community advisory boards, just like ACTG trials, and these boards must include women. All barriers to participation by women and people of color--including financial barriers--must be removed.

Women need to contribute to the development of a master protocol for alternative and holistic therapies. The way that clinical trials are designed, they automatically disqualify many

non-pharmaceutical treatments, since these therapies may have their effect through different mechanisms from mainstream drugs. We must design a trial model that evaluates alternative therapies for efficacy on their own terms.

We need to continue to alter the power relationships between doctor and patient. Without an open, comfortable, and supportive relationship with her physician, many women will be hesitant to ask about alternatives. Without discussion, some women will choose not use many substances that could improve their health; others will use treatments but not tell their physician, and thereby be deprived of medical input on the therapy or its interactions with other medications. (For more on this topic, see Michelle Roland's article in AIDS Treatment News or Project Inform's Discussion Paper, "Doctor and Patient: Building a Cooperative Relationship).

Treatment Modalities for Chemically-Dependent Women with HIV-Disease

A long tradition of limited research on women's health issues has resulted in a lack of information regarding substance abuse treatment in female drug users, and especially in those infected with HIV. Female drug users with HIV have to deal with a double stigma. Society rejects them as persons addicted to alcohol or drugs, and as persons infected by HIV. Sexist attitudes stigmatize them further, especially as inadequate, irresponsible childbearers. Such bigotry places female drug users with HIV disease among the most disenfranchised populations.

In addition, female drug users have access to far fewer resources than their male counterparts. They are underrepresented in treatment programs, and consequently, these programs are often not geared to their specific needs. Because these treatment centers do not want to take medical responsibilities, pregnant women are not accepted. There are only 4 or 5 centers in the United States which accept pregnant women; there are none in New York City. Child care is usually not offered, and children under 12 are not allowed to visit. Pre and post-natal care, training for single parents (up to 40% of female drug users are single parents), and women support groups are rarely provided[78]. Moreover, drug use is high in the lesbian community although it is rarely acknowledged nor are support groups provided.

All these factors, as well as the burden associated with HIV disease, are responsible for the major psychological problems experienced by female drug users with HIV. To the usual low self-esteem, shame and guilt associated with drug use, these women grieve what they perceive as the loss of health, body image, sexuality and childbearing potential. They experience denial and tend to neglect their health, leading to anger at being incapacitated. Depression is widespread and often results in cocaine use. Finally, drug users with HIV disease are often rejected by their peers, and feel extremely isolated.

Although women are less likely to become dependent upon illicit drugs than men, they are more likely to become addicted to prescription drugs and to use them with alcohol. They also tend to frequently use cocaine and other psychostimulants, as a way to offset depression, to induce weight loss, or simply to keep going in demanding conditions. However, female drug users with HIV are often intravenous drug users, and in addition to traditional substance abuse treatment, may be offered to participate in a methadone maintenance program.

Women's health is more vulnerable to substance use. Especially with alcohol, women are more likely

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[78] Kara L, "AIDS Prevention and Chemical Dependence Treatment Needs of Women and their Children," J. Psychoact. Drug. 1989; 21:395-760.

to develop cirrhosis of the liver, as well as damages to the central nervous, cardiovascular and reproductive systems. Drug-dependent women often have problems with menstruation, such as lack of periods, and a wide variety of medical problems (poor nutritional state, hypertension, hepatitis,...) that motivate them to look for medical attention, often the first step toward drug treatment.

Issues Concerning Medical Care for Female Drug Users with HIV Disease

Little is known of the natural history of HIV disease in women, and other articles in this document are discussing factors that might have an influence on the way HIV disease progresses in women specifically. Of concern in this article is the influence of drug use on the rate of progression of the disease. A short discussion concerning the effects of pregnancy on disease follows, mainly as an introduction to the issue of drug interactions.

Numerous studies have shown that chronic use of drugs has a deleterious effect on the immune system of users, whether infected by HIV or not. Intravenous drug users have abnormally low levels of beta-endorphin (a natural pain killer secreted by the body) in their blood, and their body tends to stop producing endorphins[79]. It is because opioids act on the same sites as endorphins that drug users' brains stop producing endorphins, since they do not seem needed anymore. When users stop drug administration, it is the lack of endorphin production that is responsible for withdrawal symptoms.

Interestingly, some white blood cells involved in immunity have receptor sites that attract endorphins. Thus, endorphins appear to regulate some immune functions. Persons with AIDS have low levels of endorphins in their blood, probably in relation to abnormally high levels of alpha-interferon (which might signal the brain to decrease endorphin production). Whether this decrease in endorphin levels plays a role in the progression of HIV disease remains unclear. Thus, drug use and HIV infection act together to dramatically decrease the blood levels of a substance involved in immune regulation.

In addition, drug users have high levels of cortisol (an hormone produced in the body to deal with stressful conditions) in their blood, and cortisol acts as an immunosuppressor, thus further diminishing the body's ability to react against HIV. Alcohol, heavy marijuana use and cocaine have been shown to have similar effects on the immune system[80], and cocaine use has been shown to increase the rate of progression of HIV disease.

In addition, it seems that the mere act of injecting a substance intravenously can be deleterious for CD4 lymphocytes. Reports indicate that drug users with HIV who stop injecting drugs and start receiving methadone experience an immediate increase in the absolute number of CD4 lymphocytes, even in the absence of any other treatment[81].

The effects of pregnancy on the progression of HIV disease have been reported in several studies in this country and abroad. In asymptomatic women with HIV, there is no evidence that pregnancy accelerates disease progression. However, pregnant female drug users with HIV are more likely to

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[79] Naegle M, "Substance Abuse Among Women: Prevalence, Patterns, and Treatment Issues," Issues Mental Health Nursing, 1988; 9:127-137.

[80] Hubbard RL, et al., "Role of drug abuse treatment in limiting the spread of AIDS," Rev. Infect. Dis., 1988;10:377-384.

[81] Cowan FM, et al., "Use of zidovudine for drug misusers infected with human immunodeficiency virus," J.Infection, 1989; 18 Suppl.:59-66.

develop bacterial pneumonia, and breech presentation is slightly more frequent[82]. The effect of a second or third pregnancy during HIV infection have not been studied. Pregnancy, with its accompanying decrease in immunity, may mask non-specific symptoms of infection, and delay diagnosis of HIV-related symptoms.

In female drug users, drug use often produces amenorrhea (absence of periods), and pregnancy is often diagnosed late, thus making difficult the assessment of fetal growth problems.

Treatment for HIV infection in drug users relies on the same bases than for tne rest of patients. AZT is taken with a high compliance level, especially in methadone maintenance programs. Dosage is similar to the one used in non- drug using population. There is a lack of data regarding the pharmacokinetics of AZT in male or female drug users. Chronic drug use induces lasting damages of the liver, and the usual AZT dosage might be either toxic or insufficient for drug users.

Tuberculosis is becoming increasingly common in drug users with HIV disease, and intradermal tuberculin skin testing should be done yearly. In addition, some practitioners use isoniazid as a chemoprophylaxis to be given daily along with methadone[83]. Diagnosed tuberculosis must be treated immediately with a multidrug combination.

Stress reduction is part of rehabilitation programs, and is likely to have positive effects on the immune system as well.

Clinical trials of experimental drugs are often excluding female drug users with HIV disease, because they are designed in ways that disqualify drug users and women. Drug users have a reputation of bad compliance, which is not true. They often show elevated liver enzymes that exclude them from most trials. Exclusion from trials on the basis of elevated liver enzymes is arbitrarily imposed by protocols in most cases. Absence of drug treatment programs and child care at the study sites also excludes female drug users.

With drug users, and especially with female drug users, the problem of drug interactions is a crucial one. Women with HIV in methadone programs often take AZT, as well as other HIV-related substances. What are the effects of these substances on the HIV-infected immune system, and what are the effects of drugs interacting with each other? In addition, pregnant female drug users with HIV face the possible consequences of drug effect on their developing child.

Methadone Treatment

The effects of methadone on immunity seem to be extremely positive. Long-term methadone treatment seems to regularize the levels and release of endorphins[84], by allowing the brain to regain progressively control of endorphin production. Individuals that have received methadone treatment for more than ll years show recovered activity of their Natural-Killer lymphocytes[85].

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[82] Selwyn PA, et al., "Prospective study of human immunodeficiency virus infection and pregnancy outcomes in intravenous drug users," JAMA, 1989; 261:1289-1294.

[83] Selwyn PA, et al., "Primary care for patients with human immunodeficiency virus (HIV) infection in a methadone maintenance treatment program," Ann. Intern. Med., 1989; 111:761-763.

[84] Cowan FM, et al, "Use of zidovudine for drug misusers infected with human immunodeficiency virus," J. Infection, 1989; 18 Suppl:59-66.

[85] Nathan JA, Karan LD, "Substance abuse treatment modalities in the age of HIV spectrum disease," J. Psychoact. Drugs, 1989;21:423-429.

Drug users with HIV disease who receive methadone usually observe a lasting increase in their number of CD4 lymphocytes, likely to be also caused by the cessation of the deleterious effects of intravenous injections of opioids. Thus, it appears that methadone has a positive effect on the immune system through normalization of immune function, as it has been observed for the neuroendocrine system.

The effects of methadone during pregnancy are extremely important to identify since it is often the case that female drug users enter a methadone program during their pregnancy, and relapse after giving birth. Women in methadone programs are more likely to show up for prenatal visits, receive better prenatal care (although still not optimal), and have less anemia[86]. Babies born from mothers receiving methadone have normal birth weights.

Evidence of methadone withdrawal symptoms in babies born from women receiving methadone lead to a reduction in methadone dosage during the third trimester of pregnancy[87]. However, such a reduced dosage is not sufficient to offset drug withdrawal, and women tend to use substitute drugs such as Valium to alleviate withdrawal. Valium abuse complicates narcotic withdrawal in newborns, and some practitioners recommend an increase in methadone dosage during the third trimester of pregnancy to avoid this type of complication[88]. In addition, there does not seem to be a direct correlation between maternal methadone dosage and the severity of withdrawal in neonates[89].

Interactions of methadone with other drugs are minimal, it does not interact with alcohol or Antabuse. However, rifampin, a drug used to treat tuberculosis and MAC (Mycobacterium Avium Complex), increases elimination of methadone by the liver, and requires an increase in the dosage of methadone (as well as other opioid analogs, such as morphine or codeine)[90].

Interactions of methadone with AZT have not been extensively investigated. Unofficial reports at an ACTG conference stated that AZT and methadone compete for the same elimination mechanism, and that individuals receiving methadone should reduce their AZT dosage, possibly by half. However, no official guideline has ever been given.

Naltrexone Treatment

Naltrexone is used in drug users to stimulate the production of endorphins and, at high doses, to block the site of action of opioids. Recently, some researchers have tried to use naltrexone to regularize the immune system in people with HIV disease. Using very small doses of naltrexone, a study identified patients that responded positively to the treatment, and tended to develop less opportunistic infections[91]. However, drug users who receive naltrexone as part of their treatment,

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[86] Edelin KC, et al., "Methadone maintenance in pregnancy: consequences to care and outcome," Obst. Gyn., 1988; 71:399-404.

[87] Nathan JA, Karan LD, "Substance abuse treatment modalities in the age of HIV spectrum disease," J. Psychoact. Drugs, 1989;21:423-429.

[88] Sutton LR, Hinderliter SA, "Diazepam abuse in pregnant women on methadone maintenance. Implications for the neonate," Clin. Pediat., 1990;29:108-111.

[89] Ibid.

[90] Nathan JA, Karan LD, "Substance abuse treatment modalities in the age of HIV spectrum disease."

[91] Bihari B, et al., "Low -dose naltrexone in the treatment of AIDS," IIIrd International Conference on AIDS, Washington, D.C., 1987.

In summary, research regarding standard of care for female drug users with HIV disease suffers from the same neglect that most issues regarding women and HIV. It is time for government and researchers you realize that drug abuse treatment is AIDS prevention, and drug users must be offered the same treatment options as other persons with HIV disease. Drug treatment programs must be expanded and made more available and acceptable to women. Admission barriers to these programs must be lowered, and programs must be able to offer primary care, pre- and post-natal care, child care during and after hospitalization, and parental training on site. In addition, increased support and resources services are needed for female drug users with HIV disease.

Prison Issues

The number of women prisoners who are HIV infected is not known. However , in states (such as NY) voluntary testing among all inmates[95] (male and female) has shown an approximate 20% rate of infection. Women specific studies in Massachusetts have shown an approximate 35% rate of infection in the inmate population[96]. Women in jail face an inequity of care as compared to their male counterparts, a reflection of gender bias in their "outside" society. Since the 1970's, the female prison population has increased steadily and at a faster rate than the male population. The number of women in prison was approximately 40,000 as of 1990[97]. Most of these are drug related convictions. Due to the stiffer penalties for drug charges and nationwide "Drug-Free Society" fervor, women (and men) are receiving stiffer penalties now prior to 1970. The influx of female prisoners has resulted in vastly overcrowded jail conditions. For example, at C.I.W. Frontera, 2,500 inmates are housed in a structure originally intended for 800 prisoners. Although C.I.W. (California Institute for Women) Frontera is a worst-case scenario, the problems of overcrowding and the resultant negligent care is a nationwide problem. Female prisoners who are HIV infected are particularly vulnerable to inadequate and inhumane prison conditions. The primary areas of focus to improve conditions for HIV infected women are as follows:

1) **Health Care**

A. Lack of access to appropriate and time medical care
   1. Lack of AIDS knowledgeable medical staff
   2. Understaffing of nurse/guards
   3. Visiting doctors rather than on-staff
   4. Transportation difficulties for access to outside hospitals
   5. Lack of state licensing for infirmaries resulting in inferior medical care
   6. Lack of state bureaucratic supervision and specific HIV/AIDS policies which lead to prison officials deciding these policies for themselves

B. Lack of access to outside opinions
C. Poor housing conditions
D. Lack of adequate nutrition
   1. Prison food
   2. Lack of access to vitamins and nutritive supplements
E. Lack of access to clinical drug trail participation
F. Lack of access to experimental HIV/AIDS drugs

2) **AIDS Education**

A. Lack of implementation of Safe Sex/Safe Works education for inmates and staff
B. Lack of AIDS education for prison health care providers
C. Lack of prisoners support and education networks inside prisons for HIV infected and the general population, including safe sex materials such as dental dams and condoms (A unique example of this is A.C.E.S. in NY)
D. Lack of drug rehabilitation programs inside prisons ("A large percentage of women prisoners have histories of IV drug use, a significant source of HIV transmission for

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[95] The Correctional Association of New York, Cathy Potler, Director, Prison Projects, Testimony on Inmate Health Services, December 12, 1989.

[96] Newsweek, "Women in Jail:Unequal Justice," June 4, 1990 pp.37-38,51.

[97] Ibid.

women[98]

E. Lack of outside support systems for HIV infected female prisoners
F. Lack of voluntary and confidential HIV antibody testing inside prison with pre and post test counseling

3) **Discriminatory Practices**

A. Quarantine of HIV infected inmates due to ignorance of HIV transmission routes
B. Lack of access to educational, job training programs and other rehabilitative programs for HIV infected inmates
C. Disparity between conditions of female vs. male HIV infected inmates
D. Lack of confidentiality for prisoners HIV status
E. Unnecessary use of face masks, rubbers gloves, etc. for dealing with HIV infected prisoners (For example, in California there is a non-official policy of making HIV infected inmates wear face masks while being transported to other facilities or going before the parole board presumably due to ignorance of HIV transmission routes.)
F. Blatant medical neglect due to the lack of AIDS/HIV education on the part of the prison staff
G. Inability to participate in overnight family visits and general discrimination in visitation rights

4) **Compassionate Releases**

A. Difficulty in obtaining due to the lengthy bureaucratic procedures out of sync with the sometime sudden and severe onset of full blown AIDS

The situation varies according to Federal, State and local policies. However, one major concern is the lack of outside monitoring of prison conditions. In most state and local prisons nationwide, prison officials create their own policies. This lead to wide discrepancies in HIV testing, quarantine, medical care and discriminatory practices.

For example, there is a law in California that inmates are not allowed to take care of other inmates making the implementation of a program such as A.C.E.S.[99] (NY) impossible to implement. Additionally, the lack of AIDS education and drug rehabilitation inside prisons (for staff and inmates) is a primary cause of many legal and human rights violations, and a primary contributor to the spread of HIV infection among the prison population and to their families on the outside. Lack of access to outside medical consultation and treatment and the inability to participate in clinical drug trails and other experimental treatments are also blatant areas of discrimination which contribute to the untimely illnesses and deaths of HIV infected inmates. Overcrowding in and limited budgets for correctional facilities nationwide is at the root of many of the inhumane conditions which HIV infected women prisoners experience. Understaffed infirmaries with illtrained and uneducated health care providers is the rule rather than the exception, nationwide.

The most effective advocacy for HIV infected women prisoners must come from the prisoners themselves. A non-intrusive stance based on individual reports from prisoners and constant communication with them will outline specific local areas of concern and action. What type of action is taken on behalf of prisoners must be outlined by the prisoners themselves in order to protect prisoners from further violations and abuses as a result of intrusive methods. Given the violent,

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[98] "Women, AIDS and Activism," ACT UP/NY Women and AIDS Book Group, Prison Issues and HIV, an introduction, pp.139-155.

[99] Ibid.

uneducated and irrational attitudes found within the prison system on every level, the utmost sensitivity is required. The most effective method of changing prison conditions is in determining specific local and state policies (or lack of policies), working with inmates to determine actual (vs. officially stated) conditions, applying public pressure (letter writing, phone zaps, media focus, coalition with other groups, legislative advocacy) to the prison bureaucracy to change specific conditions, and applying pressure for massive implementation of AIDS/HIV educational campaigns for staff and prisoners.
In conclusion, a 3-pronged approach is suggested at this time in advocating for:

1) Local activism re: HIV/AIDS education in the prison system
2) Local and State activism re: Cohesive local and state policies and outside monitoring of medical treatment and conditions inside the prison system
3) Nationwide activism re: Clinical drug trial participation and access to outside medical care and alternative drug treatments and therapies.

Women Prisoners Must Have Access to HIV/AIDS Clinical Drug Trials, Treatment INDs and Compassionate Use Drugs

Women have historically and systematically been left out of or underrepresented in HIV/AIDS clinical drug trials. They have had limited access to treatment INDs and compassionate use drugs. However, women prisoners (and men prisoners) have never been allowed to participate in these drug trials and have had no access to experimental HIV/AIDS drugs.

The inclusion of HIV positive women prisoners is an essential part of the "Women's Treatment Agenda.": Women in prison have access to substandard medical and nutritional care. Prison doctors and health care workers are for the most part not knowledgeable about HIV/AIDS. In New York State, over 1/3 of the cases of prisoners with AIDS were diagnosed after death. Also in New York State, prisoners with AIDS were found to live one-half as long as IV drug users with AIDS living in New York City. Given the lack of understanding in the medical profession about women with AIDS, these figures are probably much higher for women prisoners.

A joint report issued by the New York State AIDS Advisory Council, Ad hoc Committee on AIDS in Correctional Facilities, AIDS Institute and the New York State Department of Health concurred that it was essential that prisoners have access to clinical drug trials:

> Because of the speed and potential benefits of research, access to experimental products could be a choice for inmates as it is for others with HIV infection.
>
> New drugs become approved and available through clinical trials, many of which have often excluded women and IV drug users. The burdens and benefits of testing should be shared equitably within the populations infected or at high risk of infection. It is extremely difficult to conduct long-term clinical trials involving IV drug users in the community. If the prison population can be permitted access to these trials, while remaining protected from coercion and abuse, not only individuals but also society may benefit. An altruistic motive for behavior, which is permitted to non-incarcerated populations and which may ennoble suffering, should not be denied to inmates. Of course, particular attention must be paid, in this instance as in all others, to the process of and protection for informed consent.

Access to HIV/AIDS clinical drug trials, treatment INDs and compassionate use drugs could help prolong the life of women prisoners with AIDS, many of whom are poor African-American and Latina women. In New York City, women prisoners have an estimated seroprevalence rate of 25

percent and in New York State, almost 19 percent.[100]

Women prisoners cannot rely on prison health care to treat HIV/AIDS. Federal regulations require that prisoners who desire to be included in clinical trials make that decision for themselves. Participation must be non-coerced and voluntary and only during the Phase II and III of non-placebo drug trials so as to avoid any abusive research or experimentation. Confidentiality of medical records must be respected and upheld as much as possible. All drug trials and expanded compassionate drug use should be conducted outside of the prison environment by the trained staff of an AIDS-designated hospital or the equivalent. Prison medical staff should not administer these drug trials. Finally, any clinical trials in prison must be reviewed by an IRB with at least one prisoner representative on the panel. The active participation of AIDS activists, women's advocates and community-based AIDS service organizations is essential to the successful monitoring of this process.

Women prisoners have already taken the lead in fighting this epidemic in the prisons by establishing peer education and counseling projects like the AIDS, Counseling and Education (ACE) program at Bedford Hills Correctional Facility in New York State.

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[100] "Management of HIV Infection in New York State Prisons," Nancy Neveloff Dubler, et al., Columbia Human Rights Law Review, Vol. 21:363.

Critique of Research and Policy

- **ACTGs**
- **FDA**
- **AZT Issues**

Women, AIDS, and the AIDS Clinical Trial Group System .

The AIDS Clinical Trials Group (ACTG), funded and managed by the National Institute of Allergy and Infectious Diseases (NIAID), was created in 1987. The ACTG is the largest federally funded program of clinical trials to evaluate potentially effective agents for treatment of HIV infection. There are 47 institutions which are funded through this system to establish research priorities, develop protocols and implement clinical trials.

NIAID developed the following as goals for the ACTG system:

- o Study the full range of HIV-related disease, including primary HIV infection, opportunistic infections, malignancies, and neurologic disorders,
- o Evaluate a wide array of potentially promising agents,
- o Perform both pilot/phase I innovative trials and large comparative trials.

NIAID lists among the accomplishments of this system the development of 152 protocols and a total accrual of more than 11,000 patients. Their conclusion from these accomplishments is that "the ACTG has contributed substantially to the current status of therapy of HIV disease."

An analysis of this ACTG system of clinical trials from the perspective of women with HIV, however, falls dramatically short of any contributions toward the health and longevity of women with HIV/AIDS.

Women With HIV/AIDS: Who's Affected and Who's Enrolled

Women account for 9.1% of the adult AIDS diagnoses in the U.S. Their numbers increased by 45% over the past 12 months. Of the women affected, 73% are women of color: African-American, Latina, Native American, and Asian or Pacific Islander. Most of these women are poor, most have children, and most have been affronted by a system of health care which has inadequately met their needs over the course of a lifetime.

Although women now account for an alarmingly increasing number of cases, only 5% of all ACTG clinical trial participants are women. Only 275 of the symptomatic women in the U.S. are in ACTG-sponsored trials. Further, only 9 pregnant women have been enrolled in ACTG trials. NIAID, however, continues to report inflated and inaccurate statistics for the participation of "women" in AIDS clinical trials. Their statistics combine into a single number--women, female children, and female infants.

The ACTG System: Where are the Sites and Who Runs the Trials

The 47 ACTG trial sites were selected based on the perceived ability of a particular institute to conduct scientifically sound research. It has long been the perception that such research can take place only in the context of medical school/teaching institution-affiliated hospitals--tertiary care centers. Institutions such as Duke University, UCLA, Johns Hopkins, Columbia University and Ohio State University are part of the ACTG system.

The reality of the lives of women affected by HIV/AIDS is reflected in the places where women seek health care. Primary care (when available at all) is provided at city and county hospitals or in local or state funded clinics. The linkage between these primary care settings for women and the tertiary centers where ACTU sites are located is poor. The result--women with HIV/AIDS either do not know that these trial sites exist or do not have the financial or logistical means to access them. A 1989 National Institutes of Health survey of women giving birth at 46 medical centers where

Federally-sponsored AIDS/HIV clinical trials are underway revealed that women do not receive sufficient referral either to clinical trials or to AIDS-trained physicians.

ACTG trials are proposed and directed by a network of principal investigators (PIs) located at the various ACTU trial sites. Of the 47 PIs, only 8 are women. None of the 47 PIs specialize in gynecology, even though the reality of HIV disease in women often manifests in specific gynecological diseases.

ACTU sites are funded under contracts, called cooperative agreements, between NIAID and the specific site. These contracts request and fund particular resources which are available at the ACTU site. If an immunologist is needed, it is specified in the contract. If the ability to perform CD4 counts in the site's immunology laboratory is needed, it is specified in the contract. None of the 47 cooperative agreements request, specify or fund a gynecologist or an oncologist whose specialty is gynecology. Under the present contracts, if gynecological assessment is to be done, it must be funded through a mechanism outside the ACTG system.

How ACTG Trials are Designed to Exclude Women

Before enrolling in a trial, a woman must provide evidence of adequate birth control. While the concept of "adequate" is subjective, the interpretations of this requirement at various trial sites are diverse. Most site coordinators apply rigid criteria to the interpretation of this question, even if the woman has no plans to become pregnant. The requirement for birth control focuses on women as incubators and potential vectors of disease transmission, trades the advantage of access to experimental therapy in an HIV infected woman for the risks to a "theoretical" fetus and renders HIV infected lesbians invisible.

Although not a requirement for entry into an ACTG trial, a large number of trial sites refuse to admit individuals who are injection drug users (IDUs) and are not enrolled in a drug treatment program. Since 52% of HIV infected women, according to Centers for Disease Control (CDC) statistics, have a history of injection drug use, a majority of these women are excluded. This philosophy presumes two things: first, that there are enough treatment programs to go around, and second, that IDUs are irresponsible. Neither of these assumptions are true.

Baseline levels for liver function enzymes are used as entry criteria for clinical trials. Normal acceptable ranges for these enzyme levels are established arbitrarily and may not be scientifically necessary. These baseline levels are exclusionary to IDUs, since in individuals with a history of drug use, liver function may be impaired (and reflected in elevated liver enzyme).

Other serum markers such as baseline CD4 levels and p24 antigen have not been analyzed in women for correlation to clinical AIDS and may express at lower levels, if at all, in non-white individuals with HIV disease.

Timing for blood collections during the pharmacokinetics phase of trials may be unnecessarily rigid. Specifications for collection increments may not reflect the reality of the half-life of a specific drug and may have been established simply because "that's the way it has always been done." Requiring a 48 hour sample when children must be picked up from school or cared for in the hospital, often results in missed pharmacokinetic appointments and arbitrary removal from protocols.

Individuals who are enrolled in the ACTG-sponsored trials are required to provide their own primary health care and regular physiological assessment. Women as a group are less likely to have access to health care for economic reasons, particularly women with HIV disease who are often poor. Women also make conscious decisions not to access a system which recommends invasive procedures such as total hysterectomies; or where coercive counselling, rather than informed choice is the norm. If primary health care is a requirement for enrollment in an ACTG-sponsored trial, NIAID

must make the funds available for access to that health care.

Since ACTG trial sites are often inaccessible to HIV-infected women, and since many HIV-infected women are single heads of households and may have HIV-infected children, it is imperative that NIAID fund transportation to the site and provide childcare during a woman's visit. Operating hours must be adjusted to reflect reality of women who work. In addition, various sites have not even recognized that by simply seeing pediatric patients and women at the same time and on the same day and time, women could have the opportunity to take care of the healthcare needs of themselves as well as their children.

Most clinical trials which enroll women require urinary testing for controlled substances prior to enrollment. This requirement arbitrarily assumes that most HIV infected women are using drugs. More importantly, results of drug screening are not confidential and may by used by states in child custody decisions or in the case of child abuse (particularly for pregnant women). This requirement puts women in jeopardy and is not disclosed in the informed consent required for trial enrollment.

If cooperative agreement proposals can require institutional assets such as libraries and computers to receive funding, why can't they require the provision of primary care physicians, routine gynecological assessments, child care and transportation? These services should not only be provided during the time that a woman is on a study, but also during the years after the study is complete.

What's Being Studied Vs. What Diseases HIV Infected Women Get

Of the 152 protocols developed under the ACTG system, 63 involve the study of zidovudine (AZT or ZDV). The ACTG system has not evaluated the efficacy or safety of zidovudine for AIDS and its related illnesses in women.

There are 10 ACTG trials which study the effects of various treatment on Kaposi's Sarcoma, 17 which study various treatments on Pneumocystis Carinii Pneumonia (PCP), 12 which study cytomegalovirus (CMV) retinitis, 4 which study cryptococcus, 4 for toxoplasmosis, 1 for histoplasmosis and **19 trials which assess various compounds for efficacy and safety in treating pediatric AIDS.**

There are no trials specifically designed to evaluate the efficacy and safety of treatments for AIDS and related opportunistic infections in women. In addition, there are currently no trials, nor are trials being planned, to study treatments for AIDS manifestations specific to women -pelvic inflammatory disease (PID), human papilloma virus (HPV), cervical cancer or prophylaxis for vaginal thrush (Candida albicans). Most of the trials for opportunistic infections (OIs) target "end-stage" or lifethreatening OIs. This concept ignores the reality that women often do not live long enough to get these particular OIs. In addition, woman-specific OIs exist which are life-threatening and are currently not being studied.

ACTG 126, a trial designed to assess impediments to initial and continued enrollment of IDUs in ACTG clinical trials has been deferred.

The Pediatric Committee of the ACTG System: A Model of Sexism

The Pediatric Committee of the ACTG exists as a fully operational core committee within the ACTG committee structure. A subcommittee of the Pediatric Committee, the OB/GYN subcommittee, is where NIAID officials direct inquiries regarding enrollment of HIV-infected women into the ACTG-sponsored trials.

The reality of the OB/GYN subcommittee is that members are either pediatricians or obstetricians. None are gynecologists and none are interested in the health of women. Members of this

subcommittee speak openly about their interest solely in pediatric AIDS and research into interrupting "vertical transmission".

Out of this committee came ACTG 076, a protocol to assess the efficacy of escalating doses of zidovudine for interruption of fetal transmission. Protocol 076 targets enrollment of 700 pregnant women. The numbers are large to account for the fact that two-thirds of the infants born to these mothers will not be HIV positive. This is the largest ACTG-sponsored trial currently being planned and will use an abundance of constrained financial resources.

The trial requires that these women receive escalating doses of zidovudine, doses which may render them zidovudine-refractory when the course of their own disease may require zidovudine therapy. Maternal laboratory assessments are minimum -assessments designed solely to detect zidovudine toxicity so that doses may continue to be increased.

Although a recently revised draft of the protocol for this trial incorporates a gynecological assessment on entry, the six week follow-up evaluation does not include a gyn exam. It is unethical to use women as "animal models"; i.e. vectors of transmission. The protocol is an example of rampant sexism on the part of the investigators; there are no plans to assess the effect of zidovudine on the women in this trial.

There is substantial evidence for the use of high titer neutralizing gp120 serum antibodies as a screening indicator for fetal outcome. Women whose serum does not contain these antibodies are most likely to give birth to an HIV infected child. Investigators involved in 076 refuse to include this marker as a criterion for enrollment. It is unethical to give AZT to fetuses not likely to be HIV-infected.

In December 1989, Burroughs Wellcome Co. released data on zidovudine indicating that it may be carcinogenic. The ACTG temporarily suspended its studies in pregnant HIV-infected women and their newborns until the carcinogenicity data could be thoroughly reviewed. In the Burroughs study in mice and rats receiving oral zidovudine, histological examination revealed vaginal carcinomas in 10% of the animals tested. The panel which reviewed this alarming data was comprised of Burroughs employees and PIs involved in the 076 trial.

The panel concluded that the potential benefits to newborns outweighed the risk to mothers. These results, the composition of the review panel, and their conclusions raise additional ethical questions regarding the safety and the health of women who enroll in ACTG 076.

There are numerous additional problems with the 076 trial. These were offered simply as an example of the ways in which ACTG trials display a wanton disregard for the health and well being of women.

Why the emphasis on continuing ACTG 076? If any compound can be shown to interrupt fetal transmission of HIV, the next step will be mandatory testing for all high risk pregnant women.

ACTGs: 1990 and Beyond

As a result of activist pressure, the Executive Committee of the ACTG system voted at its last meeting in November 1990, to form a Women's Health Committee, a full core committee with in the ACTG system. There is danger, however, that members of the old OB/GYN subcommittee will simply become the newly formed Women's Health Committee. This must not happen.

The Women's Health Committee must:

- Include a gynecologist, an infectious disease specialist, a GYN oncologist, an HIV positive

woman and a women's health activist. There is no reason to include either an obstetrician or a pediatrician. Individuals with this expertise can be consulted through the Pediatric Committee.

- o Receive full finding commitments immediately

- o Develop standards for gynecological assessments which are routine for every ACTG protocol

- o Immediately write protocols to assess the efficacy of fluconazole as a treatment for vaginal thrush and work with the Oncology Committee to develop treatments for preventing HPV-related CIN and AIN.

Core Committee appointments follow the same incestuous reasoning that is exhibited in concept sheet approvals and drug company consultative agreements with principal investigators. The chair of the newly formed Women's Health Committee has been selected by the Executive Committee, and the appointed chair will select the additional members. Not exactly the ideal of democracy, especially given the lack of commitment to women's lives which has already been exhibited by members of the Executive Committee.

Activists must watch carefully the implementation of ACTG recompetition scheduled for next year. This recompetition is supposed to correct problems of trial accrual, specifically for women and HIV infected people of color. However, NIAID proposals for research initiatives being submitted to various trial sites include the following requests for resources:

- o Support for expansions of the pediatric AIDS clinical trial effort through the establishment of new pediatric clinical trial units.

- o Development of reliable methods for early diagnosis of HIV infection in newborn and infants and establishment of timing of perinatal transmission of HIV.

- o Research into development and use of animal and in vitro models for pediatric metabolism. Research into the mechanisms of transplacental infection.

- o Development of strategies for preventing transmission of HIV from mother to infant.

Where are the requests for proposals to save the lives of women?

Other NIAID Issues/Efforts Which Ignore HIV in Women

The community based trial efforts of NIAID, Community Programs for Clinical Research on AIDS (CPCRA) are following in the footsteps of the ACTG system. A major effort of CPCRA in the upcoming year is a community based version of ACTG 076. In addition, the committee (CPCRA working group) which presumably focuses on women-specific issues is the "Minority, Women's and Children's Issues Working Group." Obviously, CPCRA operates under the same sexist principles as the ACTG system: women don't exist outside the context of children and their ability to reproduce.

The National Cooperative Drug Discovery Groups (NCDDG), funded by NIAID, were developed to encourage collaborations among scientists from academia, industry, and government on research to discover and develop new AIDS therapies. The NCDDG-HIV was established in 1986. The NCDDG-OI (Opportunistic Infections) is a part of this effort. In August, 1990, funding awards were given for the development of six new NCDDG-OIs. The six new awards will focus on:

1) Mycobacterium avium

2) Fungi- cell wall inhibitors
3) Toxoplasma
4) Fungi- enzyme inhibitors
5) Pneumocystis, cytomegalovirus and Toxoplasma and
6) Cryptosporidium.

None of the new NCDDG-OI grants were awarded for Women-specific research.

NIAID also funds epidemiological studies. In 1983, two prospective cohort studies designed to follow the natural history of HIV infection in men were begun. The Multicenter AIDS Cohort Study (MACS) and the San Francisco Men's Health Study (SFMHS) continue to be funded with limited dollars to answer questions such as how treatment affects the natural history of the epidemic, why some people with high risk behavior never become infected with HIV, and how often and for how long HIV infection can occur before it is identified by seroconversion. These issues are duplicative to efforts by the CDC in the Spectrum of Disease study. Limited resources need to be used wisely.

Two other NIAID-funded epidemiology studies are the Heterosexual AIDS Transmission Study (HATS) and the Women/Infants Transmission Study (WITS). The HATS study, as a result of activist pressure, recently included a question which reads, "Have you ever had sex with another woman?" Prior to inclusion of the question, all women interviewed were presumed to be heterosexual. The addition of this question only serves to allow NIAID to obtain "clean heterosexual data"; it does nothing to provide information on woman-to-woman transmission.

NIAID has a long way to go to direct their research agenda in a way that will allow women access to trials and that will provide for the development of treatments which will prolong the lives of women with HIV. Activists will continue to watch, collect information, and demand that NIAID-funded research be directed in a way that will address the changing reality of those who are affected by HIV.

Safety and Efficacy: The FDA'S Role For Women?

The Food and Drug Administration (FDA) is responsible for regulating the entire process of testing experimental drugs in humans. It follows a drug through each phase of testing, and examines data submitted by the trial sponsor after completion of a trial, to determine if the drug meets standards legislated by Congress, and conferred by Congress onto the FDA.

The FDA's mission is to review data and determine that all drugs are both **safe** and **efficacious** prior to their approval for sale on the open market. As a part of this effort, the FDA must also approve all experimental drugs trials as reasonably safe, in relation to the possible benefits of research and risks to trial participants. How has this mission impacted the lives and health of women in the U.S.? Certainly not to the substantial good.

During the late fifties and early sixties a sleeping pill, thalidomide, was in widespread use abroad. Thalidomide was an efficacious sleeping pill, but it was also a drug which caused severe birth defects in children born to pregnant women who had taken it. Dr. Frances Kelsey, an FDA official, had serious questions about the safety of thalidomide and single handedly prevented thalidomide from being approved for use in the U.S.

The thalidomide incident brought the FDA to a devastating conclusion regarding the testing, safety and efficacy of drugs for women; don't test experimental drugs on women of child-bearing age. The one single exception to this rule, of course, is in drugs which deal with reproductive choices. Contraceptives have been developed, tested and released with such a frenzy that women have been forced to use such unsafe methods of birth control as oral contraceptives (the pill) and the Dalcon Shield. Unfortunately, the side affects of these drugs and devices, and drugs such as DES are all too well known.

Meanwhile, drugs which may be equally devastating for women in general, and particularly for women with HIV, are being released to the public with no information on their particular adverse affects in women. The disregard for the differences in women's bodies, the rejection of medical documentation of particular opportunistic infections in women with HIV (particularly gynecological infections and cancers), and the focus on the importance of a fetus as opposed to a woman, have resulted in deadly serious consequences for women with HIV. This sexist obsession with protecting a fetus also ignores the fact that 22% of women with HIV are over 40, and could enroll in trials potentially without the risk of becoming pregnant.

Zidovudine (ZDV), the only licensed antiretroviral therapy, was approved for widespread use despite evidence of its sex- and site- specific carcinogenicity in female animals, and despite alarmingly small numbers of women with HIV in its clinical trials. The few women who participated in the trials, were followed for male-defined complications associated with its use. The trials were not designed to assess the impact of ZDV on gynecological problems.

ZDV is now in widespread use for the treatment of HIV in women. The risk of vaginal carcinoma associated with its use, coupled with the increased incidence of cervical neoplasias in women with HIV is alarming. There is also evidence that fatty liver associated with the use of ZDV may be increased in women, and that individuals who are taking methadone and ZDV may be at increased risk of severe anemia.

The FDA must require immediately that Burroughs-Wellcome institute a Phase IV post-marketing study to assess the safety and efficacy of Retrovir^{R} (ZDV) in women with HIV. The study must be designed to assess parameters such as anemia, interactions with other drugs, pharmacokinetics, and gynecological endpoints. Endpoints assessed must extend beyond CDC-defined AIDS.

Even though women were excluded from the clinical trials of ZDV, women are now being

encouraged to participate in the ACTG-sponsored trial, ACTG 076, designed to assess the efficacy of ZDV in interrupting perinatal transmission of HIV. This protocol, which was reviewed and approved by the FDA, has deadly serious consequences for women (see section on ACTG 076).

Data being collected on a second antiretroviral (which works in a similar fashion to ZDV), ddI, presents a similar picture. Few women are enrolled in the NIAID-sponsored trials of ddI, and only 4% of compassionate use ddI is in women with HIV. None of the data being collected from this use includes data collected from pap smears. Data aren't available to assess the impact of ddI on gynecological problems, yet researchers already make statements that imply no differences in the adverse affects of ddI between women and men.

The FDA has direct regulatory responsibilities to demand appropriate, gender-specific research prior to clinical trial development and drug approval. Prior to initiating a clinical trial, a protocol must be developed detailing the trial's design, procedures, methods of data collection, and exclusion and inclusion criteria. The FDA must approve a clinical trial protocol before the trial can begin. The FDA must begin requiring the inclusion of HIV infected women in trials and must require that data be collected to assess the safety and efficacy of a drug on woman-specific endpoints which are not limited to CDC-defined AIDS.

Every institution which conducts clinical trials must have an Institutional Review Board (IRB) which initially approves research proposals and performs periodic reviews of such research. The IRB is directly answerable to the FDA. IRB reviews are primarily ethical, however, it is unethical for an IRB to approve a protocol which does not consider the safety and health of female trial participants or a trial which systematically and unnecessarily excludes women. Therefore, the FDA must require that IRB's review trial proposals for the inclusion of women and the provision of data collection mechanism designed to assess the effects of such drugs on women-specific opportunistic infections.

Finally, informed consent documents must be developed for every research protocol. This information, given to trial participants prior to trial enrollment must provide accurate information on the risks of a particular therapy or protocol. The informed consent is approved by the IRB. All available information including information from literature searches must be included in the informed consent, and must be written in language accessible to non-medical individuals.

In the absence of a commitment to research on the affects of HIV treatments in women, the FDA must initiate efforts to provide information on such treatments which allow women the availability to choose therapies with information which either presents what women-specific information is known, or clearly states that no supporting scientific information is available.

On March 5, 1990, FDA announced in the Federal Register the availability of a guideline entitled, "Guideline for the Study of Drugs Likely to be Used in the Elderly". The guideline provides detailed advice on the evaluation of new drugs in older patients and is intended to encourage routine and thorough evaluation of the effects of drugs in elderly populations so that physicians will have sufficient information to use drugs properly in older patients. Such guidelines must be developed immediately for studying drugs in HIV infected women.

The Federal Food, Drug, and Cosmetic act (Section 502(f)) states that a drug will be deemed to be misbranded unless its labeling bears "adequate directions for use". These directions are defined in Section 201.5 of FDA's general labeling regulations which state "directions under which the layman (or woman) can use a drug safely and for the purposes for which it is intended".

The FDA (Section 201.57) currently requires that labeling information associated with prescription drugs include information on the use of drugs in pregnant women (actually in a fetus) and in the pediatric population. A proposed rule change by the FDA was outlined in the November 1, 1990, Federal Register requiring a labeling change to include similar information in the geriatric

population.

The FDA must immediately draft an additional proposed rule change to include similar information on the use of drugs in women. All available information from the drug's sponsor relevant to its use in women, including results of controlled studies, other pre- and post-marketing studies or experience, or information obtained from a literature search must be disclosed in labeling. Included in this information must be reports of adverse reactions, required by law to be documented and reported to the FDA.

If clinical studies do not include sufficient numbers of women, a statement to that affect must be included. In addition, a recommendation for starting a drug at the low end of the dosing range should be made. For drugs that are known to be carcinogenic (such as ZDV) or are known to increase the risk of gynecological infections (such as certain antibiotic agents) a statement should be included. This is particularly important for women with HIV. Cautionary statements must not be limited to risks associated with CDC-defined AIDS symptoms/infections.

The FDA must ensure the safety and efficacy of drugs for all populations. Their concern for "special populations" has, to date, excluded women. This practice must stop. The FDA must immediately address the regulatory issues which will ensure that women have access to information which enables them to make an informed choice about their health.

ZDV For Women: A Double Blind Gamble Of Risks Vs. Benefits

The ZDV years, the years when this drug was the treatment of choice for people with HIV, were a time of hope for people with HIV and a time of fierce activist pressure to release a treatment that could save the lives of millions. The politics of expeditious release of ZDV, the intense and incestuous commitment of NIAID to the development of this drug with Burroughs-Wellcome, the subsequent information indicating that ZDV would not be the "cure for AIDS," and the economic devastation associated with the cost of this therapy have been the subject of demonstrations, writings and congressional investigations. The unique and life-threatening problems of ZDV therapy in women with HIV, however, are only beginning to be addressed.

Clinical trials supporting licensure of ZDV included an alarmingly low number of women. The reasons for this exclusion included:

1) a refusal to test experimental therapies in women of child-bearing age,
2) the rejection of the reality that women with HIV exhibit different symptoms than men, and
3) the refusal of NIAID to put into place ACTG trial sites which were both physically and economically accessible to women with HIV.

It is a testament to the willingness of researchers and regulatory authorities to change the rules according to their latest research interests, that each of these three exclusions has in some way been either rejected or ignored in subsequent research on ZDV, or in recommendations for routine ZDV therapy for women with HIV.

The refusal of researchers to test ZDV in women was a result of concerns for a theoretical fetus (see section on FDA). This information was confirmed at a recent conference on women with HIV by a Burroughs-Wellcome spokesperson. Women who enrolled in any of the original trials of ZDV had to document either "appropriate" methods of birth control or commit to abstinence during the duration of the trial. Women's "compliance" with these unnecessary rigid demands were confirmed with routine, periodic pregnancy tests during trials enrollment.

ACTG 076, a trials in which ZDV will be given to HIV infected pregnant women has incorporated a mechanism to circumvent this requirement. Pregnant women enrolled in this trial will be given ZDV during the second and third trimester of pregnancy, since organogenesis (the development of fetal body organs) is complete after the first trimester. It seems that when research interests focus on the theoretical benefits to a fetus, the "rules" no longer apply. Willingness to acknowledge the safety of experimental therapies in this cohort of women should abrogate the arbitrary exclusion of pregnant women or women of child-bearing age in future experimental protocols.

What are the clinical manifestations of HIV in women? Researchers and activists know that both the early indicators of immune dysfunction, as well as the ongoing and end-stage manifestations include gynecological infections and cancers. Refractory vaginal thrush, pelvic inflammatory disease (PID), treatment-resistant human papillomavirus (HPV), and cervical cancers are well-documented in the literature, despite the Centers for Disease Control's (CDC) denial of their existence. However, the small number of women included in the ZDV trials supporting product licensure, ignored these symptoms both from a standpoint of assessing ZDV in interrupting or exacerbating their progression. No gynecological assessments were incorporated into these trials; women were evaluated using male-defined endpoints.

Results of studies in female animals given ZDV reveal an increased incidence of carcinogenicity among these animals. In the Burroughs-Wellcome study, oral ZDV was administered to mice and rats for 18-20 months. Examinations revealed vaginal carcinomas in five female mice. Three female mice had benign vaginal tumors. Literature searches reveal three other compounds which induce vaginal tumors: DES (diethylstilbestrol) a synthetic estrogen, and two naturally-derived estrogen

compounds. The devastating effects of DES are well-known. The increased incidence of vaginal carcinomas in women with HIV, coupled with the information provided in these animal studies, raise serious questions about the long term effects of ZDV in women. Should ZDV be prescribed for HIV-infected women? The answer lies in a post-marketing study to assess the long-term gynecological effects of ZDV in women. Given the available information, the FDA must require that Burroughs-Wellcome fund and conduct just such a study, and until such information is available, these questions should be discussed in the package inserts supplied to pharmacists and physicians with Retrovir.

Additional concerns regarding the effects of ZDV in women include:

1) the increased incidence of fatty livers in women on ZDV therapy,
2) the interaction between ZDV and other concomitant therapies (ie. methadone), and
3) the effects of ZDV on CD4 counts in HIV-infected women (both symptomatic and asymptomatic). The Burroughs post-marketing study must be designed to address these issues as well.

Now that the interest in ZDV research lies in the investigations surrounding fetuses and newborns, trial sites have been selected to target geographic locations with dense populations of women with HIV. Although the intent of ACTG 076 is in no way designed to assess the impact of ZDV on any relevant parameters in women, these very same researchers who rejected women, particularly pregnant women, in the original ZDV trials, are actively seeking women, specifically pregnant women, as an entre' to the study of the "innocent victims." Indeed a woman can participate in this study at centers other than NIAID trial sites; Harlem Hospital, for example, will enroll women since Mount Sinai Medical Center has no access to qualified study subjects.

Where were the same concerted efforts to seek out, enroll, and assess the effects of ZDV on women in the original studies of this drug? If ACTG 076 targets the accrual of 748 pregnant HIV-infected women for this trial, why can't they seek out equally large numbers of women for trials of other antiretrovirals and prophylactic therapies?

There is some data from the original ZDV studies which should be retrievable to begin to answer some questions regarding the risks vs. benefits of ZDV therapy in women. NIAID must instruct the researchers and data analysts to compile and analyze that data immediately. In addition, further work must be done to assess ZDV's effect on women-specific parameters. The risks are too great and the benefits too questionable to require any less.

Transmission

- **o Viral Barriers**
- **o Vector Issues**

Transmission Issues

There are two pieces that make up the puzzle of women's lack of perceived risk. The first part has to do with the way in which public health education campaigns have failed in this epidemic to do little but scapegoat gay men. Most women can feel or have felt a false sense of security in knowing that they are not gay men. In fact, the confusion of "risk groups" with routes of transmission has practically guaranteed the spread of HIV to women. Every time a woman has sex with a man and does not use a condom or has sex with a woman and does not use a latex barrier clearly denotes the CDC's failure to adequately educate the public. As early as 1981, (this comes from the epidemiological article in AIDS: The Burdens of History) cases of women with AIDS were known to this agency. As we see with their refusal to change the definition of AIDS to include gyn-HIV infection, fear of alarm in the white middle class has been at the forefront of the creation of policy in this epidemic.

The second piece of the puzzle, fitting perfectly with the first has to do with practitioners of all varieties not seeing women as possibly HIV-infected. The lack of awareness that women can, do and are becoming HIV-infected prevents them from receiving appropriate medical treatment. Misdiagnosis of AIDS-related diseases in women occurs too often. For example, PCP is the number one documented cause of death in women with AIDS. Interestingly, Chris Norwood in Ms. Magazine in 1988 noted that the number of women in NYC dying of bacterial and other pneumonias increased dramatically over time. Whether or not these women were HIV infected is unknown, but most likely many of them were. Anecdotal reports from HIV positive women chronicle events such as their being sent home from hospital emergency rooms with a prescription for penicillin in hand only to get sicker. As women, they were not seen as possibly HIV-infected and hence in need of particular medical treatment, Finally, a woman need not know her HIV-status in order for her practitioner to begin to think "AIDS".

Finally, a third element which secures the further HIV infection of women is the artificial deflation of numbers in this epidemic. The recent figures are the only way in which people can, short of knowing individuals infected with the virus, feel any proximity to their possible infection. Unfortunately, reading that women account for only 9.1% of adult AIDS diagnoses reinforces the notion of women's safety from infection. The manner in which these numbers are kept low run the gamut from misdiagnosis and underdiagnosis to a medically inappropriate definition of AIDS for women to women's poverty and resultant lack of access to health care. It is sobering to remember that the increase in AID diagnoses in women skyrocketed when this disease's definitions was changed in 1987. One can only imagine how those numbers in women would again soar if cervical cancer, pelvic inflammatory disease, endocarditis and pulmonary tuberculosis were to be included in definition of AIDS. Of course, this is the most morbid of ways to make sure that people feel some proximity to and take some precautions against becoming HIV-infected. It would be altogether easier and less murderous to create safer-sex and safer-drug campaigns that work. In this epidemic, the great educator has been either personal loss of a loved one or feeling overwhelmed at the numbers of "your kind" that are infected. For many gay men, these two factor have been quite persuasive. What does the CDC have in store for women?

Condoms, Lesbians & The Hat Study

Many people have been given the opportunity to feel little fear of HIV or AIDS while other people (namely gay men and IVDU's) have had to shoulder the burden of being perceived as the absolute embodiment of risk. This has far reaching implications for infection control as has been previously discussed. However, it is worthwhile to take note of three ideas that predominate in a discussion of women's perceived lack of risk.

"When the media refer to heterosexual AIDS as a myth, they seem to suggest that "heterosexual" must not include women, because AIDS for heterosexual women is not only a myth, but is what, in some cities, is most likely to kill them." (Women, AIDS and Activism, p. 187)

Condom use has failed because women have been targeted to "get" men to wear these prophylactics. This idea comes from a very uninformed point of view about the real lack of power women have in heterosexual sex. That the CDC has focused very little attention on encouraging condom use among straight men has created a false sense of safety among heterosexuals. Necessary to preventing further infection in women, public art campaigns need to be created that address straight men and make condoms appealing to them. For many women who have sex with men, the fear of becoming HIV infected is insignificant in comparison to the fear of reprisal involved in even suggesting to their lovers that they use condoms. (IBID, p. 188)

Heterosexual women are vulnerable to this virus through a lack of power in sex. Simply knowing what prevents transmission is not a guarantee of behavior change in the least. However, not knowing what prevents transmission of this disease places lesbians in a rather precarious position. Of all the women who have a perceived lack of risk, lesbian's lack of information and overall denial that they are at risk is overwhelming. This problem could be somewhat remedied if the CDC would study the ways in which people become infected, and not who's infected them. Indeed, if this were to take place, by necessity cunnilingus would come to be considered a risk behavior and all people, including lesbians, could realistically assess their risk of infection by this and other modes of transmission.

How the Government and the Media Blame Women for the AIDS Crisis
"Vector Discussions"

The normal discourse about women in the HIV pandemic has focused on our role as vectors of transmission. The intent of this discussion, of course, is to continue the long and sexist tradition of sending messages of guilt to women. On an examination of the science, however, the fact is that women infrequently transmit HIV. Women are twelve times more likely to become infected during vaginal intercourse with a male sexual partner than the other way around. And, the incidence of perinatal transmission has been estimated as approximately 33%. The occurrence of perinatal transmission is reported to be as low as 15% when women receive adequate prenatal health care.

Several factors may exacerbate the alarming rate of male to female transmission of HIV. Most of these relate to circumstances causing erosions of the surface of the cervix or vagina. Note: It has been postulated that the increased incidence of cervical carcinoma associated with ZDV therapy is also a result of vaginal/cervical sloughing, resulting in increased contact of ZDV urinary by-products with the vaginal/cervical subepithelium.

Cervical infections and genital ulcers -caused particularly by syphilis, gonorrhea, Herpes simplex-2, trichomoniasis, and chlamydial infection may increase HIV transmission by disrupting the integrity of the cervical mucosa. An association has also been found between HIV transmission and the use of oral contraceptives. When cervical erosion occurs, the columnar epithelial cells lining the cervical canal extend to an area of the cervix ordinarily protected by squamous epithelium, appearing as a friable, reddened area.

As cervical erosion is a natural consequence of puberty, this may account for the increased incidence of young women of reproductive age who become HIV infected (as compared to older women). Sexual activity during menses may be an additional risk factor.

Vaginal tightening agents and vaginal herbal medicines may increase the risk of female HIV transmission. In addition, semen with increased numbers of lymphocytes may pose an additional risk. Intercourse with men who have not been circumcised or who have penile ulcers have also been implicated in increased transmission.

The lack of research into modes of transmission leaves the above questions unanswered. It is imperative, however, that women be informed of these possible risk factors when making decisions about their relative risks of infection.

Almost every current and available barrier to HIV transmission is fraught with problems, particularly from the perspective of women. Relying on women to control the use of condoms with male sexual partners is ridiculous.

Recent studies of spermicides as virucides raise serious concerns. A recent study by Joan Kreiss (University of Washington), found that nonoxynol-9, on a vaginal sponge or as a suppository, was not protective against HIV. Further, in the case of the vaginal sponge, it may have actually been associated with increased rates of transmission.

Lack of specific transmission research has led to a variety of "home remedy" viral barriers. Finger cots (latex gloves and tips used on the finger during vaginal and anal insertion) are used by some. Research into the incidence of transmission via digital to oral/anal insertion may show that this type of protection is unnecessary.

Dental dams or rubber barriers have been used for protection during oral/anal and oral/vaginal sex.

The Centers for Disease Control's Policies

Until the Center's for Disease Control changes the definition of AIDS to include gynecological infections, there is no reason to believe that NIAID will sponsor clinical trials to study HIV-related gynecological infections. Government agencies have a responsibility to each other and to the public. Scientists must use their authority to assert needed pressure on other government institutions when they stand in the way of life-saving scientific and medical research. Clearly this is what is need to stem the already overflowing epidemic of AIDS in women.

Women, The AIDS Crisis, and the Centers for Disease Control

Basic to the prevention and spread of any disease, as well as to the care of people who are ill, is the knowledge of its symptoms and routes of transmission. This information may eventually lead to understanding the cause of a disease but the most important part of epidemiological research is that the information gathered can reduce the impact of a disease even before its exact nature is understood.

Accurate information about symptoms and transmission routes is necessary, first and foremost, so that people , themselves, can take preventative measures to avoid infection, can determine if they might be infected, and can seek appropriate care (if it exists) and avoid further transmission.

Accurate information about symptoms and transmission routes is also important for health providers, although they usually see people after they are already ill. However, if they know what symptoms to look for they can be alert for signs of illness in people who may not know they are ill.

Accurate information about symptoms and transmission routes is necessary to provide the basis for focusing scientific research on appropriate treatments and for providing standards of care for people who are ill.

Finally in an epidemic, accurate information about symptoms forms the basis for establishing the extent of the epidemic. This information about symptoms is necessary in order to obtain an adequate level of funding from Federal, State and Local governments. Without adequate funding for education, prevention, social services, research and treatment we cannot end this epidemic and people will continue to die needlessly.

The Centers for Disease Control, which is part of the Public Health Service, is the agency charged with doing the appropriate epidemiological research, with developing prevention and education programs and with setting standards of care. Yet, **when it comes to the AIDS crisis, the CDC is not doing an adequate job in any of these respects.** After 10 1/2 years into this epidemic, the information they have collected (and are still collecting) is minimal and misleading. It includes no women-specific symptoms. The CDC knows very little about transmission routes for people and their method of defining AIDS which excludes the symptoms women are getting keeps the extent of this epidemic artificially low and becomes a barrier to obtaining the funding necessary to end this crisis. They have published few standards of care and the research they are now doing is inadequate and will not provide useful information for several years.

Instead of collecting and disseminating accurate information and doing appropriate research in an efficient manner, the CDC has focused most of its energies and funding on mandatory and confidential, rather than anonymous testing and is seeking to institute undemocratic and unnecessary control procedures -contact tracing, partner notification and "routine testing", especially for pregnant women. **These strategies have been shown not to work** for sexually transmitted diseases or for TB. They act to make people avoid seeking medical care, especially those people who have had a history of negative treatment by the health system, including people of color, women, poor people,

intravenous drug users and lesbians and gay men. These measures substitute a false sense of control for effective programs and practices of prevention, education and treatment which would really save lives.

In this section of our Women's Treatment and Research Agenda we will address:

- o the background and history of the current AIDS Surveillance definition;
- o the data currently being collected -what is missing and what is wrong;
- o why the CDC surveillance definition is important;
- o other problems with CDC research and policy, especially in relation to women; and
- o what we believe the CDC must do to save lives.

Background and History of the Current CDC Surveillance Definition of AIDS

AIDS is not a single disease -it is a syndrome -Acquired Immune Deficiency Syndrome. A syndrome is medically defined as a set of symptoms and diseases. This set changes and, therefore, the basis for a diagnosis changes. It is not fixed like, for example, TB. The definition of a syndrome must be continually changed as new symptoms are identified. In addition, not everyone gets symptoms. Some symptoms will be unique to specific groups because of anatomical differences. For example, women have vaginas, uteruses, fallopian tubes and ovaries. Men do not have these organs and opportunistic infections associated with AIDS cannot affect them in these sites. Some other differences which could produce different symptoms and severity of symptoms in different people might be their general state of health, the mode of HIV transmission, endocrine differences, age, geographic location, and so on.

There are at least **three different systems** the CDC refers to in relation to AIDS/HIV:

1) **The CDC has a classification system for HIV disease.** This divides people, all of whom have tested positive for HIV, into groups starting with HIV, asymptomatic. It is supposedly based on clinical manifestation of HIV disease, **although not one gynecological symptom** is listed in any category. This means that a woman who has tested positive for HIV would be considered asymptomatic even is she had any number of gynecological symptoms known to be associated with HIV. This system is supposedly not hierarchical in terms of severity, but it does range from asymptomatic to a listing of conditions. It is not used for surveillance purposes.
2) There is also an **international classification system** (MMWR, 36, No 7), in which a person doing the reporting codes "associated conditions" under categories of "with HIV", "due to HIV", "with an AIDS-like disease", "due to an AIDS-like disease", "with AIDS" and "due to AIDS". AIDS, in this system, is defined according to the CDC surveillance definition. Although there are over 50 categories of "associated conditions" on this list (and a larger number of specific infections), **not one gynecological symptom is listed in any category.**
3) <u>The CDC has a surveillance definition of AIDS.</u> The surveillance definition of AIDS is the only one used for U.S. national reporting. It is the most limited set of symptoms compared to the other two; it includes cases which are diagnosed "presumptively", that is people who show certain symptoms but whose lab tests have not been done; it also includes people who have no laboratory evidence of HIV but who show specific diseases/symptoms and for whom causes other than HIV have been ruled out. **This classification system does not include any gynecological symptoms.** The figures from this system are the only ones used for determining the extent of the epidemic and on which budget requests are based. For example, this was the data used to determine the choice of sites for the CARE Bill Funds as well as for the allocation of these funds across sites.

The CDC surveillance definition was originally published in 1982, based on a small number of cases among predominantly white gay men. The conditions then considered to constitute an AIDS case for national reporting were limited (PCP, KS, cryptococcal meningitis, and certain lymphomas). This was before HIV was discovered. No research had been done.

Here is what officials at the Centers for Disease Control said about creating that definition:[101]

> "Yes, we asked clinicians."
>
> "Yes, we went around the country looking for more cases -surveillance data -opportunistic infections -it wasn't clear that is was an epidemic at first -an epidemic of Kaposi's Sarcoma, an epidemic of pneumocystis pneumonia -so we looked for everything ...what we found got included in the definition."

AIDS was so associated with gay men at that time that, initially, it was called GRID (Gay-Related Immune Deficiency). That AIDS was associated with a "gay-male life style" can be viewed both positively and negatively. Epidemiologically speaking, on the positive side, the fact that it was discovered "Post-Stonewall" (after the Gay Liberation movement) meant that some gay men were out enough to self-identify. Therefore, the reporting of PCP, even in a small number of cases (5) who all self-identified as gay might be the only thing that led to its discovery at all. (It has since become clear that there were earlier cases, notably among intravenous drug users, which had never been identified). And, since the CDC had just been involved with the Hepatitis B studies in the gay community, they were familiar enough with gay male sexual behavior to look for possible clues to transmission. However, the negative part was the immediate connection between a gay "life-style" (including the use of "poppers") and the illness -a homophobic direction -which we have never recovered from and which not only still affects the gay community but affects everyone else as well.

Between 1983 and 1985, HIV was discovered (first by the French and called Lymphadenopathy-Associated Virus, LAV; then by the Americans and called Human T-cell Lymphotropic Virus III, HTLV-III; and finally, after an international panel arbitrated the issue, it became known as the Human Immunodeficiency Virus, HIV). It is considered to be the cause of AIDS (although there is still disagreement as to whether it is the sole cause of AIDS and, for some people, whether it is the cause of AIDS at all).

NIAID (The National Institute for Allergy and Infectious Diseases), in 1983, instituted its only major epidemiological study to date -The Multicenter AIDS Cohort Study (MACS). Initial evaluations were completed in April, 1985. 4,955 gay men were involved in this study; 1,835 were seropositive on entry, the remainder were not. This is a natural history study. Every six months the men have physical exams, answer questions, and provide lab specimens. According to NIAID, this study identified unprotected "anal-receptive" intercourse as the primary route of transmission and also showed the link between T-cell suppression and seropositivity. As it progressed it also provided information for expanding the CDC surveillance definition.

In 1985 the CDC made its first substantive revision of their surveillance definition. Some diseases were added to their list. The definition made a distinction between opportunistic diseases present with an HIV+ finding and those present with such a finding. Even so, the CDC estimated that its 1985 revisions resulted in the reclassification of less than one percent of previously reported cases and added only 3-4% new cases. At this point there had been 428 female AIDS cases reported and

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[101] These quotes and others are from a meeting which took place at the CDC, Atlanta, Nov. 19, 1990. Present were members of ACT UP and Lifeforce (a peer education project for HIV+ women) and Gary Noble, Ruth Berkelman, May Guinan, Jacob Gayle, Bert Petersen, Peter Drotman and Bill Para, all of the CDC.

1,785 intravenous drug users -1,511 male, 224 female -compared to 5,413 homosexual/bisexual males).

In 1987, the CDC once again revised its surveillance definition with changes in both adult and pediatric definitions. In describing the process they used to change the pediatric definition, the CDC stated that they gathered together clinicians and other experts who had been seeing cases of pediatric AIDS (although the number was quite small at that time) and used their information on which to define Pediatric AIDS symptoms. For adults, additions included HIV encephalopathy (dementia), HIV wasting syndrome and certain lymphomas. Finally, the CDC added diagnosis made presumptively (without having to do with laboratory tests) as long as a person was HIV+. In our opinion the diseases which were added in 1987 were probably found because the gay men being followed were starting to live longer due to medications for opportunistic infections including PCP prophylaxis. As some diseases in this group started becoming less prevalent, others began to appear at a more advanced state of illness (HIV Wasting Syndrome or HIV Dementia). **This revision had a significant impact on reported cases of AIDS:**

a) Prior to the revision, of cases meeting the CDC definition, 67% were homosexual/bisexual men and 23% were intravenous drug users. In the first year following the revision, the percent who were intravenous drug users, both homosexual and heterosexual, increased to 43%, Blacks increased from 24%-36%, Hispanics from 13%-16%, and women from 2.6%-3.6%.

b) As of 1989, nationally, approximately 30% of new cases fit only the 1987 definition. In the latest New York City Surveillance report, all cases diagnosed since January 1990, 30% of all cases fit only the 1987 revision. Furthermore, 38% of IVDU cases fit only the 1987 definition and 26% of heterosexual transmission cases fit only the 1987 definition.

c) In the August 1990 CDC National Surveillance Report, of reported cases fitting only the 1987 definition, approximately 56% were presumptively diagnosed and about 30% were people diagnosed with HIV encephalopathy or HIV wasting syndrome.

d) According to the CDC itself, "Compared with patients who meet the pre-1987 definition, a higher proportion of patients who meet only the 1987 definition were female, Black or Hispanic or were intravenous drug users." (HIV/AIDS Surveillance Report, August 1990). Both locally in NYC and nationally these categories overlap. For e.g., nationally, 58% of reported AIDS cases among Black females were listed under IVDU (August 1990).

Why was it that adding these few, new advanced diseases/symptoms and, especially presumptive diagnoses, resulted in so many new cases among women, Blacks, Latino/as, and intravenous drug users? This is the way we have pieced the story together:

o The majority of people who were not (and still are not) being counted are people who are poor, have little access to health care (including drug rehabilitation), and do not have primary care physicians or access to expensive testing. Some gay men who were not being counted had access to private physicians who did not report them until they had to enter the hospital system -at a more advanced stage of the disease.

o Due to institutionalized racism and sexism in this country, both economic and otherwise, a disproportionate number of women, Blacks and Latino/as are poor. They do not have access to private health care and have to use public health care systems when necessary (and if they are available). Women tend to come more into contact with these systems in their roles as caretakers of others and because childbirth has been moved outside the home and into the hospitals. Many poor people do not go for health care in these settings until they are very ill; women often go to emergency rooms when they are about to give birth. In both cases this is due to the way poor people have been treated, personally and medically, in such systems. Even when it comes to intravenous drug use, it is poor people who enter the public system since wealthier people can go to private physicians and avoid becoming part of published statistics.

o There began to be enough cases reported in other than gay males so that health care

providers could be alert to the possibility that AIDS was a possible diagnosis.

o The earlier opportunistic infections, in women especially, but also in intravenous drug users (many of whom are women) are not listed in the CDC definition.

o The infections/symptoms which were added in 1987 occur later on in illness and these people were probably diagnosed when they were close to death; many were not diagnosed until after death. Finally, presumptive diagnosis would allow low-funded public health care systems to diagnose people without having to do expensive diagnostic testing.

Yet, despite these additional cases, recent studies indicate that 35-40% of the serious HIV related disease treated in hospital in-patient settings do not fit the CDC definition of AIDS. (New York City Department of Health Case Projections, 1989-1993). And, in one CDC study of the death certificates for women which listed HIV/AIDS, 48% died from conditions not listed in the CDC definition.[102]

And, the CDC admits that "Diagnosed AIDS cases do not represent all cases of severe morbidity associated with HIV infection. Many HIV+ persons suffer from illnesses that are not reportable as AIDS even under the current definition and some persons may not have access to medical or diagnostic care. The number of persons with serve HIV related morbidity exceeds the number of diagnosed AIDS cases."[103]

The Data Being Collected -What's Missing and What's Wrong

When somebody already fits the CDC definition, the health provider is supposed to report the case to the CDC (or to their local surveillance unit). The CDC keeps these statistics by case number (although the names exist). Other data include age, race, sex of the person, their geographic location (by zip codes), the mode of transmission (actually a "risk group" in the way it is done) and the "life-threatening illness" at the time of the AIDS diagnosis. The CDC collects no other information about the use until the person dies. This is what the CDC has been collecting and publishing for 10 years. They don't even know what diseases someone dies from (you don't "die from AIDS"; a person dies from an AIDS-related cause). Many people become part of the CDC data only after death when an autopsy reveals HIV.

Getting counted is a catch-22. You have to already have an identified disease in order to be counted and they only identify that disease. How can a new disease be added as they should in the case of a syndrome? <u>They haven't been added since 1987</u>. Those diseases now in the definition come from a very selected sample of people, predominantly gay men.

Much research now exists which shows and association between HIV and specific opportunistic infections or indicator diseases which have atypical outcomes in immunocompromised people (not responsive to conventional therapies, much more rapid progression, and so on). <u>These are infections or diseases which are showing up primarily in women and intravenous drug users. They are severe, disabling conditions which are life-threatening. Why aren't they being included in the CDC surveillance definition?</u>

When we met with officials from the CDC on November 19th, they could not provide a satisfactory answer to this question. Here are some of the answers they gave (Although in quotes, the answers are paraphrases of longer answers):

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[102] Chu S, et al., "Impact of the Human Immunodeficiency Virus Epidemic on Mortality in Women of Reproductive Age, United States," <u>JAMA</u>, July 11, 1990, 254(4):225-229.

[103] <u>MMWR</u> Supplement, 5/12/89. AIDS and Human Immunodeficiency Virus Infection in the United States, 1988 update.

"Some women who are HIV+ show some of these symptoms while others don't" (This is also true for the symptoms in the current CDC definition; some HIV+ men get them and others don't. In fact, this is the nature of a syndrome; it does not have the same pattern in all people).

"So many women get these infections that we can't be sure they are caused by HIV". (In fact, the CDC definition now in existence lists infections which gay men had before the AIDS epidemic. One is Herpes Simplex Virus. However, there is a condition attached to its use as a definer of AIDS: "causing a mucocutaneous ulcer that persists longer than one month". Isn't it possible to do the same thing with symptoms women show?

"So many women have pelvic inflammatory disease and vaginal thrush that it would throw them into a panic if they believed they might be HIV+ or have AIDS." (Since the CDC wants to push "routine testing", their strategy would seen to raise more panic since such testing would not be based on the appearance of symptoms at all).

"How could a doctor tell the difference between severe, chronic pelvic inflammatory disease that is not AIDS related and a case that is?" (The current international classification system asks health care providers to do just that with over 50 diseases). Dr. Harold Minkoff, at the National Conference on Women and HIV Infection, December 1990, stated that clinically one could tell the difference between PID in a severely immunocompromised woman and PID in a woman without severe immunocompromise.

"The bottom line is immunosuppression -we look for immunosuppression as the cause of the disease." (There is research showing a relationship between immunosuppression, HPV and Cervical Cancer -see section on opportunistic diseases in women. PCP occurs in cases of immunosuppression other than HIV).

"When you talk about less severe diseases they really aren't AIDS -they are not life-threatening." (People who have a bout of pneumocystis pneumonia -which is in the current definition -can live for years. Certainly cervical carcinoma is not less severe than some diseases already listed in the CDC definition).

"We would be laughed out of the country for inflating the epidemic curve and simply trying to bring more money into AIDS research." (This is not a reason for giving up scientific integrity and for sacrificing women's lives. We need more money for AIDS research.)

"We need more research to show a casual relationship between the conditions women get and HIV before we can include them in the definition." (All the surveillance definitions so far have been based on clinical evidence and not on large scale research studies showing causality beyond a shadow of a doubt. There are many doctors seeing hundreds of HIV+ women and who know which symptoms they are getting. There is also more research now in terms of relating certain symptoms to HIV in women than there ever was on which to base earlier definitions. The CDC is using a double standard for women.)

Given their stated concern with research and the lack of major epidemiological studies of women, one would think that the CDC would focus on that area. Yet, last year, the CDC instituted studies designed, according to them, to finally get information on the spectrum of diseases shown by a broader range of people with HIV infection (that is, people other than gay men). The SPECTRUM

OF DISEASE STUDIES have been underway for about one year. The sites chosen were Atlanta, Dallas, Seattle and Denver. (They did not choose Newark, Brooklyn, Miami, San Juan or other cities with the largest numbers of reported cases for women or intravenous drug users). How was this study done and what type of information is being collected about whom?

- Each site was allowed to design their own study. In Atlanta, representatives from ACT UP have participated in designing the study. We were told that Atlanta will account for 60% of the data because they were the only location which used multiple sites to gather cases. In the other locations, one hospital or provider has been selected as the source of information.
- In our meeting at the CDC we confirmed our earlier information that although a total of 4,000 people are now involved in these studies only 7% are women. We were also told that there are few people of color and few intravenous drug users. Is this another study of gay men? If the CDC so desperately needs a research base for their changes in definition, how could they design yet another study which excludes women?
- We found out that when the Atlanta site presented their list of opportunistic infections/indicator diseases for approval by the CDC they were told they should not collect data on vaginal thrush because lots of women get it. Therefore, when we wanted to access this data it had not been entered into the computer and we were told that perhaps it we went through each form by hand it might be listed under "other conditions." CDC officials did not seem to know about this at all.

Clearly, the CDC is unwilling to change their surveillance definition to include infections/indicator diseases specific to women, diseases which have been documented clinically and in scientific research papers. The CDC is requiring a different procedure for adding these infections compared to the procedures used for earlier revisions. The CDC is requiring a level and type of research it did not require for earlier revisions, research will take years and years to complete. Their own research, supposedly designed to include women, has only 7% women among 4,000 people after one year. The CDC's willful use of such a double standard and their inadequate monitoring of their own research (or willful concern for its adequacy) has no scientific justification, is unethical and will be responsible for the deaths of thousands of women.

Why the CDC Surveillance Definition is Important

Many social service benefits as well as access to experimental drug trials are based on having CDC defined AIDS. Obviously, these agencies do not have to use the CDC definition. For example, the HHS has an independent responsibility to decide what constitutes a disabling condition. Yet, while the CDC does not have a legal responsibility in this regard, they do have a moral responsibility. They are the government agency charged with defining such diseases. Social services agencies, whether on the federal, state or local levels may not have the capabilities to do such epidemiological research, nor could other smaller agencies. Obviously, the CDC should be playing a leadership role in this area. By refusing to include the opportunistic infections women are getting into their definition, the CDC is ultimately responsible for the denial of these benefits and the exclusion of women from experimental drug trials, their denial of housing and so on.

The lack of acknowledgement of women specific opportunistic infections also has repercussions for women's ability to monitor their own health and to determine they are ill as well as for health providers abilities to be alert to and diagnose AIDS in women before they are so sick that they die quickly. Educational material published by the CDC does not specify these infections, making it impossible for women to know they may be ill. Instead, the CDC pushed "routine testing", confidential testing, and mandatory testing, partner notification and contact tracing. These strategies will not work. Instead of bringing women towards the health care system they will push them away from it.

One suggestion made is that the CDC should add some of these infections to their classification system but leave their surveillance definition untouched. However, we should not be willing to accept changes only at this level. While adding some new opportunistic infections to this system would help alert some health care providers to look for new symptoms, and might catch some cases earlier, this is not enough! Why?

The Current CDC surveillance definition is actively keeping the number of cases of AIDS artificially lowered.

The CDC admits that, even using their current definition they undercount cases by 40%. They admit there are people who are HIV+ who are severely ill but whose symptoms are not in the current definition. We know that there are no women-specific symptoms included in the definition.

Right now, the people who are being excluded are overwhelmingly women and intravenous drug users, who are poor and disproportionately people of color due to institutionalized racism in this country.

The CDC's unwillingness to change their surveillance definition will also affect gay men, even those with access to health care. Over the last year there have been articles claiming that the rate of new AIDS cases is dropping among gay men. This doesn't mean there are no new cases, just that the number being added each month is lower than in earlier years and the total number is rising more slowly. In these articles several explanations are offered. One is that gay men are practicing safer sex. Another is that they are using prophylaxis and treatments so that they are not yet showing up as AIDS cases, according to CDC definition.

This last point relates directly to the surveillance definition. PCP has been the major presumptive and definitive opportunistic infection at diagnosis for AIDS in the U.S. (TB is the major one worldwide but is not in the CDC definition). In New York, PCP accounts for 16,629 out of 26,205 cases. Since many gay men have access to PCP prophylaxis and will not have PCP as their first OI, they will not be counted as having AIDS until they have a more "severe" condition, one that occurs later in illness. KS is the second most frequently reported diagnosis in N.Y. (4,038), although it is substantially lower in number. However, KS is also declining, perhaps because it is an opportunistic infection that is linked to other co-factors. (We have been given hardly any information at all by the CDC as to whether specific opportunistic infections are associated with different modes of transmission). The safer sex explanation for lowered cases is beginning to be countered by papers presented at the VIth International on "relapse" behavior in relation to safer sex practices.[104]

Given this information, refusing to change the current definition has three outcomes:

1) It keeps the overall scope of the epidemic lower than it is.
2) It keeps the number of cases of other than gay men lower than they should be and it keeps the number of cases of women extremely low.
3) It keeps the rate of increase for gay men lower than it is.

This combination of effects is a perfect rationale for overall lowered funding for this epidemic. The fate of the Care Bill is a prime example. It avoids the issue of the need for national health care. It can divide one community against the other in fighting for the funding that does not exist. It still keeps AIDS an overwhelmingly "gay disease" and current studies of "relapse" behavior can be the

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[104] When we raised this point during our meeting at the CDC we were told that the rate among gay men was not decreasing; that there was a "trend toward a decrease in urban areas with large numbers of cases but that elsewhere in the country the rates were increasing". When asked why they had not countered newspaper reports about the decrease, they finally admitted that they should have but did not.

basis for another homophobic attack in the future.

In order to get the type of funding needed for health care, research and treatment and education It is essential that the true scope of this epidemic be recorded. This can only happen if the opportunistic infections/indicator diseases affecting all people be represented in the CDC surveillance definition of AIDS.

Other Problems with CDC Research and Policy

a. The CDC is not collecting data on the progression of HIV disease, that is, its natural history in all people affected. Nor is it collecting data on the entire spectrum of diseases after diagnoses. Progression studies do not require the abandonment of anonymous testing. We can find ways to gather this data.

b. Without data on disease progression and OIs after diagnosis we:

1. do not really know how HIV is being transmitted and how transmission routes relate to opportunistic infections/indicator diseases and cannot focus the development of preventative treatments and protocols where they are needed
2. cannot develop standards of care because we don't know why some people are living while others are dying. Of particular interest here is research showing that women with HIV who receive primary health care live longer than those who don't, regardless of specific medical treatment.
3. cannot effectively educate people, both people with HIV who don't know it and health care providers who don't recognize it. A woman reading the usual pamphlet describing symptoms of HIV disease will not recognize herself unless she is desperately ill. (An exception here that I know of is a pamphlet put out by the New Jersey Women and AIDS Network which lists likely opportunistic infections in women). A doctor reading the CDC classification system (let alone the AIDS Surveillance definition) will not recognize a woman who is HIV positive.

c. Instead of doing the type of epidemiological research and massive education they should be doing, the CDC is instead focusing on "routine" testing of pregnant women, and moving towards confidential, rather than anonymous, testing, partner notification and contact tracing. These are not preventative strategies that work.

d. Furthermore, the CDC is still focusing on women as "fetus carriers" and seem more concerned about the fetus than the woman. In addition to the spectrum of diseases studies discussed earlier, the CDC has two other major studies now:

1) a study to assess behavior in "high-risk" women in decisionsabout contraceptive and pregnancy choices; and
2) a study of biological markers of pregnant women that correlate with the outcome of the fetus (U.S. and Africa). We were told that only if they get more funding this year will they look at "non-pregnant" women. In reality they are not looking at the woman at all--they are looking at the fetus.

e. The CDC epidemiology still relies on "risk groups" and does not explicitly describe modes of transmission. If you look at their tables you see a category for "homosexual/bisexual sexual contact". Is this meant to imply "anal intercourse without a condom"?

f. Women are listed as the sex partners of men (sex partner of an IVDU, for example). Men are presumed to be their sex partners since none of the studies or

questionnaires ask explicit questions about woman to woman sexual behavior. Yet,

- o From 1981 to 1984 there were 101 reported cases of AIDS in which the women self-identified as lesbians or bisexual. The CDC decided not to collect this information any longer because there "weren't enough cases."
- o While many cases of lesbians with AIDS are among lesbians who are also or were intravenous drug users, there have been documented cases of woman-to-woman sexual transmission (Ribble, D. HIV Infection in Lesbians. Poster presented at the 5th International AIDS Conference, Montreal, 1989; Cohen, J.B., Hauer, L.B. and Wofsy, C.B.: Women and IV Drugs: Parenteral and Heterosexual Transmission of Human Immuno-Deficiency Virus: The Journal of Drug Issues, 1989, 19:39-56; Marmor, M., Weiss, L.R., Lyden, M., Weiss, S.H., Saxinger, W.C., Spira, T.J., and Feorino, P.M. Possible female-to-female transmission of Human Immunodeficiency Virus (letter): Annals of Internal Medicine: 105: 969; Mondanaro, J.: Treating Chemically Dependent Women. Lexington Books, 1988.
- o The percent of "undetermined risk" cases for women nationally is twice that of men: 7% vs. 3% in New York: 10% vs. 5%. The CDC recently acknowledged that this is where woman-to-woman cases would be listed.
- o Cunnilingus is not listed as a possible mode of transmission (female-to-female or male-female) even though there was a letter last year in one of the major medical journals documenting a case of a man who apparently became HIV+ and had only cunnilingual sex with a woman for 13 years.
- o Without detailing all possible ways that a woman might transmit HIV to another woman sexually, the most obvious way is through oral-vaginal unprotected sex during menstruation. Somehow no one puts menstrual blood in the same category as "blood".
- o Even now, NIAID is beginning what they call a "heterosexual" transmission study in women. When we confronted Dan Hoth about his inability to say these women were definitively heterosexual because no one is asking questions about woman-to-woman sexual behavior, he finally replied that they would add a question asking "Have you ever had sex with a woman?". This may allow him to separate the two groups but it will provide no information about what type of woman-to-woman sexual behavior occurred. It's goal is to keep their sample "clean" and not to provide transmission information about all women.

g. The CDC Surveillance definition places people hierarchically. For example, if a woman has ever used drugs she will be placed in the IVDU category even if she has also had unprotected vaginal intercourse with a man who was HIV positive, or who fits some other "suspect" group. Surveillance reports list overlaps between categories, although the only one which forms its own separate category is homosexual/bisexual IVDU.

- o Of 18,469 cases for which they list overlapping categories in August 1990, 13,201 are counted in their main surveillance statistics as homosexual/bisexual contact (men), of whom 8.714 were also IVDUs; 1,726 had heterosexual contact in addition to homosexual contact and are listed under homosexual/bisexual (these must be men because no women are listed under bisexual). Of 6,572 cases of heterosexual contact which overlap, 3,499 also were IVDUs but are listed in the main surveillance report under IVDU (the report does not divide these overlapping categories by sex).

- o Given that the CDC often relies on local reporting and given the sloppiness of its own categories, how do we know what the real story of transmission is, especially for women?

Obviously the CDC definition of AIDS as well as its epidemiology are bad science and are political as well as medical issues.

What the CDC Must do in Order to Save Lives

November 25, 1990

Memorandum

TO: Gary Noble, M.D., Centers for Disease Control
FROM: Maxine Wolfe for the ACT UP Network
RE: Demands for Changes in the CDC Epidemiology and AIDS Policies

1. We demand that the CDC's surveillance definition of AIDS immediately be revised so that opportunistic infections and/or indicator diseases with atypical outcomes in immunocompromised people, presently being diagnosed, be added. These include but are not limited to: chronic pelvic inflammatory disease unresponsive to conventional therapy, including but not limited to repeated episodes of endometritis, salpingitis, tuboovarian abscesses leading to multiple pelvic adhesions and chronic pelvic pain; chronic refractory vaginal thrush (candidiasis); chancroid, unresponsive to conventional therapy; anal, vulvar or vaginal condylomas (caused by Human Papillomavirus), unresponsive to conventional therapy; genital ulcers of undetermined etiology which last for more than 4 weeks and which are unresponsive to empiric therapy; vulvar, vaginal, cervical and anal squamous cell neoplasias of the lower genital track; chronic, refractory urinary tract infections unresponsive to conventional therapies; neurosyphilis, with laboratory evidence of HIV, or definitively diagnosed reactivation of syphilis; renal failure with laboratory evidence of HIV and with exclusion of other causes; pulmonary tuberculosis with laboratory evidence of HIV; endocarditis' unresponsive to conventional treatment; neutropenia (non-AZT related); bacterial and atypical pneumonias unresponsive to conventional therapy; chronic or fulminant hepatitis; thrombocytopenia.

2. We demand that the CDC immediately institute a mechanism for regular periodic review and revision of its surveillance definition on a quarterly basis to include newly discovered or developing opportunistic diseases in all affected people. Representatives from all communities must be included in this process of review and revision.

3. We demand that the CDC immediately revise its system of collecting and publishing AIDS statistics:

   - o The CDC must abandon its system of collecting and publishing statistics by "risk group" and, instead, collect and disseminate statistics based explicitly described modes of transmission. For example, "anal-intercourse -no condom" should be a mode of transmission which can occur for both men and women.

   - o The CDC must collect and publish statistics on modes of transmission which do not now appear in their surveillance reports, for example, "cunnilingus -no latex barrier", and this data should be collected for both female-female and male-female sexual partners.

   - o The CDC must stop listing women according to the behavior of their presumed male sex partner and, instead, list both men and women according to specific modes of transmission.

4. We demand that the CDC abandon their misguided strategies and intentions for "routine" and mandatory testing, partner notification and contact tracing, as well as their policy of counseling women with HIV disease to delay pregnancies. These strategies and policies protect no one. Instead,

- o The CDC must direct its resources towards developing and widely disseminating educational materials which include explicit descriptions of all transmission routs and possible opportunistic infections/symptoms, especially those affecting women and intravenous drug users. These would include but not be limited to repeated chronic and severe urinary tract infections, refractory pelvic inflammation, genital warts, chronic refractory vaginal yeast infections, syphilis or venereal ulcers (chancroid), frequent herpes outbreaks, abnormal pap smears, chronic fatigue and loss of appetite

- o The CDC must instruct counselors and health providers to give women accurate information on which they can base their decisions about pregnancy.

- o The CDC must audit grants given to State and local governments for educational purposes to insure that they are being used in a timely and appropriate fashion. The CDC should publicly report State or local governments which leave such funds unspent and reallocate them to agencies who will use them appropriately.

5. We demand that the CDC make opportunistic infection diagnosis and prevention a priority:

- o The CDC must research and collect statistics on the types of opportunistic infections people with HIV have from diagnosis through their course of illness and collect statistics on the causes of death of all persons with HIV disease. All of this must be done in a manner which protects the anonymity of people and the CDC must include substantial numbers of women, intravenous drug users and people of color in this research.

- o The CDC must provide, free of charge, the most up-to-date immune system monitoring along with appropriate counseling and referral services at all HIV testing sites.

- o The CDC must publish, on a timely basis, standards of care for the prevention and treatment of all opportunistic infections and/or indicator diseases with atypical outcomes in immunocompromised people or associated with HIV disease. These standards should include but not be limited to: a minimum of two pap smears annually for detection of possible cervical cancers; on site or rapid referrals for colposcopic examination and definitive therapy for all abnormal paps; testing for chlamydia at every gynecological screening; accurate testing for syphilis; viratyping for genital and anal warts; and health maintenance appropriate to age including but not limited to mammography.

- o The CDC must advocate, within HHS, to Congress, and to State and local governments and health departments for the provision of programs and funding to make preventative treatments available to all persons with HIV disease.

Individuals Interested in More Information
May Contact the Following People
(Listed by Topic/s)

Women with HIV/AIDS: Global Issues
Nima Eshghi
708 11th Ave. E
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Pelvic Inflammatory Disease
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Bacterial Pneumonias
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Menstrual Irregularities
Carrie Wofford
1123 Park St., NE
Washington, D.C. 20002

Vaginal Candidiasis
Amy Myer
ACT UP/Columbus, OH

Sexually Transmitted Diseases
Karen Starr
RR #5, Box 117
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Tuberculosis
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Alternative Therapies
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3718 Jasmine Ave.
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Chemical Dependency
Stephen Corsia
c/o ACT UP/LA

Prison Issues
Lauren Leary
c/o ACT UP/LA

Judy Greenspan
c/o ACLU
Washington, D. C.

Research and Policy
(NIH, FDA, AZT Issues)
Linda Meredith
1123 Park St., NE
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Transmission Issues
Linda Meredith
Tracy Morgan

CDC Policy Issues
Maxine Wolfe
c/o ACT UP/NY
135 W. 29th St. #10
New York, NY 10001

Additional Reading on Women and HIV/AIDS*

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* These additional references are provided for individuals who wish to learn more about the issues and problems facing women with HIV/AIDS in the U.S. and elsewhere. They are by no means complete (despite government assertions that there is "no data" on issues of science, opportunistic infections and problems facing women with HIV/AIDS).

DEPARTMENT OF
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NEWS NEWS

NUMBER: 103-90
FOR RELEASE: IMMEDIATE

DATE: November 29, 1990
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STATE HEALTH DIRECTOR ANNOUNCES FINAL RESULTS OF STUDY OF HIV INFECTION AMONG CHILD-BEARING WOMEN

State Health Director Kenneth W. Kizer, M.D., M.P.H, today announced the release of final results from a California Department of Health Services study of Human Immunodeficiency Virus (HIV) infection among California women who gave birth in 1989.

After anonymously testing blood specimens from 144,284 live births among California women during July, August and September of 1989, departmental researchers found the HIV infection rate statewide to be 6.4 per 10,000, or one in every 1,568 women who gave birth in the study period. However, there was significant variability among the rates based on race and geographic location.

For example, among the 10,802 black mothers, 32 tested positive, for a rate of 29.6 per 10,000 women. The rate for the 58,667 white women who gave birth in the study period was 3.9 per 10,000. Thus, the rate for black women was more than seven times

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that for white women. The rates for Hispanic, Asian and women of other racial/ethnic groups did not differ significantly from that for whites. "These results underscore the seriousness of the epidemic in California's African-American community," Kizer said.

Twenty-one of California's 58 counties had at least one HIV positive birth during the study period. The remaining, typically smaller counties, had no HIV positive births. Compared to the rate for the rest of the State (3.8 per 10,000), the six-county San Francisco Bay Area rate (11.8 per 10,000) was three times higher, and the Los Angeles County rate (7.9 per 10,000) was twice as high. However, high rates are not limited to these two densely populated, urban areas. Other counties with rates higher than six per ten thousand were Merced, Sacramento, San Luis Obispo, Santa Barbara, Santa Cruz and Sonoma Counties. "HIV infection is by no means limited to California's largest urban centers," Director Kizer remarked.

Women under 20 at the time that they gave birth were slightly less likely to be HIV infected, as were those 35 years of age and over. However, these differences are relatively small and they are not consistent throughout the State. The Department's Office of AIDS is engaged in further exploration of the relationship between mother's age and HIV infection. "All childbearing women,

regardless of age, need to avoid high-risk behaviors such as unsafe sex and intravenous drug use, if they are to protect themselves and their children from this deadly disease, " Kizer advised.

The 1989 rate was essentially unchanged from 1988: 7.4 per 10,000 in 1988 compared to 6.4 per 10,000 childbearing women in 1989. "The lack of a significant change in this measure of the infection rate is encouraging. It indicates that California is holding the line on the spread of HIV infection in childbearing women and their infants. We are encouraged, and importantly, we believe that California's prevention programs are working," added Kizer.

The study used blood samples routinely taken from infants shortly after birth for the purpose of screening for several genetic diseases that is required by law. Infants acquire HIV antibodies from their mothers. Thus, a positive HIV test for a newborn infant means that the mother has HIV infection. Not all of the infants will develop the disease themselves. Currently, experts predict that about one-third of the infants born to HIV infected women will eventually develop HIV infection themselves. In order to protect the mothers' and infants' rights to privacy, the HIV test results were not linked to any individual baby or mother.

However, using standard "unlinked survey" techniques, the researchers were able to link the mother's age group, race/ethnicity, and area of residence to their HIV status, making these analyses possible.

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HIV Test Results for Mothers of Newborn Californians
Third Quarter 1989

Area of Residence and Age

	Positive	Negative	Percent Positive	95% Confidence Interval Lower	Upper	1 in Every
Statewide	**92**	**144192**	**0.064**	**0.052**	**0.079**	**1568**
S.F. Bay	**25**	**21192**	**0.118**	**0.078**	**0.177**	849
under 20	2	1726	0.116	0.020	0.465	864
20-24	8	4054	0.197	0.092	0.404	508
25-29	4	6259	0.064	0.021	0.175	1566
30-34	6	5230	0.115	0.047	0.263	873
35 and over	3	2924	0.102	0.027	0.326	976
Unknown	2	999	0.200	0.035	0.802	500
L.A. County	**39**	**49315**	**0.079**	**0.057**	**0.109**	**1265**
under 20	4	5615	0.071	0.023	0.196	1405
20-24	11	12594	0.087	0.046	0.161	1146
25-29	12	14061	0.085	0.046	0.153	1173
30-34	7	9929	0.070	0.031	0.152	1419
35 and over	5	5098	0.098	0.036	0.243	1021
Unknown	0	2018	0.000	-----	-----	----
Rest Calif.	**28**	**73685**	**0.038**	**0.026**	**0.056**	**2633**
under 20	2	8542	0.023	0.004	0.094	4272
20-24	11	19094	0.058	0.030	0.106	1737
25-29	6	22063	0.027	0.011	0.062	3679
30-34	9	14620	0.062	0.030	0.121	1625
35 and over	0	6511	0.000	-----	-----	----
Unknown	0	2855	0.000	-----	-----	----

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San Francisco Bay Area includes Alameda, Contra Costa, Marin, San Francisco, San Mateo and Santa Clara counties.

All HIV positive tests were confirmed by Western blot. Excludes cases for which the blood specimen was either not available or inadequate for HIV testing. Only one result included for multiple births. Excludes mothers who were not residents of California and those for whom residence was not known.

California Department of Health Services
Office of AIDS
November 1990

HIV Test Results for Mothers of Newborn Californians
Third Quarter 1989

Area of Residence and Race/Ethnicity

	Positive	Negative	Percent Positive	95% Confidence Interval Lower	Upper	1 in Every
Statewide	**92**	**144192**	**0.064**	**0.052**	**0.079**	**1568**
S.F. Bay	**25**	**21192**	**0.118**	**0.078**	**0.177**	**849**
Asian	0	2764	0.000	-----	-----	---
Black	9	2161	0.415	0.203	0.816	241
Hispanic	4	4571	0.087	0.028	0.240	1144
Others	4	2190	0.182	0.059	0.500	548
Unknown	1	327	0.305	0.018	1.955	328
White	7	9179	0.076	0.033	0.165	1312
L.A. County	**39**	**49315**	**0.079**	**0.057**	**0.109**	**1265**
Asian	1	3188	0.031	0.002	0.203	3189
Black	17	5094	0.333	0.200	0.544	301
Hispanic	16	26045	0.061	0.036	0.102	1629
Others	0	2047	0.000	-----	-----	----
Unknown	0	268	0.000	-----	-----	----
White	5	12673	0.039	0.015	0.098	2536
Rest Calif.	**28**	**73685**	**0.038**	**0.026**	**0.056**	**2633**
Asian	0	3226	0.000	-----	-----	----
Black	6	3515	0.170	0.069	0.391	587
Hispanic	9	25231	0.036	0.017	0.070	2804
Others	2	4075	0.049	0.009	0.198	2038
Unknown	0	846	0.000	-----	-----	----
White	11	36792	0.030	0.016	0.055	3346

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HIV Test Results for Mothers of Newborn Californians
Third Quarter 1989

Area of Residence, Age Group, Race/ethnicity

	Positive	Negative	Percent Positive	95% Confidence Interval Lower	Upper	1 in Every
Area of Residence						
Total	**92**	**144192**	**0.064**	**0.052**	**0.079**	**1568**
S.F. Bay Area	25	21192	0.118	0.078	0.177	849
L.A. County	39	49315	0.079	0.057	0.109	1265
Rest of Calif.	28	73685	0.038	0.026	0.056	2633
Age Group						
Total	**92**	**144192**	**0.064**	**0.052**	**0.079**	**1568**
under 20	8	15883	0.050	0.023	0.103	1986
20-24	30	35742	0.084	0.058	0.121	1192
25-29	22	42383	0.052	0.033	0.080	1928
30-34	22	29779	0.074	0.047	0.114	1355
35 and over	8	14533	0.055	0.026	0.113	1818
Unknown	2	5872	0.034	0.006	0.137	2937
Race/ethnicity						
Total	**92**	**144192**	**0.064**	**0.052**	**0.079**	**1568**
Asian	1	9178	0.011	0.001	0.071	9179
Black	32	10770	0.296	0.206	0.423	338
Hispanic	29	55847	0.052	0.035	0.076	1927
Others	6	8312	0.072	0.029	0.165	1386
Unknown	1	1441	0.069	0.004	0.449	1442
White	23	58644	0.039	0.025	0.060	2551

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California Department of Health Services
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HIV Test Results for Mothers of Newborn Californians
Third Quarter 1989

Odds Ratios for:
Area of Residence, Age Group, Race/Ethnicity

	Positive	Negative	Percent Positive	Odds Ratio	95% Confidence Interval Lower	Upper
Area of Residence						
S.F. Bay Area	25	21192	0.118	3.10	1.81	5.32
L.A. County	39	49315	0.079	2.08	1.28	3.38
Rest of Calif.*	28	73685	0.038	----	----	----
Age Group						
under 20*	8	15883	0.050	----	----	----
20-24	30	35742	0.084	1.67	0.76	3.63
25-29	22	42383	0.052	1.03	0.46	2.31
30-34	22	29779	0.074	1.47	0.65	3.29
35 and over	8	14533	0.055	1.09	0.41	2.91
Unknown	2	5872	0.034	n.a.	n.a.	n.a.
Race/Ethnicity						
Black	32	10770	0.296	7.58	4.30	13.38
Hispanic	29	55847	0.052	1.33	0.77	2.29
White*	23	58644	0.039	----	----	----
Other/Unknown	8	18931	0.042	1.08	0.48	2.41

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San Francisco Bay Area includes Alameda, Contra Costa, Marin, San Francisco, San Mateo and Santa Clara counties.

* Signifies reference groups for computing odds ratios. The odds ratio is a measure of how much more likely a particular group is to be HIV infected as compared to the reference group. "n.a." means that odds ratio and confidence intervals were not computed as the expected number of positive tests for one cell was less than 5. Odds ratios were computed by the computer program "Epi Info, Version 5," using Cornfeld's approximation, as described by Joseph Fleiss, *Statistical Methods for Rates and Proportions*. New York: John Wiley & Sons, 1981, pp. 71-75.

All HIV positive tests were confirmed by Western blot. Excludes cases for which the blood specimen was either not available or inadequate for HIV testing. Only one result included for multiple births. Excludes mothers who were not residents of California and those for whom residence was not known.

California Department of Health Services
Office of AIDS
November 1990

HIV Test Results for Newborn Californians
Third Quarter 1989

Area and County of Residence
(page 1 of 2)

	Positive	Negative	Percent Positive	95% Confidence Interval Lower	Upper	1 in Every
Statewide	**92**	**144192**	**0.064**	**0.052**	**0.079**	**1568**
S.F. Bay Total	**25**	**21192**	**0.118**	**0.078**	**0.177**	**849**
Alameda	10	5380	0.186	0.094	0.353	539
Contra Costa	9	3252	0.276	0.135	0.544	362
Marin	0	725	0.000	-----	-----	---
San Francisco	4	2543	0.157	0.050	0.431	637
San Mateo	1	2425	0.041	0.002	0.267	2426
Santa Clara	1	6867	0.015	0.001	0.094	6868
Los Angeles County	**39**	**49315**	**0.079**	**0.057**	**0.109**	**1265**
Other Counties	**25**	**68973**	**0.036**	**0.024**	**0.054**	**2760**
Butte	0	689	0.000	-----	-----	----
El Dorado	0	429	0.000	-----	-----	----
Fresno	1	3701	0.027	0.002	0.175	3702
Humboldt	0	421	0.000	-----	-----	----
Imperial	0	771	0.000	-----	-----	----
Kern	1	2983	0.034	0.002	0.217	2984
Kings	0	491	0.000	-----	-----	----
Madera	0	475	0.000	-----	-----	----
Merced	1	970	0.103	0.006	0.666	971
Napa	0	393	0.000	-----	-----	----
Orange	2	11995	0.017	0.003	0.067	5999
Riverside	2	5807	0.034	0.006	0.139	2905
Sacramento	3	4383	0.068	0.018	0.218	1462
San Bernadino	3	7508	0.040	0.010	0.127	2504
San Diego	6	11375	0.053	0.021	0.121	1897
San Joaquin	1	2463	0.041	0.002	0.263	2464
San Luis Obispo	1	708	0.141	0.008	0.910	709
Santa Barbara	2	1528	0.131	0.023	0.526	765
Santa Cruz	1	1076	0.093	0.005	0.600	1077
Shasta	0	590	0.000	-----	-----	----
Solano	0	1370	0.000	-----	-----	----
Sonoma	1	1545	0.065	0.004	0.419	1546
Stanislaus	0	1817	0.000	-----	-----	----
Tulare	0	1779	0.000	-----	-----	----
Ventura	0	3147	0.000	-----	-----	----
Yolo	0	559	0.000	-----	-----	----

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California Department of Health Services
Office of AIDS
November 1990

HIV Test Results for Newborn Californians
Third Quarter 1989

Area and County of Residence
(page 2 of 2)

	Positive	Negative	Percent Positive	95% Confidence Interval Lower	Upper	1 in Every
Region 1 Counties	**0**	**407**	**0.000**	**-----**	**-----**	**----**
Del Norte						
Lassen						
Modoc						
Plumas						
Sierra						
Siskiyou						
Trinity						
Region 2 Counties	**2**	**1691**	**0.118**	**0.021**	**0.475**	**847**
Monterey						
San Benito						
Region 3 Counties	**0**	**353**	**0.000**	**-----**	**-----**	**----**
Colusa						
Glenn						
Tehama						
Region 4 Counties	**1**	**515**	**0.194**	**0.011**	**1.248**	**516**
Lake						
Mendocino						
Region 5 Counties	**0**	**790**	**0.000**	**-----**	**-----**	**----**
Nevada						
Placer						
Region 6 Counties	**0**	**575**	**0.000**	**-----**	**-----**	**----**
Inyo						
Sutter						
Yuba						
Region 7 Counties	**0**	**381**	**0.000**	**-----**	**-----**	**----**
Alpine						
Amador						
Calaveras						
Mariposa						
Mono						
Tuolumne						

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All HIV positive tests were confirmed by Western blot. Excludes cases for which the blood specimen was either not available or inadequate for HIV testing. Only one result included for multiple births. Excludes mothers wh were not residents of California and those for whom residence was not known.

California Department of Health Services
Office of AIDS
November 1990

Fax → [illegible] copy to all A.C.
S.F. Neighborhood Survey Co P.K.

DEPARTMENT OF
HEALTH SERVICES
714 P STREET, SACRAMENTO, CA, 95814

NEWS NEWS

NUMBER: 63-91
FOR RELEASE: IMMEDIATE

DATE: October 8, 1991
CONTACT: Betsy Hite
or Jaime Arteaga
(916) 657-3064

1990 HIV SEROPREVALENCE AMONG CHILDBEARING WOMEN

SACRAMENTO - "One in every 1,420 childbearing women test HIV positive according to a California Department of Health Services study on statewide HIV prevalence in childbearing women conducted during 1990," said State Health Director Molly Joel Coye, M.D., M.P.H.

DHS researchers tested anonymous blood specimens from 150,494 infants born to California women during July, August and September of 1990. One-hundred and six tested positive, for a statewide HIV prevalence rate of seven per 10,000, or one in every 1,420 women who gave birth during the study period.

RISK OF INFECTION GREATER FOR BLACKS

Fifty-seven of the 11,703 African-American mothers in the sample tested positive for HIV infection, for a rate of 48.7 per 10,000 mothers. For white mothers, the rate was 3.4 per 10,000 or 20 HIV infected mothers out of 59,189. Thus the rate for African-American mothers was 14 times higher than that for white mothers. In addition, the infection rate is higher for African-American mothers in every age group studied. This shows that the high rate for African-American mothers is not a reflection of differences in the ages of woman giving birth.

"The consistently higher rate of HIV infection for African-American mothers gives us great concern," Dr. Coye said. "But the risk of HIV infection is widespread: no racial/ethnic group is immune from that risk."

SMALLER COUNTIES NOT IMMUNE FROM INFECTION

"At least one mother tested positive for HIV infection in 26 of California's 58 counties," said Mary Jess Wilson, M.D., M.P.H, Public Health Medical Officer with the State Office of AIDS. "HIV infection was more prevalent in the State's two largest urban areas -- the San Francisco Bay Area and Los Angeles County -- than it was in the rest of the State."

However, the counties in those areas differed greatly in infection rate among themselves. In Alameda County, one out of every 510 was infected, giving them the highest rate of infection. The next highest rates were in San Joaquin County with one out of every 777 and Contra Costa County with one out of every 811.

"Most of the HIV infected mothers were from the larger, more urban counties, but mothers from smaller and less urban counties are not immune from infection," Dr. Coye remarked.

IS THE RATE OF INFECTION INCREASING?

The rate for 1990 was slightly higher than that for 1989 and slightly lower than it was in 1988. DHS researchers concluded that these differences were not large enough to suggest any significant change in the prevalence of HIV infection among California's childbearing women.

"While the absence of an increasing trend is welcome, we cannot be sure of the reasons for it," Dr. Coye cautioned. "Although HIV infection among California women of childbearing age may not be increasing, it could mean that more infected women may be choosing not to have children. This could make the rate appear to be steady, while the actual rate among all women of childbearing age could be increasing."

Finally, since the project began in 1988, the rate has been higher for African-American mothers in the San Francisco Bay Area, Los Angeles County and all other counties, the three areas the State was broken into to conduct the study. On the other hand, the rates among Latina, Asian, Pacific Islander, and mothers of other racial/ethnic backgrounds did not differ significantly from that for whites.

METHOD OF TESTING

The study used blood samples routinely taken from infants shortly after birth to screen for several genetic diseases. Because infants acquire HIV antibodies from their mothers, a positive HIV test for a newborn infant means that the mother is infected. To protect each mother's and infant's right to privacy, the HIV test results were not linked to any identified mother or baby. For the same reason, age and race/ethnicity were grouped and smaller counties combined.

Not all the infants who tested positive will develop HIV disease themselves. Currently, experts predict that about one-fifth to one-third of the infants born to HIV infected mothers will become ill themselves. Separate studies are being conducted to identify the stages of HIV disease in children under the age of 13.

HIV Seroprevalence among California Childbearing Women
Third Quarter 1990

Office of AIDS
California Department of Health Services
September 1991

	Total Tested	HIV Positive No.	HIV Positive Pct.	95% Conf. Int. Lower %	95% Conf. Int. Upper %	1 in Every
Statewide	**150494**	**106**	**0.0704**	**0.0579**	**0.0855**	**1420**
San Francisco Bay Area	**21397**	**23**	**0.1075**	**0.0698**	**0.1640**	**930**
Alameda	5612	11	0.1960	0.1032	0.3620	510
Contra Costa	3245	4	0.1233	0.0396	0.3384	811
Marin	743	0	0.0000			
San Francisco	2438	2	0.0820	0.0144	0.3302	1219
San Mateo	2369	0	0.0000			
Santa Clara	6990	6	0.0858	0.0349	0.1969	1165
Los Angeles County	**52166**	**52**	**0.0997**	**0.0752**	**0.1318**	**1003**
Rest of California	**76931**	**31**	**0.0403**	**0.0279**	**0.0580**	**2482**
Butte	658	0	0.0000			
El Dorado	431	0	0.0000			
Fresno	3869	4	0.1034	0.0332	0.2839	967
Humboldt	440	0	0.0000			
Imperial	827	0	0.0000			
Kern	3225	0	0.0000			
Kings	490	0	0.0000			
Madera	554	0	0.0000			
Merced	1043	0	0.0000			
Napa	331	0	0.0000			
Orange	12922	2	0.0155	0.0027	0.0624	6461
Riverside	6258	3	0.0479	0.0124	0.1526	2086
Sacramento	4607	3	0.0651	0.0169	0.2072	1536
San Bernardino	7993	3	0.0375	0.0097	0.1195	2664
San Diego	11624	8	0.0688	0.0320	0.1414	1453
San Joaquin	2330	3	0.1288	0.0334	0.4094	777
San Luis Obispo	752	0	0.0000			
Santa Barbara	1638	0	0.0000			
Santa Cruz	1020	0	0.0000			
Shasta	579	0	0.0000			
Solano	1394	1	0.0717	0.0041	0.4643	1394
Sonoma	1452	1	0.0689	0.0040	0.4458	1452
Stanislaus	1986	0	0.0000			
Tulare	1846	0	0.0000			
Ventura	3287	0	0.0000			
Yolo	549	0	0.0000			
Region 1 Del Norte, Lassen, Modoc, Plumas, Sierra, Siskiyou, Trinity	371	1	0.2695	0.0155	1.7306	371
Region 2 Monterey, San Benito	1794	1	0.0557	0.0032	0.3610	1794
Region 3 Colusa, Glenn, Tehama	361	0	0.0000			
Region 4 Lake, Mendocino	460	0	0.0000			
Region 5 Nevada, Placer	811	1	0.1233	0.0071	0.7964	811
Region 6 Sutter, Yuba	371	0	0.0000			
Region 7 Alpine, Amador, Calaveras, Inyo, Mariposa, Mono, Tuolumne	458	0	0.0000			

HIV positive tests were confirmed by Western Blot. Cases with missing or inadequate blood specimens were omitted. Only one result is presented for multiple births. Excludes [illegible] or whose residence was unknown.

HIV Seroprevalence among California Childbearing Women
Third Quarter 1990

Office of AIDS
California Department of Health Services
September 1991

	Total Tested	HIV Positive No.	HIV Positive Pct.	95% Conf. Int. Lower %	95% Conf. Int. Upper %	1 in Every
Statewide	150494	106	0.0704	0.0579	0.0855	1420
Area of State and Age Group						
San Francisco Bay Area	21397	23	0.1075	0.0698	0.1640	930
under 20	1801	2	0.1110	0.0195	0.4467	901
20-24	4258	3	0.0705	0.0183	0.2242	1419
25-29	6231	10	0.1605	0.0816	0.3055	623
30-34	5553	7	0.1261	0.0553	0.2720	793
35 and over	3010	1	0.0332	0.0019	0.2154	3010
Unknown	544	0	0.0000			
Los Angeles County	52166	52	0.0997	0.0752	0.1318	1003
under 20	6272	3	0.0478	0.0124	0.1523	2091
20-24	13766	11	0.0799	0.0420	0.1477	1251
25-29	14990	27	0.1801	0.1211	0.2659	555
30-34	10813	6	0.0555	0.0226	0.1273	1802
35 and over	5556	3	0.0540	0.0140	0.1719	1852
Unknown	769	2	0.2601	0.0456	1.0428	385
Rest of California	76931	31	0.0403	0.0279	0.0580	2482
under 20	9311	5	0.0537	0.0198	0.1331	1862
20-24	20540	5	0.0243	0.0090	0.0604	4108
25-29	22739	10	0.0440	0.0224	0.0838	2274
30-34	15584	5	0.0321	0.0118	0.0795	3117
35 and over	7237	4	0.0553	0.0178	0.1519	1809
Unknown	1520	2	0.1316	0.0231	0.5290	760
Area of State and Race/Ethnicity						
San Francisco Bay Area	21397	23	0.1075	0.0698	0.1640	930
Asian/P.I.	2741	0	0.0000			
Black	2399	13	0.5419	0.3017	0.9511	185
Hispanic	5350	4	0.0748	0.0240	0.2054	1338
White	9294	6	0.0646	0.0263	0.1481	1549
Other	1151	0	0.0000			
Unknown	462	0	0.0000			
Los Angeles County	52166	52	0.0997	0.0752	0.1318	1003
Asian/P.I.	2970	1	0.0337	0.0019	0.2183	2970
Black	5403	31	0.5738	0.3969	0.8240	174
Hispanic	29692	16	0.0539	0.0319	0.0896	1856
White	12409	3	0.0242	0.0063	0.0770	4136
Other	1216	0	0.0000			
Unknown	476	1	0.2101	0.0121	1.3521	476
Rest of California	76931	31	0.0403	0.0279	0.0580	2482
Asian/P.I.	2543	0	0.0000			
Black	3901	13	0.3332	0.1855	0.5854	300
Hispanic	29448	7	0.0238	0.0104	0.0513	4207
White	37486	11	0.0293	0.0154	0.0542	3408
Other	2813	0	0.0000			
Unknown	740	0	0.0000			

San Francisco Bay Area includes Alameda, Contra Costa, Marin, San Francisco, San Mateo Santa Clara Counties.

HIV Seroprevalence among California Childbearing Women
Third Quarter 1990

Office of AIDS
California Department of Health Services
September 1991

	Total Tested	HIV Positive No.	HIV Positive Pct.	95% Conf. Int. Lower %	95% Conf. Int. Upper %	1 in Every	Odds Ratio
Statewide	150494	106	0.0704	0.0579	0.0855	1420	
Area of State							
San Francisco Bay Area	21397	23	0.1075	0.0698	0.1640	930	2.67
Los Angeles County	52166	52	0.0997	0.0752	0.1318	1003	2.47
Rest of California*	76931	31	0.0403	0.0279	0.0580	2482	----
Race/Ethnicity							
Asian/Pacific Islander	8254	1	0.0121	0.0007	0.0786	8254	0.36
Black	11703	57	0.4871	0.3724	0.6353	205	14.41**
Hispanic	64490	27	0.0419	0.0281	0.0618	2389	1.24
White*	59189	20	0.0338	0.0212	0.0532	2959	----
Other	5180	0	0.0000				
Unknown	1678	1	0.0596	0.0034	0.3859	1678	1.76
Age group							
under 20	17384	10	0.0575	0.0292	0.1096	1738	1.14
20-24	38564	19	0.0493	0.0305	0.0785	2030	0.97
25-29	43960	47	0.1069	0.0794	0.1434	935	2.11**
30-34	31950	18	0.0563	0.0344	0.0910	1775	1.11
35 and over*	15803	8	0.0506	0.0236	0.1040	1975	----
Unknown	2833	4	0.1412	0.0453	0.3876	708	2.79

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HIV positive tests were confirmed by Western Blot. Cases with missing or inadequate bloc specimens were omitted. Only one result is presented for multiple births. Excludes mothers who were not residents of California or whose residence was unknown.

* Designates the reference group for computing relative risks.

** Indicates that the relative risk for the group is significantly larger (or smaller) than 1 at the 95% confidence interval, using the Taylor Series as programmed in "Epi Info" version 5, in the "STATCALC" module.

EPIDEMIOLOGICAL OVERVIEW

In May of 1985;. the Los Angeles County Sheriff's Department began maintaining statistical information on inmates with HIV Disease. A that time, it was the best "quesstimate" that the seroprevalance rate for HIV infection in the nations prisons and jails was anywhere between 8 and 30% and the general public's perception was that the virus would be spreading rapidly by sexual activity in our correctional institutions.

Since that time, we have gained invaluable insight into the epidemiology of "HIV Disease behind bars", primarily thru the four annual surveys done by Dr. Ted Hammett, supported by the National Institute of Justice and the John Hopkins/CDC Sero-Prevalance Study in 10 correctional facilities across the United States.

Based on these, as well as other efforts, we know that:

- The Seropervalance Rates among new entrants into U.S. correctional facilities ranges from 0.17% to 20%.
- The annual rate of increase in the number of cases of AIDS in correctional facilities for 1990 was 29%.

The annual rate of increase in the United States, in the free community, for 1990 was 38%.

- Of the transmission that is occurring in our jails and prisons, 85% is reported to be related to Intravenous Drug Use/Sharing of Needle works.

In terms of our Los Angeles County Jail Systems, the seroprevalance rate of new entrants has been as follows:

1988 - 2.6%

1989 - 2.5%

1990 - 2.4.%

The significance of our seroprevalance rate is that on any given day we may have as many as 550+ inmates who are asymptomatic HIV positive. The cummulative HIV statistics for our service (May 5, 1985 thru February 28, 1991 are attached for your review (Attachment I)).

SHERIFF'S DEPARTMENT MEDICAL SERVICES

AIDS CASELOAD STATISTICS*

1.	Number of Confirmed Cases of AIDS (Includes ARC)**.....	523
	Males..... 508	
	Females..... 15	
2.	Number of AIDS Related Deaths***.....	25
3.	Number of Employee/Possible HIV Exposure Injury Report..	215
4.	Ethnicity of the Confirmed Cases:	
	a) Caucasian.....	260
	b) Black.....	168
	c) Hispanic.....	87
	d) Other.....	04
	e) Unknown.....	04
5.	Risk Group Distribution of Confirmed Cases:	
	a) Gay Males.....	311
	b) Lesbians.....	0
	c) I.V. Drug Users.....	182
	d) Blood Transfusions.....	13
	e) Other.....	02
6.	Average Daily Census of PWA (Month of November, 1990)...	04
7.	Average Daily Census of known HIV Positive Inmates.....	39
8.	Seroprevalence rate in New Entrants****.....	2.6%
9.	Number of HIV Test done in Month of January, 1991.....	194
10.	Number of HIV Test done in Month of December, 1990.....	187
11.	Number of HIV Test done in Month of November, 1990.....	185
12.	Number of HIV Test done in Month of October, 1990.....	184
13.	Number of HIV Test done in Month of September, 1990.....	189
14.	Number of HIV Test done in Month of August, 1990.....	167
15.	Number of Positive Test for Month of January, 1991.....	24
16.	Number of Positive Test for Month of December, 1990.....	43
17.	Number of Positive Test for Month of November, 1990.....	20
18.	Number of Positive Test for Month of October, 1990.....	29
19.	Number of Positive Test for Month of September, 1990....	30
20.	Number of Positive Test for Month of August, 1990.....	22

*As of January 31, 1991
**Cumulative from May 2, 1985
***Includes LCMC Jail Ward
****1988 Blind Study of 1,000 New Bookings

JOHN H. CLARK, M.D., M.P.H.
CHIEF PHYSICIAN III

SHERIFF'S DEPARTMENT MEDICAL SERVICES

AIDS CASELOAD STATISTICS*

1.	Number of Confirmed Cases of AIDS (Includes ARC)**.....	526
	Males..... 511	
	Females..... 15	
2.	Number of AIDS Related Deaths***.....	25
3.	Number of Employee/Possible HIV Exposure Injury Report..	222
4.	Ethnicity of the Confirmed Cases:	
	a) Caucasian.....	262
	b) Black.....	169
	c) Hispanic.....	87
	d) Other.....	04
	e) Unknown.....	04
5.	Risk Group Distribution of Confirmed Cases:	
	a) Gay Males.....	311
	b) Lesbians.....	0
	c) I.V. Drug Users.....	183
	d) Blood Transfusions.....	13
	e) Other.....	04
6.	Average Daily Census of PWA (Month of November, 1990)...	04
7.	Average Daily Census of known HIV Positive Inmates.....	36
8.	Seroprevalence rate in New Entrants****.....	2.6%
9.	Number of HIV Test done in Month of February, 1991.....	157
10.	Number of HIV Test done in Month of January, 1991.....	194
11.	Number of HIV Test done in Month of December, 1990.....	187
12.	Number of HIV Test done in Month of November, 1990.....	185
13.	Number of HIV Test done in Month of October, 1990.....	184
14.	Number of HIV Test done in Month of September, 1990.....	189
15.	Number of Positive Test for Month of February, 1991....	24
16.	Number of Positive Test for Month of January, 1991.....	24
17.	Number of Positive Test for Month of December, 1990.....	43
18.	Number of Positive Test for Month of November, 1990.....	20
19.	Number of Positive Test for Month of October, 1990.....	29
20.	Number of Positive Test for Month of September, 1990....	30

*As of February 28, 1991
**Cumulative from May 2, 1985
***Includes LCMC Jail Ward
****1988 Blind Study of 1,000 New Bookings

JOHN H. CLARK, M.D., M.P.H.
CHIEF PHYSICIAN III

Acquired Immunodeficiency Syndrome (AIDS)
Monthly Surveillance Summary - October 31, 1991
Los Angeles County AIDS Epidemiology Program - Surveillance Unit

	1991	1990	% Change 90 to 91
Los Angeles County			
New cases reported in October	232	301	-23%
New cases reported year-to-date	2,450	2,180	+12%
Cumulative cases	13,647[1]	10,756[2]	+27%
Cumulative deaths	9,534[1]	7,322[2]	+30%
Cumulative case-fatality rate	70%	68%	
California			
Cumulative cases	38,018[3]	30,422[4]	+25%
Cumulative deaths	25,980[3]	19,898[4]	+31%
Cumulative case-fatality rate	68%	65%	
United States			
Cumulative cases	195,718[5]	152,126[6]	+29%
Cumulative deaths	126,159[5]	93,775[6]	+35%
Cumulative case-fatality rate	64%	62%	

[1] Includes all cases reported to the AIDS Epidemiology Program as of October 31, 1991.
[2] Includes all cases reported to the AIDS Epidemiology Program as of October 31, 1990.
[3] California Office of AIDS. California AIDS Update, October 31, 1991.
[4] California Office of AIDS. California AIDS Update, October 31, 1990.
[5] Centers for Disease Control. HIV/AIDS Surveillance Report, October 1991:1-18.
[6] Centers for Disease Control. HIV/AIDS Surveillance Report, October 1990:1-16.

AIDS SURVEILLANCE REPORT

Los Angeles County - Department of Health Services
AIDS Epidemiology Program
Surveillance Unit

October 31, 1991

Acquired Immunodeficiency Syndrome (AIDS)
Monthly Surveillance Report - October 31, 1991
Los Angeles County AIDS Epidemiology Program - Surveillance Unit

1. *REPORTED AIDS CASES AND DEATHS BY DISEASE CATEGORY*

Disease Category[1]	Adult Cases	Adult Deaths[2]	Pediatric[3] Cases	Pediatric Deaths	Total Cases	Total Deaths
	No. (%)	No. (CFR[4])	No. (%)	No. (CFR[4])	No. (%)	No. (CFR[4])
PCP w/o KS	6499 (48)	4579 (70)	47 (43)	31 (66)	6546 (48)	4610 (70)
KS w/o PCP	2037 (15)	1431 (70)	1 (01)	1 (100)	2038 (15)	1432 (70)
KS and PCP	975 (07)	803 (82)	1 (01)	1 (100)	976 (07)	804 (82)
Other OI	4026 (30)	2653 (66)	61 (55)	35 (57)	4087 (30)	2688 (66)
Total	**13537**	**9466**	**110**	**68**	**13647**	**9534**
[% of Total]	[99]		[01]			[100]

2. *REPORTED AIDS CASES BY AGE AND RACE/ETHNICITY*

Age at Diagnosis	White	Black	Hispanic	Asian[5]	Total[6]
	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)
Less than 13	30 (00)	37 (02)	39 (01)	4 (02)	110 (01)
13 - 19	10 (00)	9 (00)	12 (00)	0 (00)	31 (00)
20 - 29	1229 (15)	461 (21)	612 (23)	28 (14)	2356 (17)
30 - 39	3745 (44)	1018 (46)	1189 (44)	71 (36)	6067 (44)
40 - 49	2244 (27)	457 (21)	556 (21)	68 (35)	3353 (25)
50 - 59	877 (10)	174 (08)	207 (08)	19 (10)	1283 (09)
Greater than 60	325 (04)	56 (03)	57 (02)	7 (04)	447 (03)
Total	**8460**	**2212**	**2672**	**197**	**13647**
[% of Total]	[62]	[16]	[20]	[01]	[100]

3. *REPORTED ADULT/ADOLESCENT AIDS CASES BY SEXUAL ORIENTATION AND INTRAVENOUS DRUG USE*

Sexual Orientation	History of Intravenous Drug Use: No	Yes	Unknown	Total
	No. (%)	No. (%)	No. (%)	No.
Male, homosexual	4298 (73)	731 (46)	4937 (81)	9966
Male, bisexual	953 (16)	216 (14)	638 (10)	1807
Male, heterosexual	326 (06)	253 (16)	123 (02)	702
Male, orientation unknown	82 (01)	257 (16)	260 (04)	599
Female, heterosexual	199 (03)	131 (08)	133 (02)	463
Total	**5858**	**1588**	**6091**	**13537**
[% of Total]	[43]	[12]	[45]	[100]

[1] Disease categories are ordered hierarchically; KS=Kaposi's sarcoma, PCP=Pneumocystis carinii pneumonia, OI=opportunistic infection.
[2] Reporting of deaths is incomplete.
[3] Includes all patients less than 13 at the time of diagnosis.
[4] CFR=Case-fatality rate.
[5] Includes 1 Burmese, 3 Cambodian, 23 Chinese, 60 Filipino, 3 Indonesian, 37 Japanese, 7 Korean, 3 Mayalan, 11 Pacific Islanders, 4 Taiwanese, 13 Thai, and 11 Vietnamese; 21 are of unknown ethnicity.
[6] Total includes 16 American Indians/Alaskan Natives, and 90 persons whose race/ethnicity is unknown.

4. *REPORTED AIDS CASES BY EXPOSURE CATEGORY AND GENDER*

Exposure Category[7]	Male		Female		Total	
	No.	(%)	No.	(%)	No.	(%)
Adult/Adolescent						
Homosexual/bisexual male contact	10826	(83)	0	(00)	10826	(80)
Intravenous drug use (IVDU)	510	(04)	131	(28)	641	(05)
Homosexual or bisexual IVDU	947	(07)	0	(00)	947	(07)
Hemophilia or coagulation disorder	59	(00)	5	(01)	64	(00)
Heterosexual contact	87	(01)	152	(33)	239	(02)
Transfusion recipient	142	(01)	105	(23)	247	(02)
Undetermined	503	(04)	70	(15)	573	(04)
Adult Subtotal	*13074*		*463*		*13537*	
[% of Adult Subtotal]	*[97]*		*[03]*		*[100]*	
Pediatric						
Hemophilia or coagulation disorder	4	(06)	1	(02)	5	(05)
Parent with or at risk of AIDS[8]	26	(41)	33	(72)	59	(54)
Transfusion recipient	33	(52)	11	(24)	44	(40)
Undetermined	1	(02)	1	(02)	2	(02)
Pediatric Subtotal	*64*		*46*		*110*	
[% of Pediatric Subtotal]	*[58]*		*[42]*		*[100]*	
Total	**13138**		**509**		**13647**	
[% of Total]	[96]		[04]		[100]	

5. *REPORTED AIDS CASES BY EXPOSURE CATEGORY AND RACE/ETHNICITY*

Exposure Category[7]	White		Black		Hispanic		Other	
	No.	(%)	No.	(%)	No.	(%)	No.	(%)
Adult/Adolescent								
Homosexual/bisexual male contact	7233	(86)	1425	(66)	1930	(73)	238	(80)
Intravenous drug use (IVDU)	217	(03)	254	(12)	160	(06)	10	(03)
Homosexual or bisexual IVDU	572	(07)	213	(10)	154	(06)	8	(03)
Hemophilia or coagulation disorder	38	(00)	10	(00)	9	(00)	7	(02)
Heterosexual contact	81	(01)	87	(04)	67	(03)	4	(01)
Transfusion recipient	137	(02)	34	(02)	58	(02)	18	(06)
Undetermined	152	(02)	152	(07)	255	(10)	14	(05)
Adult Subtotal	*8430*		*2175*		*2633*		*299*	
[% of Adult Subtotal]	*[62]*		*[16]*		*[19]*		*[02]*	
Pediatric								
Hemophilia or coagulation disorder	2	(07)	0	(00)	2	(05)	1	(25)
Parent with or at risk of AIDS[8]	12	(40)	25	(68)	22	(56)	0	(00)
Transfusion recipient	16	(53)	10	(27)	15	(38)	3	(75)
Undetermined	0	(00)	2	(05)	0	(00)	0	(00)
Pediatric Subtotal	*30*		*37*		*39*		*4*	
[% of Pediatric Subtotal]	*[27]*		*[34]*		*[35]*		*[04]*	
Total	**8460**		**2212**		**2672**		**303**	
[% of Total]	[62]		[16]		[20]		[02]	

[7] Exposure categories are ordered hierarchically. Except for the combination listed, cases with multiple risk factors are tabulated in the category listed first.

[8] Includes one case transmitted by breast milk.

6. *REPORTED AIDS CASES BY EXPOSURE CATEGORY AND YEAR OF DIAGNOSIS*

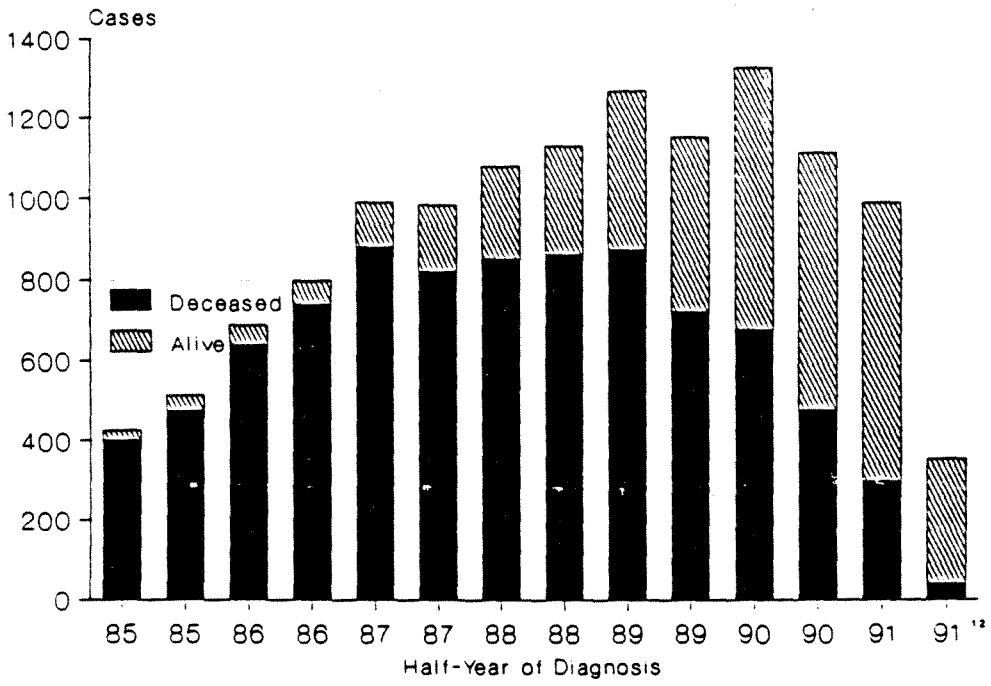
Exposure Category[9]	Before 1987	1987	1988	1989	1990	1991[10]
Adult/Adolescent	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)
Homosexual/bisexual male contact	2707 (83)	1600 (81)	1749 (80)	1901 (79)	1860 (77)	1009 (76)
Intravenous drug use (IVDU)	80 (02)	79 (04)	122 (06)	126 (05)	151 (06)	83 (06)
Homosexual or bisexual IVDU	262 (08)	147 (07)	164 (07)	165 (07)	138 (06)	71 (05)
Hemophilia or coagulation disorder	22 (01)	4 (00)	14 (01)	3 (00)	10 (00)	11 (01)
Heterosexual contact	35 (01)	34 (02)	40 (02)	43 (02)	53 (02)	34 (03)
Transfusion recipient	65 (02)	48 (02)	42 (02)	32 (01)	42 (02)	18 (01)
Undetermined	71 (02)	52 (03)	65 (03)	122 (05)	166 (07)	97 (07)
Adult Subtotal	*3242*	*1964*	*2196*	*2392*	*2420*	*1323*
[% of Adult Subtotal]	*[24]*	*[15]*	*[16]*	*[18]*	*[18]*	*[10]*
Pediatric						
Hemophilia or coagulation disorder	0 (00)	2 (17)	2 (14)	0 (00)	0 (00)	1 (07)
Parent with or at risk of AIDS[11]	12 (38)	6 (50)	6 (43)	19 (79)	8 (57)	8 (57)
Transfusion recipient	20 (63)	4 (33)	6 (43)	4 (17)	6 (43)	4 (29)
Undetermined	0 (00)	0 (00)	0 (00)	1 (04)	0 (00)	1 (07)
Pediatric Subtotal	*32*	*12*	*14*	*24*	*14*	*14*
[% of Pediatric Subtotal]	*[29]*	*[11]*	*[13]*	*[22]*	*[13]*	*[13]*
Total	**3274**	**1976**	**2210**	**2416**	**2434**	**1337**
[% of Total]	[24]	[14]	[16]	[18]	[18]	[10]

7. *REPORTED AIDS CASES BY RACE/ETHNICITY AND YEAR OF DIAGNOSIS*

Race/Ethnicity	Before 1987	1987	1988	1989	1990	1991[10]
	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)
White, not Hispanic	2287 (70)	1328 (67)	1322 (60)	1433 (59)	1356 (56)	734 (55)
Black, not Hispanic	464 (14)	290 (15)	412 (19)	389 (16)	427 (18)	230 (17)
Hispanic	482 (15)	319 (16)	439 (20)	535 (22)	564 (23)	333 (25)
Asian/Pacific Islander	30 (01)	23 (01)	27 (01)	46 (02)	52 (02)	19 (01)
Other/Unknown	11 (00)	16 (01)	10 (00)	13 (01)	35 (01)	21 (02)
Total	**3274**	**1976**	**2210**	**2416**	**2434**	**1337**
[% of Subtotal]	[24]	[14]	[16]	[18]	[18]	[10]

[9] Exposure categories are ordered hierarchically. Except for the combination listed, cases with more than one risk factor are tabulated in the category listed first.
[10] Cases diagnosed this year and reported to the AIDS Epidemiology Program as of the date of this report; these data are provisional.
[11] Includes one case transmitted by breast milk.

8. *REPORTED AIDS CASES AND FATALITY BY HALF-YEAR OF DIAGNOSIS*



Half-Year of Diagnosis		Cases	Deaths	Case-Fatality Rate
Before 1985		851	788	93 %
1985	January - June	425	400	94 %
	July - December	513	474	92 %
1986	January - June	689	640	93 %
	July - December	796	740	93 %
1987	January - June	991	881	89 %
	July - December	985	821	83 %
1988	January - June	1080	852	79 %
	July - December	1130	863	76 %
1989	January - June	1266	874	69 %
	July - December	1150	720	63 %
1990	January - June	1323	674	51 %
	July - December	1111	472	42 %
1991	January - June	988	294	30 %
	July - December[12]	349	41	12 %
Total		**13647**	**9534**	**70 %**

[12] Cases diagnosed this year and reported to the AIDS Epidemiology Program as of the date of this report; these data are provisional (Total excludes 851 cases and 788 deaths prior to 1985.

9. *REPORTED AIDS CASES BY MONTH AND YEAR OF DIAGNOSIS*

Month	Before 1986	1986	1987	1988	1989	1990	1991[13]
January	112	106	178	174	197	231	187
February	102	98	157	170	174	189	180
March	128	116	141	184	232	223	172
April	117	113	168	190	208	234	190
May	145	125	174	189	202	215	149
June	167	131	173	173	253	231	110
July	154	133	157	200	190	201	134
August	183	121	146	213	194	218	121
September	162	152	183	186	212	184	72
October	168	131	192	172	199	167	22
November	149	106	130	178	194	169	0
December	202	153	177	181	161	172	0
Total	**1789**	**1485**	**1976**	**2210**	**2416**	**2434**	**1337**

10. *REPORTED AIDS CASES BY HEALTH DISTRICT OF RESIDENCE AT ONSET*

Health District	No. (%)	Rate per 100,000[14]
Alhambra	193 (01)	60
Bellflower	138 (01)	43
Central	1329 (10)	448
Compton	201 (01)	74
East Los Angeles	153 (01)	80
East Valley	804 (06)	248
El Monte	169 (01)	44
Foothill	138 (01)	52
Glendale	576 (04)	168
Harbor	99 (01)	56
Hollywood-Wilshire	3700 (27)	821
Inglewood	369 (03)	86
Long Beach	1136 (08)	295
Northeast	377 (03)	151
Pasadena	143 (01)	114
Pomona	230 (02)	56
San Antonio	163 (01)	47
San Fernando	205 (02)	54
South	160 (01)	120
Southeast	158 (01)	130
Southwest	547 (04)	174
Torrance	190 (01)	58
West	853 (06)	163
West Valley	642 (05)	99
Whittier	129 (01)	47
Unknown	845 (06)	NA[15]
Total	**13647**	**170**

[13] Cases diagnosed this year and reported to the AIDS Epidemiology Program as of the date of this report; these data are provisional.
[14] 1985 population estimates based on 1980 Census.
[15] NA=not applicable.

11. *ANNUAL ADULT/ADOLESCENT AIDS CASES AND RATES[16] PER 100,000 BY RACE/ETHNICITY AND GENDER*

Year of Diagnosis	White		Black		Hispanic		Other		Total[17]	
Male	No.	Rate	No.	Rate	No.	Rate	No.	Rate	No.	Rate
1984	349	22	61	19	56	7	1	0	469	16
1985	637	41	121	38	129	16	13	4	900	30
1986	991	64	196	62	225	26	17	5	1433	47
1987	1295	84	268	84	297	34	21	6	1897	61
1988	1286	85	380	119	414	45	27	7	2114	67
1989	1396	93	355	111	511	54	46	11	2317	73
1990	1323	89	388	122	523	53	51	12	2315	72
1991[18]	712	48	208	65	313	32	17	4	1269	39
Female	No.	Rate	No.	Rate	No.	Rate	No.	Rate	No.	Rate
1984	4	0	5	1	1	0	0	0	10	0
1985	18	1	3	1	4	0	0	0	25	1
1986	15	1	16	4	10	1	1	0	42	1
1987	30	2	19	5	16	2	2	1	67	2
1988	35	2	26	7	19	2	2	0	82	2
1989	31	2	23	6	18	2	3	1	75	2
1990	28	2	35	9	36	4	4	1	105	3
1991[18]	17	1	16	4	17	2	3	1	54	2

12. *REPORTED AIDS-INDICATOR CONDITIONS*

Condition[19]	No.	(%)
Bacterial infections, multiple or recurrent[20]	35	(0.3)
Candidiasis of bronchi, trachea, or lungs	283	(2.1)
Candidiasis of esophagus	1216	(8.9)
Coccidioidomycosis, disseminated or extrapulmonary	33	(0.2)
Cryptococcosis, extrapulmonary	939	(6.9)
Cryptosporidiosis, chronic intestinal	499	(3.7)
Cytomegalovirus disease other than retinitis	791	(5.8)
Cytomegalovirus retinitis	514	(3.8)
HIV encephalopathy	619	(4.5)
Herpes simplex: chronic ulcers, pneumonitis or esophagitis	409	(3)
Histoplasmosis, disseminated or extrapulmonary	85	(0.6)
Isosporiasis, chronic intestinal	94	(0.7)
Kaposi's sarcoma	3014	(22.1)
Lymphoid interstitial pneumonitis[20]	18	(0.1)
Lymphoma, Burkitt's	115	(0.8)
Lymphoma, immunoblastic	306	(2.2)
Lymphoma, primary in brain	87	(0.6)
Mycobacterium avium or *M. kansasii*, disseminated	976	(7.2)
M. tuberculosis, disseminated or extrapulmonary	324	(2.4)
Mycobacterium, other or unidentified species	216	(1.6)
Pneumocystis carinii pneumonia	7522	(55.1)
Progressive multifocal leukoencephalopathy	99	(0.7)
Salmonella septicemia, recurrent	42	(0.3)
Toxoplasmosis of the brain	544	(4)
Wasting syndrome	1331	(9.8)

[16] Annual population estimates based on 1980 Census.

[17] Total includes persons whose race/ethnicity is unknown.

[18] Cases diagnosed this year and reported to the AIDS Epidemiology Program as of the date of this report; these data are provisional.

[19] Patients may have more than one condition.

[20] Patients less than 13 at the time of diagnosis.

AIDS - LOS ANGELES COUNTY
SURVEILLANCE SUMMARY
DEATHS DURING SEPTEMBER 1991*
AS OF 10/31/91

PLACE OF DEATH	NUMBER OF DEATHS	PERCENT
County Facility	13	10.9
Private Facility	52	43.7
Home	24	20.2
Nursing Home/Hospice	18	15.1
Outside Los Angeles/Unk	12	10.1
Total	119	100.0

* These data are provisional due to delays in mortality reporting.

LOS ANGELES COUNTY STD CONTROL PROGRAM
Gonorrhea Data

(Annual Report 1/1/89 - 12/30/89 And Third Quarter 1990)

Reported by Public/Private Sector/Military/Other Jurisdictions

Gonorrhea Los Angeles County 1/1/89 - 12/30/89

Total Reported Cases = 25,719

	Black	Hispanic	White
Male	10,602	3,036	1,170
Female	5,178	1,283	928
TOTAL:	15,780 (61%)	4,319 (17%)	2,098 (8%)

Gonorrhea South Area 1/1/89 - 12/30/89

Total Reported Cases = 8,047 (31% of County Wide Total)

	Black	Hispanic	White
Male	3,813	562	88
Female	2,176	283	121
TOTAL:	5,989 (74%)	845 (11%)	209 (3%)

Gonorrhea Los Angeles County Third Quarter 1990 (7/1/90 - 9/29/90)

Total Reported Cases = 4,650

	Black	Hispanic	White
Male	1,822	529	260
Female	802	249	167
TOTAL:	2,624 (56%)	778 (17%)	427 (9%)

Gonorrhea Metro South Area Third Quarter 1990 (7/1/90 - 9/29/90)

Total Reported Cases = 1,844 (40% of County Wide Total)

	Black	Hispanic	White
Male	916	92	29
Female	447	61	21
TOTAL:	1,363 (74%)	153 (8%)	50 (3%)

NOBCO/King- Drew
5/91 C. Davis

LOS ANGELES COUNTY STD CONTROL PROGRAM
Syphilis Data
(Annual Report 1/1/89 - 12/30/89 And Third Quarter 1990)

Reported by Public/Private Sector/Military/Other Jurisdictions

Syphilis Los Angeles County 1/1/89-12/30/89

Total Reported Cases = 2,844

	Black	Hispanic	White
Male	957	566	185
Female	740	159	95
TOTAL:	1,697 (60%)	725 (25%)	280 (10%)

Syphilis South Area 1/1/89-12/30/89

Total Reported Cases = 937 (33% of County Wide Total)

	Black	Hispanic	White
Male	397	125	18
Female	307	50	15
TOTAL:	704 (75%)	175 (19%)	33 (4%)

Syphilis Los Angeles County Third Quarter 1990 (7/1/90 - 9/29/90)

Total Reported Cases = 466

	Black	Hispanic	White
Male	142	94	33
Female	115	33	15
TOTAL:	257 (55%)	127 (27%)	48 (10%)

Syphilis Metro South Area Third Quarter 1990 (7/1/90 - 9/29/90)

Total Reported Cases = 176 (37% of County Wide Total)

	Black	Hispanic	White
Male	58	17	6
Female	67	9	2
TOTAL:	125 (68%)	26 (14%)	8 (5%)

NOBCO/King-Drew
5/91 C. Davis

Table 1.1. Demographic characteristics of STDs in Los Angeles County during 1986.

Demographic Characteristic	Percent
Sex	
Male	63.7
Female	35.4
Race	
White	9.7
Hispanic	14.7
Black	55.4
Asian/Am. Indian	0.4
Other/Unknown	18.8
Report Source	
Public	60.1
Private	39.9

Of the cases reported by public sources 11 percent were from custodial facilities. The number of positive cultures from these facilities is presented in Table 1.2.

Table 1.2. Positive gonorrhea cultures from custodial facilities in Los Angeles County during 1986.

Facility	Number of Cultures	Number of Positive Cultures (percent)
Men		
Los Padrinos Juvenile Hall	542	44 (8.9)
Men's Central Jail	464	139 (31.2)
Hall of Justice Jail	51	4 (7.8)
Central Juvenile Hall	8	0 (0.0)
Women		
Sybil Brand Institute	17,585	1,989 (11,4)
Central Juvenile Hall	1,544	139 (14.8)
Los Padrinos Juvenile Hall	1,239	137 (17.6)

Table 1.3. Annual rate of gonorrhea in Los Angeles County during 1986, by health district.

Health District	Number of Cases	Annual Rate (cases/100,000)
South	4,828	3,631.3
Southeast	4,364	3,593.8
Southwest	8,452	2,686.7
Compton	5,730	2,102.0
Inglewood	6,889	1,610.7
Central	3,109	1,048.1
Hollywood-Wilshire	3,770	836.2
East Los Angeles	725	379.1
Northeast	915	367.3
Harbor	647	363.5
El Monte	1,351	351.1
Foothill	879	329.4
East Valley	1,255	326.0
San Antonio	1,063	305.1
West	1,593	303.9
Torrance	821	249.9
Pomona	967	234.2
Bellflower	696	218.9
West Valley	1,395	214.9
San Fernando	740	194.8
Whittier	484	176.0
Alhambra	415	129.5
Glendale	418	122.0

Race-specific rates indicate that Blacks not only had the highest percentage of reported cases, but the highest incidence rate (Figure 1.2).

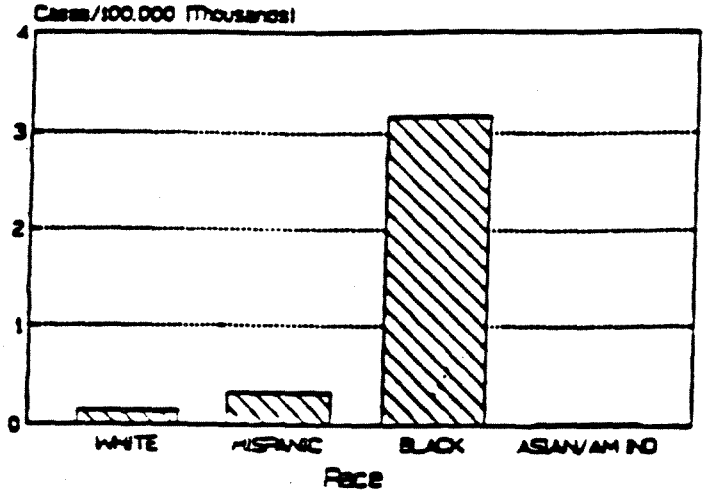


Figure 1.2. Annual rate of gonorrhea in Los Angeles County during 1986, by race.

The age-specific incidence is presented in Figure 1.3. Persons between the ages of 15 and 29 accounted for 73.4 percent of all reported cases.

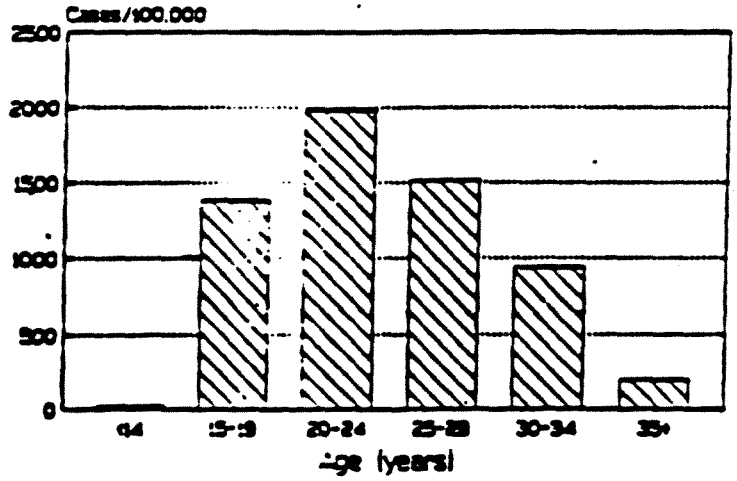


Figure 1.3. Annual rate of gonorrhea in Los Angeles County during 1986, by age.

The apparent decrease in gonorrhea is in contrast with an increase during 1986 in the rate of penicillinase-producing Neisseria gonorrhea (PPNG). The rate of gonorrhea may have decreased among White homosexual males as a result of altered sexual practices in response to

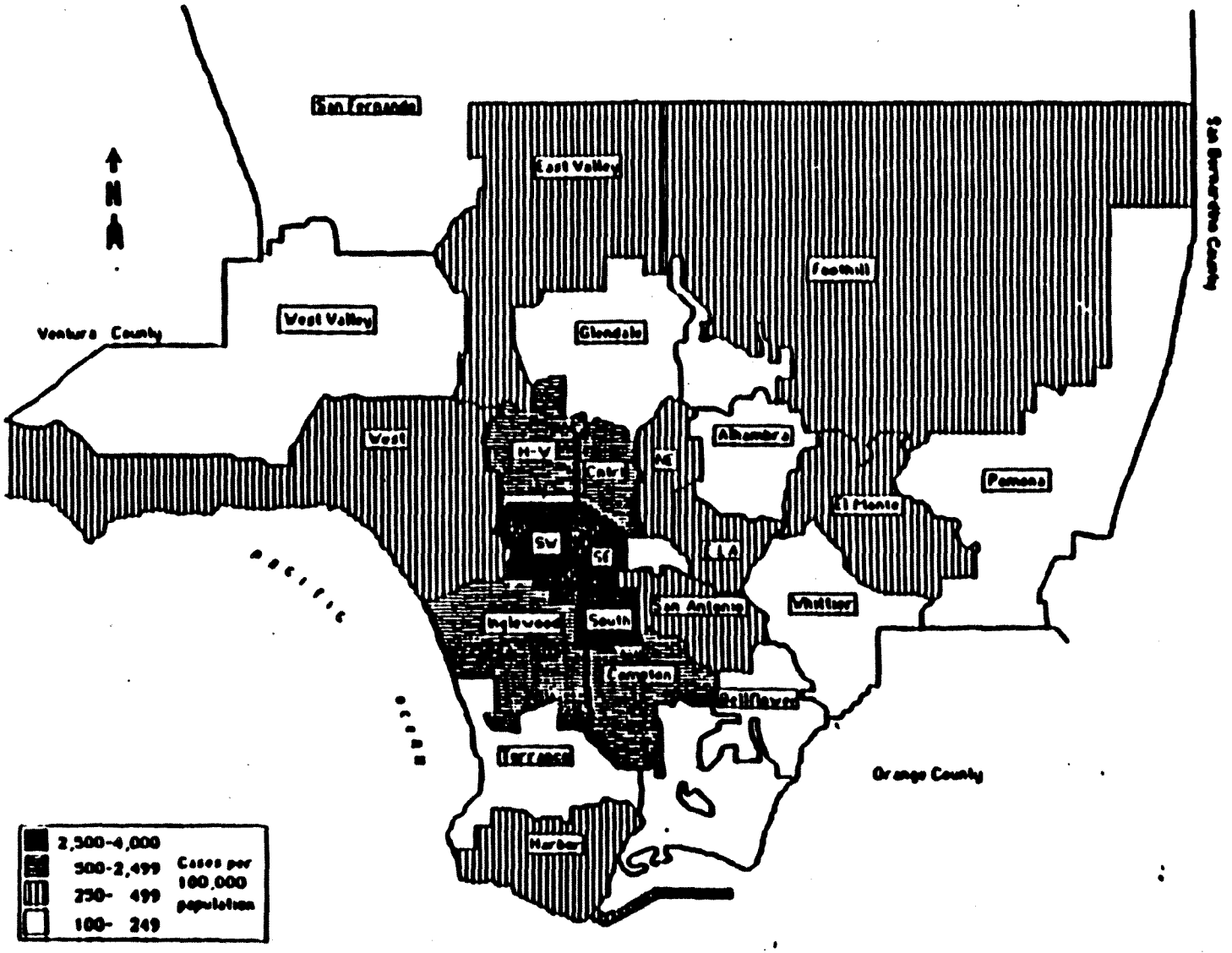


Figure 1.4. Annual rate of gonorrhea in Los Angeles County during 1986, by health district.

LOS ANGELES COUNTY DEPARTMENT OF HEALTH SERVICES
SEXUALLY TRANSMITTED DISEASE FACT SHEET

EPORTED MORBIDITY TRENDS

	1982	1983	1984	1985	1986**
GONORRHEA					
nited States	949,237	900,435	878,556	911,419	895,781
alifornia	109,860	108,066	110,208	118,579	110,849
os Angeles County	39,834*	48,115	49,807	59,387	52,604
NFECTIOUS SYPHILIS (Primary & Secondary)					
nited States	33,613	32,698	28,607	27,131	26,678
alifornia	5,096	5,290	4,503	4,370	4,893
os Angeles County	1,895*	1,896	1,571	1,854	2,687
YPHILIS (All Stages)					
nited States	75,579	74,637	69,888	67,563	67,929
alifornia	11,272	11,681	11,204	10,747	12,600
os Angeles County	5,127*	4,988	5,000	5,735	6,813

OMPLICATIONS - LOS ANGELES COUNTY STATISTICS - ELABORATION

ONOCOCCAL PELVIC INFLAMMATORY DISEASE (G/PID)

1982	1,176	reported cases
1983	1,161	reported cases
1984	1,659	reported cases
1985	1,826	reported cases
1986	1,881	reported cases

REPORTED CHILD SEXUAL ABUSE
(STDs in 0-11 year olds)

1982	69	reported cases
1983	93	"
1984	107	"
1985	124	"
1986	80	"

ENICILLINASE-PRODUCING NEISSERIA GONORRHOEAE (PPNG)

1982	139	reported cases
1983	169	reported cases
1984	286	reported cases
1985	489	reported cases
1986	942	reported cases

ONGENITAL SYPHILIS (Among children less than 1 year of age)

1982	10	reported cases
1983	8	reported cases
1984	5	reported cases
1985	10	reported cases
1986	31	reported cases

*Automated record keeping system introduced in Los Angeles County in 1982.
**Estimated/provisional data for 1986.

or disease information or clinics for diagnosis and treatment call the STD Hotline. Monday - Thursday 8 a.m. to 6 p.m. and Friday 8 a.m. through 5 p.m.

(213) 588-5221

MINORITY AIDS CONSORTIUM

FACT SHEET

The Minority AIDS Consortium was established in February 1989. The purpose of the Consortium is to promote and enhance HIV/AIDS education, prevention and intervention programs in ethnic minority communities throughout Los Angeles County. The Consortium's membership is comprised of agencies and individuals from the public and private sectors who are providing services to the HIV/AIDS infected and/or affected community. Additionally, many members serve as advocates for HIV infected/affected individuals, their families and the community-at-large. The Consortium's current membership totals thirty-six individuals representing twenty-two (22) community-based organizations, twelve (12) public sector agencies and/or programs (Department of Health Services Los Angeles County, Department of Health Services Long Beach, UCLA, California State University Los Angeles, California State University Long Beach and two (2) laypersons.

Member agencies of the Consortium have worked collaboratively on numerous occasions to promote and support HIV/AIDS-related programming being implemented throughout Los Angles County. In addition, the Consortium publishes and disseminates a quarterly calendar of HIV/AIDS-related events and programs to its membership as well as over two hundred (200) agencies and individuals from the public and private sectors in Los Angeles County.

For the past eighteen months, member agencies have been actively involved in the development of the AIDS Regional Board of Los Angeles County to ensure that the unmet HIV/AIDS-related service needs of ethnic minority communities are adequately addressed.

MINORITY AIDS CONSORTIUM ROSTER

Community Based Organizations	Services Provided
Ms. Collette Jacques Executive Director S.O.A.P. 945 S. Prairie, Ste. #103 Inglewood, CA 90301 (213) 671-1185	HIV/AIDS Outreach Targeting the Caribbean Community: Referrals
Mr. Phill Wilson Community Development Dept. 215 W. Sixth Street, 6th Floor Los Angeles, CA 90014 (213) 485-6320	Directs the City of Los Angeles Education and Prevention Programs targeting city employees and L.A. City residents.
Mr. Alvin Ransom, Coordinator ATTN: Mr. Johnnie Johnson AIDS Program Office 600 S. Commonwealth, 6th Floor Los Angeles, CA 90005 (213) 351-8076	Coordination of services and technical assistance to community-based organizations.
Dr. Perry Brown, Director Population Studies ATTN: Lisa Clements 1621 E. 120th Street Los Angeles, CA 90059 (213) 563-5843	HIV/AIDS related planning, coordination, development and research: epidemiology and prevention.
Mr. Michael Puentes Health Educator Cara A Cara Latino AIDS Project 3324 Sunset Blvd. Los Angeles, CA 90026 (213) 661-6752 (213) 660-1408 FAX	Education and prevention programs targeting the Latino community.
Mr. Andre Cunningham Director ATTN: Msadiki Gray Blanca Hernandez Southern California Youth and Family Center 101 N. LaBrea Ave, Ste. #100 Inglewood, CA 90301 (213) 671-1222	Teen pregnancy prevention and HIV/AIDS education targeting school age, out-of-school youth and the general community.

Ms. Ramona Hall The Gathering Place 3536 W. Slauson Avenue Los Angeles, CA 90043 (213) 295-2687	Services targeting HIV infected individuals and their families: emotional and spiritual support groups: massage therapy; AIDS referral: library. Lunch is served and a safe environment to "hand out" is provided.
Ms. Nola Thomas T.H.E. Clinic for Women 3860 W. Martin Luther King Blvd. Los Angeles, CA 90008 (213) 295-6571	OB/GYN clinic: health care for women and children: pregnancy testing; prenatal care: pediatric services: family planning; STD treatment; counseling; physical check-ups: multilingual staffing.
Danita Henderson Program Mananger Case Management AIDS Project Los Angeles 6721 Romaine Street Los Angeles, CA 90038 (213) 962-1600	Assists people affected by AIDS through advocacy and providing vital human services like food, counseling, support groups, referrals, dentistry and transportation: helps reduce the incidence of HIV infection through educational programs.
Ms. Yealanda Charles Metro South HIV Program Florence Firestone Health Center 8019 S. Compton Avenue Los Angeles, CA 90001 (213) 586-6588	Confidential and anonymous HIV testing; pre and post HIV counseling; referrals, community outreach.
Rev. Carl Bean, Director Minority AIDS Project ATTN: Mr. Paul Davis 5149 W. Jefferson Blvd. Los Angeles, CA 90016 (213) 936-4949	Assists with rent, food, utilities and transportation: give anonymous HIV antibody testing; early intervention: case management: in-home nursing care. Dignity House and housing referrals: outreach to Black gay men and Black and Latino women: psycho-social support.
Ms. Rochelle Jefferson P.O.Box 4763 Diamond Bar, CA 91765-0763	Community layperson interested in HIV/AIDS advocacy.

Ms. Cynthia Davis Drew University/NOBCO AIDS Information & Education Projects 1631 E. 120th Street, Bldg. C Los Angeles, CA 90059 (213) 567-7799	HIV/AIDS Education, prevention and control programs targeting youth, women of reproductive age; incarcerated individuals and the general community; material development; training programs: community outreach and referrals. Program has national and local funds.
Mr. Milton Ortega Comprehensive AIDS Resource Education (C.A.R.E.) St. Mary Medical Center 1050 Linden Avenue Long Beach, CA 90813 (213) 491-9050	Services to the South Bay community; comprehensive case management; services to people with HIV, ARC and AIDS for ambulatory health status clients; support groups.
Dr. Betty Jackson, Director AIDS Education and Prevention Center 3737 Martin Luther King Blvd. Lynwood, CA 90262 (213) 638-0460	HIV/AIDS education and executive prevention program targeting the Black, Latino and Haitian community.
Mr. Robert Ming Cal State University, Long Beach AIDS Research & Education Project Psychology Dept. Community Site:1229 Cedar Ave. Long Beach, CA 90813 (213) 985-7508	Health and family services for women; referrals; HIV testing and counseling; research targeting female sex partners of injection drug users: has component for outreach to Black churches, community groups within the greater Long Beach area, to do presentations.
Ms. Guadalupe Carreon Milagros AIDS Project- El Centro Mujeres Project 741 S. Atlantic Blvd. Los Angeles, CA 90022 (213) 261-2722	Crisis Intervention; Case Management; Support Groups; Education and Prevention; Consultation.

Ms. Ruth Slaughter Prototypes/WARN 5601 W. Slauson Ave. Suite #200 Culver City, CA 90230 (213) 641-7795	Outreach and education program that assesses women's needs holistically; gives referral: counseling and information.
Ms. Janet Rochester Clinic Manager Family Planning AIDS Education and Prevention Project, UCLA 22-222 CHS 10833 LeConte Avenue Los Angeles, CA 90024 (213) 825-2753	Education and Prevention program for Latino and other women of childbearing age. Provides basic AIDS information: sex negotiation workshops: referrals to testing sites: anonymous and confidential testing; provides info for pregnant women with AIDS; community programs, including some presentations.
Mr. Levi Kingston Community Consortium 3109 1/4 S. Western Avenue Suite B Los Angeles, CA 90018 (213) 731-9227 (213) 591-1261	HIV/AIDS education targeting the Black/Hispanic community.
Ms. Melvina Luke Minority Council on AIDS 1133 Rhea Street Long Beach, CA 90806 (213) 591-3381 (office) (213) 591-8334 (home)	HIV/AIDS education targeting the Black/Hispanic community.
Ms. Laurie Aronoff Hospice/AIDS Project L.A. Bar Association 617 S. Olive Street Los Angeles, CA 90014 (213) 896-6436	Free legal referrals to attorneys for terminally ill, indigent clients.

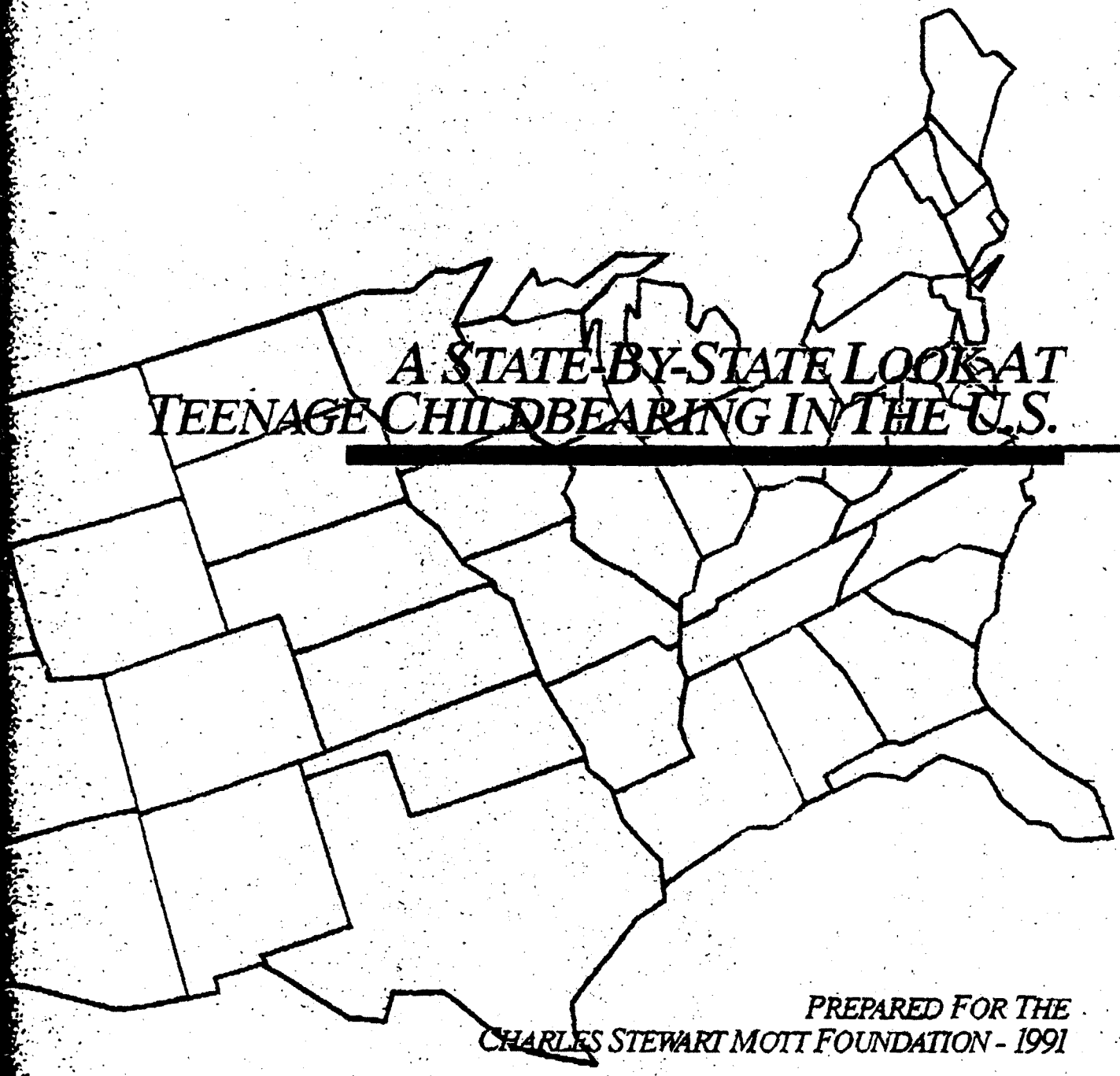
Rev. Carl Bean, Director Minority AIDS Project ATTN: Mr. Paul Davis 5149 W. Jefferson Los Angeles, CA 90016 (213) 936-4949	Assists with rent, food, utilities and transportation: gives anonymous HIV antibody testing; early intervention: case management: in-home nursing care. Dignity House and housing referrals: outreach to Black gay men and Black and Latino women: psycho-social support.
Connie M. Wynn People Who Care Youth Center 1504 W. Slauson Avenue Los Angeles, CA 90047 (213) 778-8905	Graffiti Abatement Program: AIDS outreach to Black and Hispanic youth aged 18-21; Youth Advocacy Senior Citizens checking and sharing program: parenting education and Black parenting education.
Ms. Mbete Kiambe 10636 Woodley Ave.,Suite #81 Granada Hills, CA 91344	Community layperson interested in HIV/AIDS advocacy.
Ms. Pamela Coleman 10215 S. Dixon Ave., #1 Inglewood, CA 90303	Community layperson interested in HIV/AIDS advocacy.
Cleante Stain Watts Health Foundation 4116 E. Compton Blvd. Compton, CA 90221 (213) 639-3068	The South Los Angeles AIDS Community AIDS Program (SLACAP) Drug Abuse AIDS Outeach Services: Case Management Referral Services.
Ms. Carolyn Williams 11107 Lamaida, Suite #107 North Hollywood, CA 91601	Community layperson interested in HIV/AIDS advocacy.

Vanessa Parker Program Manager Tobacco Control Program 12012 S. Compton Avenue I&R Bldg., Room #211, MP. 31 Los Angeles, CA 90059 (213) 603-3558 or 3559 & 3561	Hospital clinic-based tobacco prevention and cessation educational program. The target populations include current smokers, parents of children 6 years/younger and nurses.
Mr. John Morant Health Center Cal State University, L.A. 5151 State University Drive Los Angeles, CA 90032 (213) 343-3346	AIDS Education and Prevention Program; provide limited medical services. College-age 18 years and older.
Mr. Howard Eley, Director Institute of Alternate Attitudes Substance and Chemical Abuse Consultants 856 South St. Andrews Place Los Angeles, CA 90005 (213) 385-1847	Substance and chemical abuse/use counseling for adults: multicultural.
Mr. Mike Sims Early Intervention Project Hospital Social Services Martin Luther King Jr Hospital 12021 S. Wilmington Avenue Los Angeles, CA 90059 (213) 603-4218 or 603-3467	Services for people who are HIV infected.

Ms. Fay Nugent Hubert Humphrey Comprehensive Health Center, Room #2030 5850 So. Main Street Los Angeles, CA 90003 (213) 235-7401	Free HIV testing, T-cell count, Psychosocial counseling, physician evaluation and referral services.
Dr. Wilbert Jordan, Director Graduate Medical Education Augustus Hawkins Bldg. MP. 56A Martin Luther King Jr Hospital 1720 East 120th Street Los Angeles, CA 90059 (213) 603-8166	Testing, counseling, social support, and clinical services for HIV+ persons.
Barbara Walker YWCA of Los Angeles Executive Offices 1125 W. 6th Street, #400 Los Angeles, CA 90017 (213) 482-3470	AIDS Information and Education
Rue Thais Williams Rue's House P.O. Box 37036 Los Angeles, CA 90037 (213) 295-9575 (Office) (213) 734-2467 (Fax)	Provides residential housing to HIV+ women and their children.
Mike Neeley, Director Homeless Outreach Project 846 E. 6th Street Los Angeles, CA 90021 (213) 683-8304	Provides HIV testing, counseling and referral to homeless individuals in the City of Los Angeles. Also, provides drug abuse counseling and referral.
Stephanie Farrington 6238 Haas Avenue Los Angeles, CA 90047 (213) 751-3030	HIV/AIDS Consultant.
Cornelia Owens 3707 Coliseum Street Los Angeles, CA 90016 (213) 298-5526	Los Angeles Unified School District staff implementing AIDS Education, Risk Reduction Program targeting students and teachers.
Marcus Kuilard Community Outreach Worker c/o JWCH Institute 2829 S. Grand Avenue Los Angeles, CA 90007 (213) 744-3916	Operate women's clinic on skid row; provide medical outreach to the homeless; referrals; HIV/AIDS community outreach to the community.

Ray Johnson Long Beach Comprehensive Health Center 1333 Chesnut Avenue Long Beach, CA 90813 (213) 599-8711	The clinic provides the full range of services to the HIV positive client, including early intervention care, management of infections or complications related to HIV, ongoing follow-up, and referral as needed, for further evaluation or management.
Calvin Williams Public Policy Department APLA 6430 Sunset Blvd, Suite 421 Los Angeles, CA 90028 (213) 962-1600 ext. 505	Assists people affected by AIDS through advocacy and providing vital human services like food, counseling, support groups, referrals, dentistry and transportation: helps reduce the incidence of HIV infection through educational programs.
Sue Crumpton Executive Director L.A. Shanti Foundation 6855 Santa Monica Blvd. Los Angeles, CA 90038 (213) 962-8197	Services targeting HIV infected men and women and their families; one on one volunteers and emotional support groups. A speakers bureau on Education and Prevention; 7-week Education/Support Group; and positive Living for Us seminars for those recently tested or testing for HIV positive.

STATE FACTS-AT-A-GLANCE



A STATE-BY-STATE LOOK AT TEENAGE CHILDBEARING IN THE U.S.

PREPARED FOR THE CHARLES STEWART MOTT FOUNDATION - 1991

CALIFORNIA

TEENAGE CHILDBEARING IN THE U.S.

Number of births (all races) by mother's age in:

	1988	1980	1970
Ages under 15	1,089	773	734
15-17	20,629	18,643	na
18-19	37,232	36,722	na
Total 15-19	57,861	55,365	60,864
Total under 20	58,950	56,138	61,598
All ages	533,148	402,949	362,756

Number of births to unmarried* mothers in:

	1988	1980	1970
Ages under 15	945	673	621
15-17	15,560	11,937	na
18-19	21,801	15,709	na
Total 15-19	37,361	27,646	18,888
Total under 20	38,306	28,319	19,509
All ages	152,607	86,142	45,993

Percent of births to females under age 20 that occurred outside of marriage in:

	1988	1980	1970
All races	65%	50%	32%
White	61%	44%	25%
Black	86%	82%	65%
Hispanic	64%	na	na

Of all first births to mothers of all ages, percent to a mother under age 20 in:

	1988	1980	1970
All races	21.6%	25.0%	33.4%
White	21.4%	24.5%	32.0%
Black	36.1%	38.1%	52.0%

Number of Births by Race, 1988:

	Whites	Blacks	Asian & Pacific Islander	Number of Births to Hispanics,** 1988
Ages under 15	712	284	72	578
15-17	15,394	3,804	1,088	10,418
18-19	28,814	5,832	2,018	17,074
Total 15-19	44,208	9,636	3,106	27,492
Total under 20	44,920	9,920	3,178	28,070

Percent of females 15-19 pregnant in:

	1985	1980
National	11.0%	11.1%
California	15.1%	14.0%

Percent of females 15-19 having an abortion in:

	1985	1980
National	4.4%	4.3%
California	7.9%	6.9%

Percent of females 15-19 having a birth in:

	1985	1980
National	5.1%	5.3%
California	5.4%	5.3%

Number of abortions in:

	1985	1980
Ages under 15	2,280	na
15-17	30,290	na
18-19	44,230	na
Total 15-19	74,520	72,030
Total under 20	76,800	na

Percent of pregnancies to females under age 20 ending in abortion in:

	1985	1980
Ages under 15	64%	na
15-19	52%	49%
Total under 20	53%	na

[Note: Abortion data for California are estimates based on the proportion of abortions obtained by women of the same age in neighboring or similar states.]
*Marital status of parents inferred from names on the birth certificate. **This column distinguishes ethnicity from race. Hence, Hispanic persons are also reported as white, black, or other.
na = data not available

BIRTHS TO TEENAGE MOTHERS IN CALIFORNIA CITIES IN 1988

	Births to Teens			Births to Unwed Teens			Percent of all births to mothers under 20	Percent of all teen births to unwed mothers	Number of Births to Teens	
City	Total under 20	17 and Younger	Ages 18-19	Total under 20	17 and Younger	Ages 18-19			White	Black
ANAHEIM	568	199	369	328	142	186	10%	58%	516	28
BAKERSFIELD	1,058	419	639	762	353	409	16%	72%	835	199
FREMONT	178	47	131	121	43	78	6%	68%	135	29
FRESNO	1,304	586	718	892	443	449	15%	68%	863	219
GLENDALE	140	47	93	77	30	47	6%	55%	127	6
HUNTINGTON BEACH	156	50	106	99	39	60	6%	63%	137	5
LONG BEACH	1,180	460	720	839	370	469	13%	71%	658	341
LOS ANGELES	9,429	3,717	5,712	6,869	3,016	3,853	12%	73%	6,798	2,429
OAKLAND	1,024	429	595	741	330	411	14%	72%	154	792
RIVERSIDE	748	282	466	487	217	270	13%	65%	612	103
SACRAMENTO	1,527	588	939	1,103	466	637	13%	72%	814	503
SAN DIEGO	1,962	732	1,230	1,354	587	767	10%	69%	1,254	510
SAN FRANCISCO	764	297	467	527	224	303	8%	69%	314	325
SAN JOSE	1,577	566	1,011	1,129	465	664	10%	72%	1,252	155
SANTA ...	...	...	...	...	...	...	...	...	...	...

LOS ANGELES REGIONAL FAMILY PLANNING COUNCIL INC.
3250 WILSHIRE BLVD., SUITE 320 • LOS ANGELES, CALIFORNIA 90010 • (213) 386-5614

ADOLESCENT PREGNANCY FACT SHEET
1986
NATIONAL, STATE AND COUNTY STATISTICS

Prepared by: Paraskevy Goltsos, MPH, Associate
Ron Frezieres, MSPH, Research Manager
November, 1986

COUNTY STATISTICS

TABLE 3:

BIRTH RATES TO ADOLESCENTS
AGES 15 - 19 IN LOS ANGELES COUNTY
BY ETHNICITY, 1980*

ETHNICITY	RATE PER 1,000 FEMALES
White	26.8
Black	78.5
Hispanic	96.7
Other	26.4
Overall	57.1

TABLE 4:

% LIVE BIRTHS BY REGION FOR ADOLESCENTS
IN LOS ANGELES COUNTY, 1979*

REGION	% TOTAL LIVE BIRTHS
San Fernando Valley	11.2%
Coastal L.A.	12.9%
San Gabriel Valley	14.5%
Central L.A.	15.8%
Southeast L.A.	22.3%

* Source: Center for Health Statistics, 1979-1980

TABLE 5:

SUMMARY STATISTICS FOR ADOLESCENT

PREGNANCY, 1981

NATIONAL, STATE AND COUNTY PREGNANCY, BIRTH, ABORTION AND MISCARRIAGE RATES PER 1,000 FEMALES 15-19 YEARS OLD.

Outcome	UNITED STATES (Rate per 1,000 based on a total of 10,010,000)*		CALIFORNIA (Rate per 1,000 based on a total of 1,005,520)*		L.A. COUNTY (Rate per 1,000 based on a total of 318,499)*	
	Rate	Number	Rate	Number	Rate	Number
Birth	52.7	527,390	54.7	55,040	58.1	18,519
Abortion	43.3	433,330	72.0	72,440	71.0 ± 26**	22,607
Miscarriages	14.5	148,810	18.2	18,250	18.7 ± 2.6**	5,965
Total Pregnancies	110.8	1,109,530	144.9	145,730	147.9 ± 28.4**	47,091

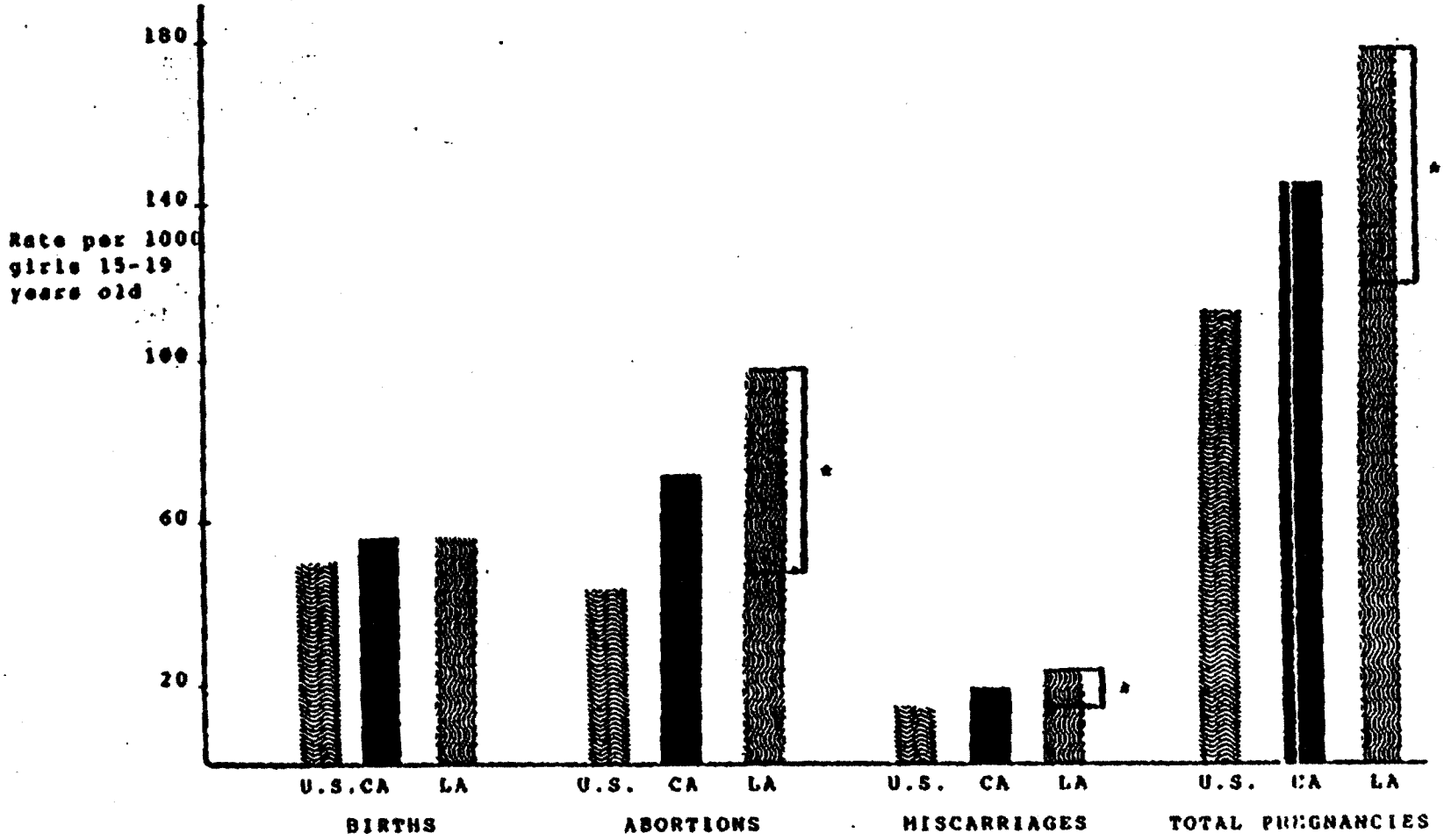
* Totals are of females between the ages of 15 and 19

** Actual numbers for abortion, miscarriages for teens in Los Angeles County are not available. Therefore, pregnancy rates have been approximated based on estimates of adolescent abortions and miscarriages in California for 1981 (27.8% of all abortions occur to teens, total number of abortions for women in L.A. County is 82,120).

Table 6:

PREGNANCY OUTCOME RATES AT THE

NATIONAL, STATE AND COUNTY LEVELS, 1981



PREGNANCY OUTCOME AT THE NATIONAL (U.S.), STATE (CA) AND COUNTY (LA) LEVELS

*Bar indicates range of estimate

WRITTEN TESTIMONY SUBMITTED

TESTIMONY

"FUNDING AIDS PROGRAMS"

HEARING OF THE SENATE COMMITTEE ON HEALTH AND HUMAN SERVICES
OF THE CALIFORNIA STATE LEGISLATURE

DECEMBER 17, 1991

WAYNE E. SAUSEDA, CHIEF
OFFICE OF AIDS, DEPARTMENT OF HEALTH SERVICES

MADAM CHAIRWOMAN, MEMBERS OF THE COMMITTEE, DR. TATE, ON BEHALF OF THE DEPARTMENT OF HEALTH SERVICES, THANK YOU FOR YOUR INVITATION TO DISCUSS THE STATE'S AIDS PROGRAM. DURING MY TESTIMONY, I WILL OVERVIEW: (1) PROGRAMS ADMINISTERED BY THE STATE OFFICE OF AIDS; (2) EPIDEMIOLOGIC TRENDS; AND (3) STATE FUNDING FOR EDUCATION AND PREVENTION, TESTING, CARE AND TREATMENT AND RESEARCH.

OVERVIEW OF STATE OFFICE OF AIDS

THE OBJECTIVE OF THE OFFICE OF AIDS IS TO PROVIDE INFORMATION AND EDUCATION, TESTING, EPIDEMIOLOGICAL INVESTIGATION AND SURVEILLANCE, RESEARCH, AND TREATMENT TO ADDRESS THE PUBLIC HEALTH PROBLEMS RESULTING FROM ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS).

THE OFFICE OF AIDS PROVIDES A COMPLETE AND TIMELY REGISTRY OF AIDS

CASES, EDUCATIONAL INFORMATION FOR HIGH-RISK GROUPS, HEALTH PROFESSIONALS, AND THE PUBLIC AND POLICY DIRECTION AND DEVELOPMENT OF PILOT PROJECTS FOR THE CARE OF PEOPLE WITH AIDS AND EARLY INTERVENTION PROJECTS TO PROVIDE SERVICES TO HIV-INFECTED PERSONS. ADDITIONALLY, THE OFFICE CONDUCTS SURVEILLANCE ACTIVITIES TO IDENTIFY RISK GROUPS AND PATTERNS OF TRANSMISSION, AND EPIDEMIOLOGY FOR SELECTED CASES. THE OFFICE ALSO ADMINISTERS A PROGRAM WHICH TESTS FOR THE ANTIBODY TO THE AIDS VIRUS AT OVER 100 ALTERNATIVE TEST SITES, WHICH ARE FREE AND ANONYMOUS. LOCAL ASSISTANCE BLOCK GRANTS ARE PROVIDED TO LOCAL AGENCIES FOR AIDS EPIDEMIOLOGICAL INVESTIGATION AND SURVEILLANCE.

THIS PAST YEAR, FIVE SIGNIFICANT LEGISLATIVE MEASURES WERE PASSED BY THE CALIFORNIA STATE LEGISLATURE AND SIGNED BY GOVERNOR WILSON. THESE MEASURES REFLECT THE GOVERNOR'S COMMITMENT TO PREVENTION, PATIENTS' RIGHTS, INTEGRATION OF SERVICES, AND EXPANDED ACCESS TO HEALTH CARE.

AB 11 (HUGHES) - AIDS IN-SCHOOL EDUCATION - COMMENCING WITH THE 1992-93 SCHOOL YEAR, INSTRUCTION FOR THE PREVENTION OF AIDS WILL BE PROVIDED BY ADEQUATELY TRAINED TEACHERS TO STUDENTS IN GRADES 7-12, AT LEAST ONCE IN JUNIOR HIGH OR MIDDLE SCHOOL AND ONCE IN

HIGH SCHOOL. AB 11 FITS INTO THE CURRENT CALIFORNIA DEPARTMENT OF EDUCATION HEALTHY KIDS/HEALTHY CALIFORNIA PROJECT WHICH IS FUNDED BY THE OFFICE OF AIDS TO PROVIDE TRAINING TO TEACHERS AND SCHOOL ADMINISTRATORS ON PROVIDING INSTRUCTION ON HIV TRANSMISSION TO STUDENTS IN THE 7TH AND 8TH GRADES, AS WELL AS HIGH SCHOOLS. STUDIES ON YOUTH SHOW INCREASES IN DRUG USE AND SEXUALLY TRANSMITTED DISEASES, WHICH ARE MAJOR CO-FACTORS FOR HIV INFECTION. SURVEYS ON YOUTH OUT OF MAINSTREAM SCHOOLS INDICATE THAT NEARLY ALL OF THEIR HEALTH AND HIV/AIDS RELATED KNOWLEDGE WAS OBTAINED FROM THEIR SCHOOL EXPERIENCES.

SB 1070 (THOMPSON) - PATIENT PROTECTION ACT OF 1991 - THIS BILL REQUIRES THE DEPARTMENT OF HEALTH SERVICES TO DEVELOP WRITTEN GUIDELINES AND REGULATIONS AS NECESSARY TO MINIMIZE THE RISK OF TRANSMISSION OF BLOOD-BORNE INFECTIOUS DISEASES FROM HEALTH CARE WORKER TO PATIENT, FROM PATIENT TO PATIENT, AND FROM PATIENT TO HEALTH CARE WORKER. SB 1070 REINFORCES THE DEPARTMENT OF HEALTH SERVICES' LEADERSHIP ROLE IN ESTABLISHING CONSENSUS-BASED RECOMMENDATIONS FOR THE PREVENTION OF TRANSMISSION OF HIV AND HEPATITIS B VIRUS BETWEEN HEALTH CARE WORKERS AND PATIENTS.

AB 305 (FRIEDMAN) - DEFINITION OF AIDS - REDEFINES THE TERM CHRONIC,

LIFE-THREATENING ILLNESS TO MEAN HIV DISEASE OR AIDS. AB 305 ALSO PROVIDES THAT THE DEPARTMENT OF HEALTH SERVICES MAY PROVIDE SUPPLEMENTAL FUNDING TO RESIDENTIAL AIDS SHELTERS AND TO RESIDENTIAL CARE FACILITIES.

AB 1281 (FILANTE) - HIV ANTIBODY TESTS/INSURANCE - UPDATES CURRENT LAW WHICH PROHIBITS THE USE OF HIV ANTIBODY BLOOD TESTS AS A PREREQUISITE FOR DETERMINING ELIGIBILITY FOR HEALTH INSURANCE. AB 1281 REDEFINES HIV TESTING AND DISCLOSURE STATUTES TO BE MORE REFLECTIVE OF CURRENT MEDICAL TECHNOLOGY, THEREBY SERVING TO PROTECT THOSE PEOPLE AT RISK FOR HIV INFECTION FROM BEING DENIED HEALTH OR DISABILITY INSURANCE BASED ON OTHER "LEGAL" HIV LABORATORY TESTS.

AB 1287 (VASCONCELLOS) - HIV TEST DISCLOSURE - INSURES THAT HIV/AIDS VACCINE CLINICAL TRIAL VOLUNTEERS WHO TEST HIV ANTIBODY POSITIVE OR NEGATIVE AS A RESULT OF THEIR PARTICIPATION IN HIV/AIDS CLINICAL TRIALS WILL NOT BE DENIED HEALTH CARE, DISABILITY, WELFARE, OR LIFE INSURANCE COVERAGE.

EPIDEMIOLOGY

TO PLACE MY TESTIMONY INTO PERSPECTIVE, I WOULD LIKE TO GIVE YOU

SOME FACTS AND FIGURES ABOUT THE SCOPE AND COURSE OF THE AIDS EPIDEMIC IN THE STATE AND LOS ANGELES COUNTY.

AS OF NOVEMBER 30, 1991, 38,660 CUMULATIVE CASES OF AIDS AND 26,369 AIDS-RELATED DEATHS HAVE BEEN REPORTED IN CALIFORNIA. AS OF THIS DATE, 13,672 CASES AND 9,576 DEATHS HAVE BEEN REPORTED IN LOS ANGELES COUNTY. 7,683 NEW CASES WERE DIAGNOSED AND 6,036 DEATHS WERE REPORTED DURING THE MOST RECENT 12-MONTH PERIOD. DURING THIS TIME PERIOD, AN AVERAGE OF 640 NEW AIDS CASES WERE DIAGNOSED AND 503 AIDS-RELATED DEATHS WERE REPORTED TO THE OFFICE OF AIDS, AIDS CASE REGISTRY EACH MONTH.

AS THE EPIDEMIC IN CALIFORNIA CONTINUES TO GROW, THE REGIONS OF THE STATE WHERE CASES ARE REPORTED FROM CONTINUES TO CHANGE. CUMULATIVELY, LOS ANGELES COUNTY HAS ACCOUNTED FOR 35 PERCENT OF ALL AIDS CASES REPORTED IN THE STATE. SAN FRANCISCO HAS ACCOUNTED FOR 27 PERCENT; OTHER BAY AREA COUNTIES 13 PERCENT; SOUTHERN METROPOLITAN COUNTIES (ORANGE, RIVERSIDE, SAN BERNARDINO, AND SAN DIEGO) 16 PERCENT; AND THE REST OF CALIFORNIA 9 PERCENT. THE PROPORTION OF NEW AIDS CASES BEING DIAGNOSED <u>OUTSIDE</u> SAN FRANCISCO AND LOS ANGELES COUNTIES CONTINUES TO INCREASE. DURING 1986, SAN FRANCISCO AND LOS ANGELES

COLLECTIVELY ACCOUNTED FOR 68 PERCENT OF ALL CASES DIAGNOSED IN THE STATE. FOR THE YEAR ENDING JUNE 30, 1991, LOS ANGELES ACCOUNTED FOR 38 PERCENT OF ALL NEW CASES REPORTED IN THE STATE. THE SOUTHERN METROPOLITAN COUNTIES ACCOUNTED FOR 12 PERCENT OF ALL AIDS CASES REPORTED IN CALIFORNIA DURING 1986. BY THE END OF NOVEMBER 1991, THEY WERE REPORTING 24 PERCENT OF ALL NEW CASES.

AN ESTIMATED 12,500 CALIFORNIANS WERE LIVING WITH AIDS AT THE END OF 1990. AT THE END OF 1993, THERE WILL BE AN ESTIMATED 16,200 PEOPLE ALIVE WITH AIDS.

THE INCIDENCE OF AIDS CONTINUES TO INCREASE IN ALL ETHNIC AND RACIAL GROUPS WITHIN THE STATE. OF THE CUMULATIVE TOTAL AIDS CASES REPORTED IN CALIFORNIA THROUGH JUNE 1991, WHITES HAVE ACCOUNTED FOR 71 PERCENT OF THE TOTAL; AFRICAN AMERICANS 13 PERCENT; LATINOS 14 PERCENT; AND ASIANS/PACIFIC ISLANDERS 2 PERCENT. IN CONTRAST TO STATEWIDE RACIAL/ETHNIC DISTRIBUTIONS, 62 PERCENT OF AIDS CASES REPORTED IN LOS ANGELES COUNTY HAVE BEEN AMONG WHITES; 16 PERCENT AMONG AFRICAN AMERICANS; 19 PERCENT AMONG LATINOS; AND 1 PERCENT AMONG ASIAN/PACIFIC ISLANDERS. BETWEEN 1986 AND 1991, THE PROPORTION OF NEW AIDS CASES REPORTED AMONG WHITES IN CALIFORNIA DECREASED FROM

77 PERCENT TO 65 PERCENT. CONVERSELY, AMONG AFRICAN AMERICANS THE PERCENTAGE OF NEW CASES INCREASED FROM 10 PERCENT IN 1986 TO 14 PERCENT IN 1991. LATINOS ACCOUNTED FOR 11 PERCENT OF NEW CASES REPORTED IN 1986 AND 18 PERCENT IN 1991. THE PERCENTAGE OF NEW CASES REPORTED AMONG ASIAN/PACIFIC ISLANDERS INCREASED FROM 1 PERCENT IN 1986 TO 2 PERCENT IN 1991 (SEE ATTACHMENTS I AND II).

THE PROPORTION OF NEW AIDS CASES AMONG DIFFERENT TRANSMISSION CATEGORIES HAS REMAINED RELATIVELY STABLE OVER TIME. THE MAJORITY OF NEW AIDS CASES CONTINUE TO BE REPORTED AMONG GAY AND BISEXUAL MALES. APPROXIMATELY 83 PERCENT OF CALIFORNIA AIDS CASES DIAGNOSED IN 1991 WERE AMONG THIS GROUP. CUMULATIVELY, NEARLY NINE OUT OF EVERY TEN CALIFORNIA AIDS CASES HAVE BEEN DIAGNOSED AMONG GAY AND BISEXUAL MEN.

THE NUMBER OF CASES ATTRIBUTABLE TO HETEROSEXUAL INJECTION DRUG USE CONTINUES TO INCREASE. NEARLY 1,250 OF THE 2,211 CASES IN THIS TRANSMISSION CATEGORY HAVE BEEN REPORTED IN THE LAST TWO YEARS. NOTABLY, AFRICAN AMERICANS ACCOUNT FOR 12 PERCENT OF ALL AIDS CASES, BUT 40 PERCENT OF CASES AMONG INJECTION DRUG USERS.

THE NUMBER OF NEW CASES ATTRIBUTABLE TO HETEROSEXUAL CONTACT

WITH AN INFECTED PERSON ALSO CONTINUES TO INCREASE. AS OF NOVEMBER 30, 1991, A TOTAL OF 702 AIDS CASES HAVE BEEN REPORTED AMONG PERSONS WHO CITE HETEROSEXUAL CONTACT AS THEIR PRIMARY RISK FOR INFECTION. MORE THAN HALF OF REPORTED CASES HAVE BEEN DIAGNOSED IN THE PAST TWO YEARS. TO DATE, 204 CASES OF AIDS HAVE BEEN DIAGNOSED AMONG HEMOPHILIACS. 802 CASES HAVE BEEN DIAGNOSED AMONG TRANSFUSION RECIPIENTS.

A TOTAL OF 258 AIDS CASES HAVE BEEN DIAGNOSED AMONG CHILDREN IN CALIFORNIA. CASES HAVE BEEN ALMOST EVENLY DISTRIBUTED AMONG WHITE (34 PERCENT), AFRICAN AMERICAN (29 PERCENT), AND HISPANIC (33 PERCENT) CHILDREN. BECAUSE OF UNDER-REPORTING AND MIS-DIAGNOSIS, THE ACTUAL NUMBER OF CHILDREN WITH AIDS MAY BE AS MUCH AS 50 PERCENT HIGHER (SEE ATTACHMENTS III AND IV).

IT IS ESTIMATED THAT THERE WERE ABOUT 146,000 CALIFORNIANS LIVING WITH HIV INFECTION IN 1990. AN ESTIMATED 83 PERCENT OF THE PEOPLE WITH HIV INFECTION ARE GAY OR BISEXUAL MEN; 9 PERCENT ARE HETEROSEXUAL INJECTION DRUG USERS; 2 PERCENT ARE WOMEN INFECTED THROUGH HETEROSEXUAL TRANSMISSION; AND 6 PERCENT TRANSFUSION RECIPIENTS, HEMOPHILIACS, MEN INFECTED THROUGH HETEROSEXUAL TRANSMISSION, OR INFANTS INFECTED PERINATAL.

THE CENTERS FOR DISEASE CONTROL (CDC) ESTIMATES THAT THERE ARE AT LEAST 40,000 NEW HIV INFECTIONS OCCURRING PER YEAR NATIONALLY; THIS COULD IMPLY THAT AS MANY AS 8,000 NEW HIV INFECTIONS WERE OCCURRING ANNUALLY IN CALIFORNIA, ASSUMING THE PROPORTION OF RECENT AIDS IN THE UNITED STATES FROM CALIFORNIA IS THE SAME AS THAT FOR HIV INFECTIONS. AN ESTIMATED 100-150 NEW INFECTIONS OCCURRED ANNUALLY IN NEWBORNS AS THE RESULT OF PERINATAL HIV TRANSMISSION IN 1988 AND 1989.

THE CDC ESTIMATES THAT ABOUT 60 PERCENT OF THE 1 MILLION HIV-INFECTED PERSONS IN THE UNITED STATES MAY HAVE T-HELPER LYMPHOCYTE (CD4+ CELL) COUNTS BELOW 500 CUBIC MILLIMETERS OF BLOOD AND MAY BENEFIT FROM EARLY TREATMENT WITH AZT. IN CALIFORNIA IT IS LIKELY THAT AT LEAST 60 PERCENT OF THE ESTIMATED 146,000 HIV-INFECTED PERSONS WOULD BENEFIT FROM EARLY AZT TREATMENT SINCE THE HIV EPIDEMIC BEGAN EARLIER IN SAN FRANCISCO AND LOS ANGELES COMPARED TO THE REST OF THE UNITED STATES.

THE NUMBER OF AIDS CASES REPORTED IN CALIFORNIA WILL CONTINUE TO INCREASE THROUGH 1993, WITH PROJECTIONS OF 8,600 CASES TO BE DIAGNOSED IN 1990; 9,200 IN 1991; 9,500 IN 1992; AND 9,700 IN 1993. BY 1993,

THE CUMULATIVE NUMBER OF AIDS CASES DIAGNOSED IN CALIFORNIA IS EXPECTED TO REACH 68,000. THESE PROJECTIONS ARE BASED ON THE METHOD OF BACK-CALCULATION, WHICH USES THE DISTRIBUTION OF TIME FROM HIV INFECTION TO AIDS TO ESTIMATE THE NUMBER OF PAST HIV INFECTIONS MOST CONSISTENT WITH OBSERVED AIDS INCIDENCE. THESE PROJECTIONS ARE ADJUSTED UPWARDS TO ACCOUNT FOR AN ESTIMATED 15 PERCENT UNDER-REPORTING OF AIDS CASES AND ALLOWS A MORE ACCURATE REFLECTION OF THE EXTENT OF SEVERE HIV DISEASE.

AIDS CASE PROJECTIONS ARE INFLUENCED BY THE SLOWING OF THE RAPID UPWARD TREND IN AIDS INCIDENCE THAT OCCURRED IN 1987 AMONG HOMOSEXUAL/BISEXUAL MEN IN SAN FRANCISCO AND LOS ANGELES. THIS SLOWING HAS ALSO OCCURRED TO A LESSER EXTENT AMONG WHITE HOMOSEXUAL/BISEXUAL MEN IN THE COUNTIES SURROUNDING SAN FRANCISCO AND LOS ANGELES. INCIDENCE AMONG INTRAVENOUS DRUG USERS AND HETEROSEXUAL CONTACT CASES IS STILL INCREASING STEADILY.

POSSIBLE EXPLANATIONS FOR THE SLOWING OF INCIDENCE IN CERTAIN POPULATIONS INCLUDE ADVANCES IN MEDICAL THERAPY, A DECLINE IN INCIDENCE OF NEW HIV INFECTIONS AMONG HOMOSEXUAL/BISEXUAL MEN IN THE EARLY 1980'S, AND DECREASED TIMELINESS AND COMPLETENESS OF

AIDS CASE REPORTING. THE RELATIVE CONTRIBUTIONS OF THESE FACTORS REQUIRE FURTHER INVESTIGATION.

STATE AIDS FUNDING

OVERALL, FUNDING FOR AIDS PROGRAMS ADMINISTERED BY THE STATE TOTAL $124,626,000. OF THIS AMOUNT, $76,595,000 IS STATE FUNDS AND $48,031,000 IS FEDERAL FUNDS AS REFLECTED IN ATTACHMENTS V AND VI.

FUNDING FOR EDUCATION AND PREVENTION PROJECTS BEGAN DURING FY 1983-84. AT THAT TIME, A TOTAL OF $450,000 WAS AVAILABLE FOR EDUCATION AND PREVENTION PROJECTS. SINCE THEN, THE EDUCATION AND PREVENTION BUDGET HAS GROWN TO $16 MILLION FOR FY 1991-92. WHILE THE SPECIFIC NUMBERS OF CLIENTS SERVED ARE UNAVAILABLE, THE NUMBERS OF EDUCATION AND PREVENTION CONTRACTORS HAVE INCREASED FROM 15 IN FY 1983-84 TO 137 IN FY 1991-92.

THE OFFICE OF AIDS BEGAN DISTINGUISHING BETWEEN EDUCATION AND PREVENTION SERVICES TO MINORITIES AND OTHER GROUPS DURING FY 1988-89. DURING THAT FISCAL YEAR, THE TOTAL EDUCATION AND PREVENTION BUDGET WAS $16 MILLION, OF WHICH 38 PERCENT WAS TARGETED FOR MINORITY PROJECTS. IN FY 1991-92, THE AMOUNT AVAILABLE AGAIN IS $16 MILLION. OF THE 137 CONTRACTORS FUNDED, 52 PERCENT ARE

MINORITY OWNED AND/OR SERVE MORE THAN 50 PERCENT MINORITY POPULATIONS.

STATE-FUNDED HIV ANTIBODY TESTING IS PROVIDED THROUGH VARIOUS SOURCES IN THE STATE. FREE AND ANONYMOUS TESTING IS PROVIDED THROUGH THE ALTERNATIVE TEST SITE (ATS) PROGRAM. ADDITIONALLY, CONFIDENTIAL HIV TESTING IS PROVIDED THROUGH VARIOUS COUNTY PRIMARY CARE CLINICS AND OTHER FREE STANDING COMMUNITY PRIMARY CARE CLINICS, SUCH AS FAMILY PLANNING AND RURAL COMMUNITY CLINICS. OF ALL TESTING AND COUNSELING SERVICES PROVIDED DURING JANUARY-DECEMBER 1990, 25 PERCENT WERE RECEIVED BY LATINOS AND 13 PERCENT WERE RECEIVED BY AFRICAN AMERICANS. THE TESTING PROGRAM IS ALSO CONDUCTING AN OUTREACH CAMPAIGN TO PROVIDE INFORMATION ON TESTING AND THE SERVICES AVAILABLE TO THE PUBLIC. OF THE $300,000 EARMARKED FOR THE CAMPAIGN, ONE-THIRD IS BEING USED IN THE LATINO COMMUNITY AND ONE-THIRD IS BEING USED IN THE AFRICAN AMERICAN COMMUNITY.

THE EARLY INTERVENTION PROGRAM PROVIDES BEHAVIOR CHANGE INTERVENTIONS, PSYCHOSOCIAL SUPPORT, HEALTH EDUCATION, CASE MANAGEMENT SERVICES, AND EARLY MEDICAL ASSESSMENT AND TREATMENT TO HIV-INFECTED PERSONS. THE GOAL OF THE PROGRAM IS TO PROLONG

THE HEALTHY AND PRODUCTIVE LIVES OF THOSE INFECTED WITH HIV. STATEWIDE, 22 PERCENT OF EARLY INTERVENTION PROGRAM CLIENTS ARE LATINO AND 11 PERCENT ARE AFRICAN AMERICAN. THESE PERCENTAGES ARE EVEN HIGHER AT SOME LOCATIONS SUCH AS THE EARLY INTERVENTION PROGRAM IN SAN FRANCISCO WHERE 52 PERCENT OF THE CLIENTS ARE LATINO AND SOUTH/SOUTH-CENTRAL LOS ANGELES WHERE 49 PERCENT ARE AFRICAN AMERICAN. THE TOTAL 1990-91 STATE FUNDING OF THE EARLY INTERVENTION PROGRAM IS $2.6 MILLION.

FUNDING FOR PILOT HOME AND COMMUNITY-BASED CARE PROJECTS BEGAN IN FY 1985-86. AT THAT TIME, THE PILOT CARE PROJECT BUDGET WAS $1.6 MILLION. SINCE THEN, THE BUDGET HAS GROWN TO $6.6 MILLION FOR FY 1991-92. PILOT CARE PROJECTS HAVE OFFICIALLY TARGETED 25 PERCENT OF THEIR FUNDS FOR SERVICES TO MINORITIES; HOWEVER, THE ACTUAL PERCENTAGE HAS BEEN OVER 35 PERCENT SINCE FY 1988-89 (SEE ATTACHMENT VII FOR PILOT CARE CLIENT SERVICES BY RACE/ETHNICITY).

THE OFFICE OF AIDS FUNDS A VARIETY OF MINORITY PROJECTS THROUGHOUT THE STATE WHICH ADDRESS ETHNIC MINORITY GROUPS INCLUDING LATINOS, AFRICAN AMERICANS, ASIAN/PACIFIC ISLANDERS, AND AMERICAN INDIANS. ALL MINORITY-BASED PROJECTS PROVIDE EDUCATION AND MATERIALS IN THE TARGET GROUPS' NATIVE LANGUAGE WITH A SPECIAL

EMPHASIS ON CULTURAL VALUES. SOME EXAMPLES OF OFFICE OF AIDS-FUNDED MINORITY PROJECTS ARE:

- MINORITY AIDS PROJECT - OPERATES HOME AND COMMUNITY-BASED CARE PILOT PROJECT. APPROXIMATELY TWO-THIRDS OF THE POPULATION SERVED ARE AFRICAN AMERICAN. MINORITY AIDS PROJECT ALSO OPERATES A RESIDENTIAL AIDS SHELTER, DIGNITY HOUSE, WHICH SERVES PRIMARILY AFRICAN AMERICANS AND LATINOS. SERVICES INCLUDE: COMMUNITY OUTREACH, HEALTH EDUCATION, BILINGUAL SERVICES, SERVICES FOR THE HOMELESS, MENTAL HEALTH (PSYCHOLOGY AND PSYCHIATRY), WOMEN-SPECIFIC SERVICES, AND SUPPORT GROUP SERVICES FOR SIGNIFICANT OTHERS.

- ASIAN AIDS PROJECT - PROVIDES OUTREACH EDUCATION TO GROUPS OF HARD-TO-REACH GAY MEN IN SAN FRANCISCO CLUBS. THIS PROJECT ALSO PROVIDES GENERAL EDUCATION TO COMMUNITY LEADERS IN AN EFFORT TO REDUCE FEAR AND OVERCOME THE MANY BARRIERS OF DISCUSSING SEXUALITY AND DRUG USE.

- LA FAMILIA COUNSELING SERVICES - PROVIDES SPECIALIZED BILINGUAL (ENGLISH AND SPANISH) AIDS EDUCATION AND PREVENTION TRAINING TO "PEER" YOUTH EDUCATORS TO ASSURE EFFECTIVE COMMUNICATION

WITH THE TARGET AUDIENCE. THE PEER AIDS EDUCATORS PROVIDE OUTREACH EDUCATIONAL ACTIVITIES TO SELECTED COMMUNITY YOUTH GROUPS IN THE HAYWARD AND SAN LEANDRO AREA.

- YWCA, OAKLAND - TRAINS PEER EDUCATORS (PRIMARILY AFRICAN AMERICAN). THIS PROGRAM DEVELOPED THE FIRST PEER EDUCATION TRAINING MODULE (WHICH INCLUDES A VIDEO AND LESSON PLAN) FOR AFRICAN AMERICAN YOUTH.

- FAME - SERVES AFRICAN AMERICANS IN THE SOUTH CENTRAL AREA OF LOS ANGELES PROVIDING EDUCATIONAL ACTIVITIES TO MEN WHO HAVE SEX WITH MEN, YOUTHS, JAILS, AND SUBSTANCE ABUSERS VIA COMMUNITY CENTERS, DETENTION CENTERS, CHURCHES, AND NEIGHBORHOOD YOUTH CENTERS. A YOUTH RAP CONTEST IS ALSO SPONSORED.

- AVANCE HUMAN SERVICES, INC. - PROVIDES HIV EDUCATION AND REFERRAL SERVICES THROUGH THE SOUTHERN CALIFORNIA HIV/AIDS SPANISH HOTLINE.

- SALUD PARA LA GENTE/PROYECTO ALARMA SIDA (PAS) PROJECT - SPECIALIZES IN PROVIDING AIDS EDUCATION AND PREVENTION

INFORMATION TO MONOLINGUAL SPANISH-SPEAKING FARM WORKERS, YOUTH, INJECTION DRUG USERS, AND WOMEN OF CHILDBEARING AGE IN THE PAJARO VALLEY AREA (SOUTHERN SANTA CRUZ COUNTY).

- NIPOMO FAMILY HEALTH CENTER, NIPOMO, SAN LUIS OBISPO COUNTY - THIS PROJECT HAS DEVELOPED AN AIDS EDUCATION, PREVENTION, AND INFORMATION CAMPAIGN SPECIFICALLY TARGETING MONOLINGUAL SPANISH-SPEAKING MIGRANT FARM WORKERS AT THEIR WORK PLACE (FIELDS, MIGRANT WORK CAMPS, AND CANNERIES).

- CENTRAL VALLEY INDIAN HEALTH PROJECT - PROVIDES HIV/AIDS EDUCATION AND PREVENTION ACTIVITIES TO AMERICAN INDIAN YOUTH, INJECTION DRUG USERS AND OTHER SUBSTANCE ABUSERS, WOMEN, AND HOMOSEXUAL/BISEXUAL MALES. THESE SERVICES ARE PROVIDED IN FRESNO, MADERA, AND KINGS COUNTIES.

- SOUTH LOS ANGELES COMMUNITY AIDS PROGRAM (WATTS HEALTH FOUNDATION) - PROVIDES HOME AND COMMUNITY-BASED SERVICES TO PREDOMINANTLY AFRICAN AMERICAN AND LATINO PERSONS WITH AIDS IN THE SOUTH-CENTRAL LOS ANGELES AREA. ADDITIONALLY, THE STAFF DEVELOPS AND IMPLEMENTS WRITTEN HEALTH PLANS DESIGNED TO REACH WOMEN AND SUBSTANCE ABUSERS IN TREATMENT. THE

PRIMARY GOAL IS TO INFLUENCE BEHAVIOR THROUGH THE IDENTIFICATION OF KNOWLEDGE, ATTITUDES, AND BELIEFS ABOUT HIGH-RISK BEHAVIORS AND HOW IT RELATES TO HIV.

OTHER OFFICE OF AIDS SIGNIFICANT ETHNIC MINORITY ACHIEVEMENTS INCLUDE:

- THE OFFICE OF AIDS BEGAN WORKING LAST FALL TO DEVELOP A COMPREHENSIVE PLAN IN RESPONSE TO THE RYAN WHITE COMPREHENSIVE AIDS RESOURCES EMERGENCY (CARE) ACT OF 1990. EVERY EFFORT WAS MADE TO ADDRESS THE NEEDS OF ETHNIC MINORITIES. A 41-MEMBER WORKING GROUP, REPRESENTING A BROAD DIVERSITY OF PERSPECTIVES WAS APPOINTED TO HELP DEVELOP THE RESPONSE. LATINO, AFRICAN AMERICAN, ASIAN/PACIFIC ISLANDER, FILIPINO, AND NATIVE AMERICAN REPRESENTATIVES WERE APPOINTED TO AND MADE UP 50 PERCENT OF THE WORKING GROUP. IN CONSIDERING AN EQUITABLE DISTRIBUTION OF THESE FUNDS THROUGHOUT THE STATE, A FORMULA WAS DEVELOPED THAT TOOK INTO ACCOUNT EPIDEMIOLOGICAL DATA, IMPACT TO HIGH INCIDENT AREAS, RURAL AREAS, AND COMMUNITIES OF COLOR. SPECIFICALLY, A "NON-WHITE" INDEX FACTOR WAS ADOPTED AND WEIGHTED AT 20 PERCENT.

- THE MINORITY AIDS RESOURCE CENTER PROVIDES INFORMATION, TRAINING, AND TECHNICAL ASSISTANCE TO OFFICE OF AIDS EDUCATION AND PREVENTION CONTRACTORS. THE INFORMATION CENTER INCLUDES A LIBRARY, COMPUTER DATABASE, BULK LITERATURE, AND A RESOURCE GUIDE. THE TRAINING CURRICULUM INCLUDES A BASIC AIDS INFORMATION CLASS, ORGANIZATIONAL DEVELOPMENT, COMMUNITY DEVELOPMENT, GRANT WRITING, AND LEADERSHIP TRAINING. TECHNICAL ASSISTANCE IS AVAILABLE TO ALL CONTRACTORS. THE FOCUS OF THE ASSISTANCE IS TO HELP CONTRACTORS TO OVERCOME CULTURAL BARRIERS THAT PREVENT DELIVERY OF QUALITY EDUCATION AND PREVENTION SERVICES TO ETHNIC MINORITY COMMUNITIES.

- THE OFFICE OF AIDS PROVIDED FUNDING TO THE MULTICULTURAL TRAINING RESOURCE CENTER (MTRC) TO SPONSOR MULTICULTURAL AIDS CONSENSUS AND COLLABORATION WORKSHOPS. THE PARTICIPANTS ARE OFFICE OF AIDS CONTRACTORS PRESENTLY PROVIDING DIRECT EDUCATION AND PREVENTION CLIENT SERVICES. THE PURPOSE OF THE WORKSHOPS IS TO DISCUSS BARRIERS AND FIND SOLUTIONS TO PROVIDING QUALITY AIDS EDUCATION AND PREVENTION SERVICES TO MINORITY COMMUNITIES. WORKSHOPS FOCUS ON

BARRIERS AS THEY PERTAIN TO RURAL, URBAN, COMMUNITY-BASED ORGANIZATIONS, AND HEALTH DEPARTMENT ISSUES.

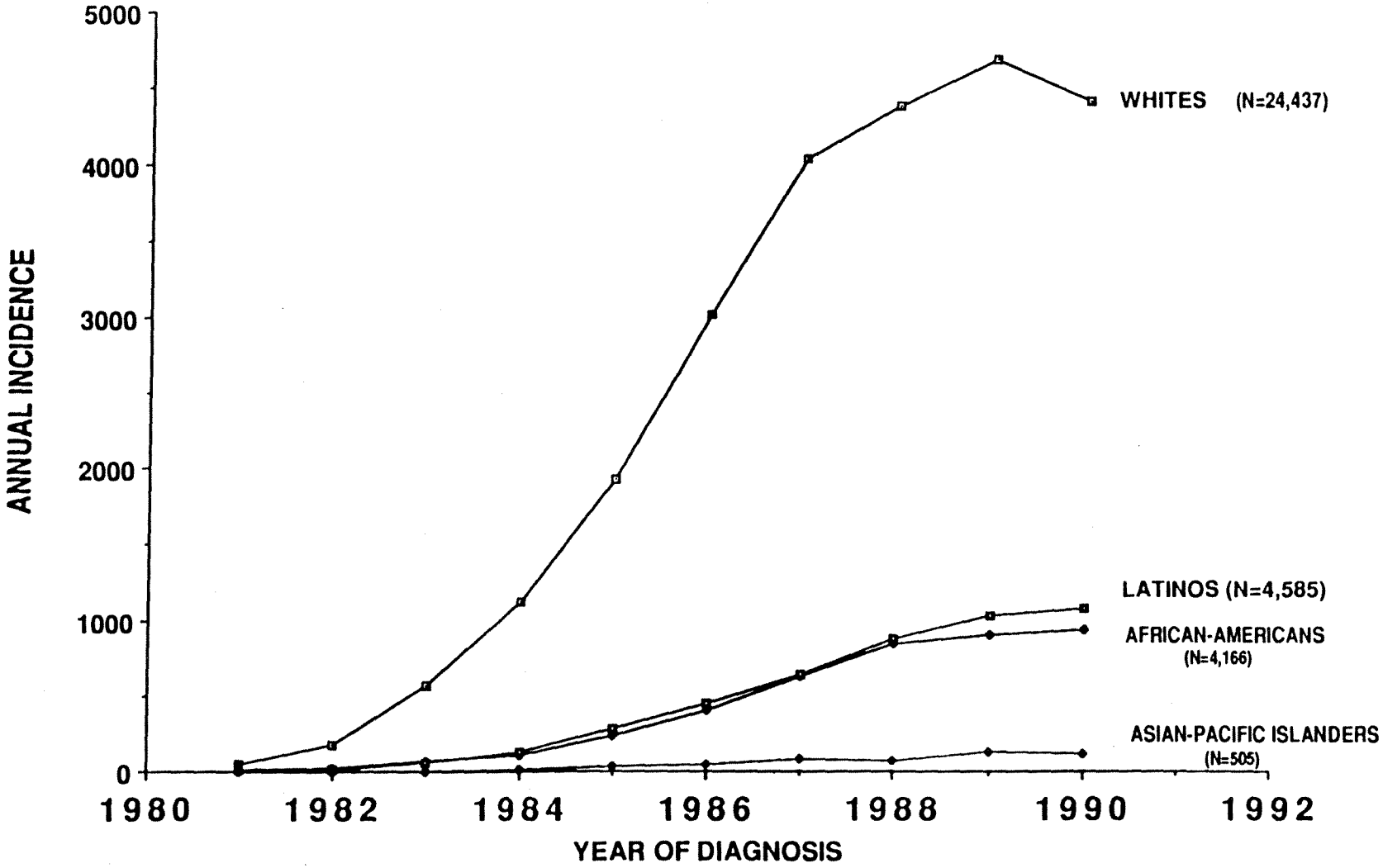
- THE OFFICE OF AIDS PROVIDED FUNDING FOR A STATEWIDE "PEOPLE OF COLOR" CONFERENCE IN THE SUMMER OF 1991 WITH THE GOAL OF IMPROVING THE "SURVIVABILITY" OF SERVICE PROVIDERS IN MINORITY-BASED COMMUNITIES AND FOCUSING ON STRATEGIES TO IMPROVE OUTREACH AND PREVENTION ACTIVITIES TO ETHNIC MINORITY POPULATIONS. AT THE CONFERENCE, THE GROUP ELECTED REPRESENTATIVES TO SERVE ON THE NEWLY FORMED OFFICE OF AIDS MULTICULTURAL LIAISON BOARD. THIS ELECTED GROUP WILL SERVE AS AN EFFECTIVE AND IMPORTANT LIAISON BETWEEN THE OFFICE OF AIDS AND MULTICULTURAL PROVIDERS/COMMUNITIES.

CONCLUSION

IN CLOSING, THE OFFICE OF AIDS IS COMMITTED TO STOPPING THE AIDS EPIDEMIC IN COMMUNITIES OF COLOR. WE RECOGNIZE THAT THIS MUST BE DONE NOT IN ISOLATION, BUT IN CONCERT WITH A COMPREHENSIVE APPROACH TO OVERALL HEALTH CARE ACCESS. THANK YOU FOR THIS OPPORTUNITY TO APPEAR BEFORE YOU TODAY. I AM AVAILABLE TO ANSWER QUESTIONS YOU MAY HAVE.

ATTACHMENTS

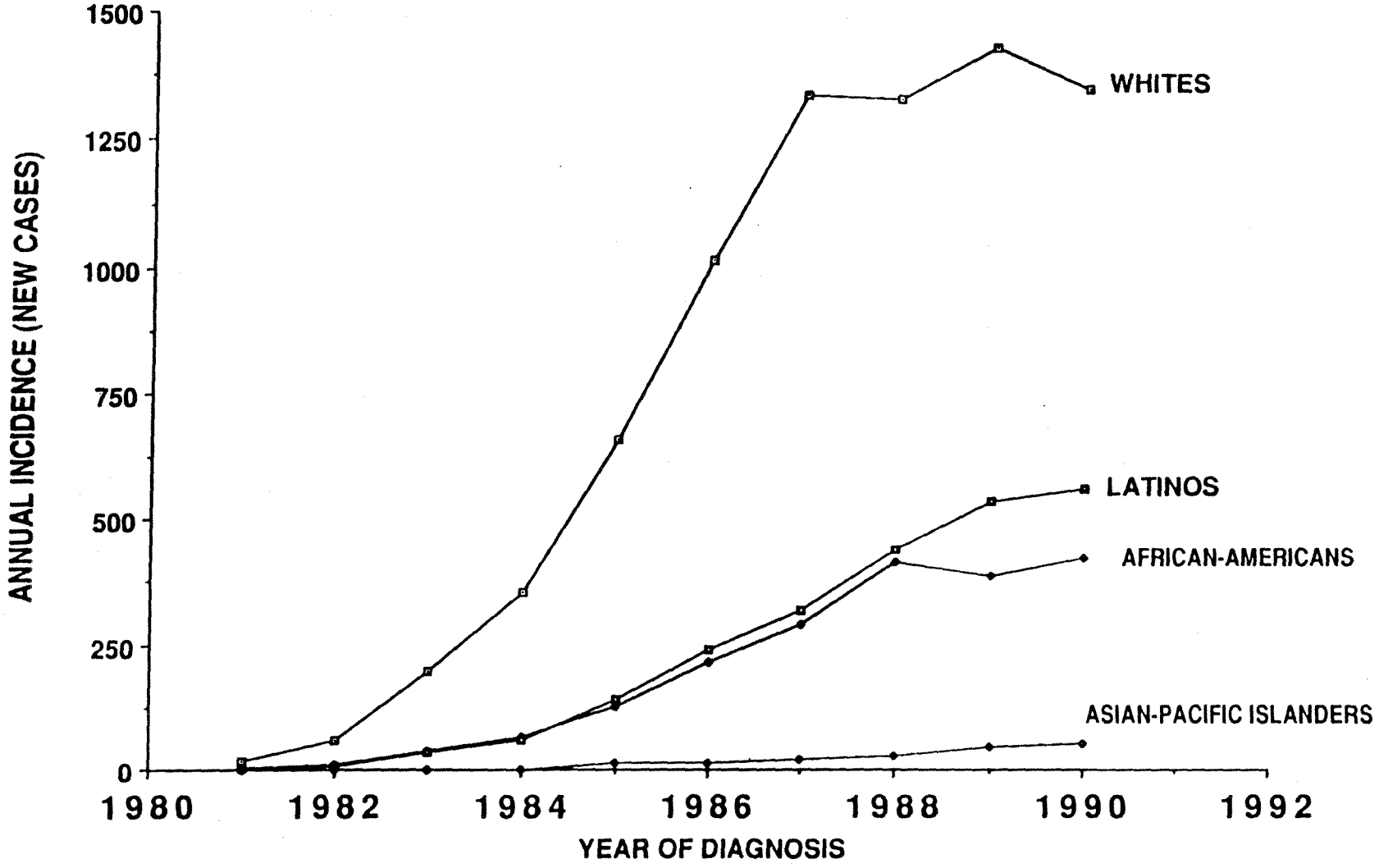
ANNUAL INCIDENCE OF CALIFORNIA AIDS CASES
BY RACE-ETHNICITY 1981 - 1990



SOURCE: CALIFORNIA DEPARTMENT OF HEALTH SERVICES, OFFICE OF AIDS, EPIDEMIOLOGIC RESEARCH SECTION, DECEMBER 1991

ATTACHMENT I

ANNUAL INCIDENCE OF LOS ANGELES COUNTY AIDS CASES
BY RACE-ETHNICITY 1981 - 1990



SOURCE: CALIFORNIA DEPARTMENT OF HEALTH SERVICES, OFFICE OF AIDS, EPIDEMIOLOGIC RESEARCH SECTION, DECEMBER 1991

Annual Incidence of California AIDS Cases and Deaths 1981-1991
by Year of Diagnosis and Race/Ethnicity

Format: Cases/Deaths

	White	Black	Hispanic	Asian	Native American	Unknown	Total	Percent of Total
Before 1981	7/5	2/1	2/2	0/0	0/0	0/0	11/8	0.0
1981	44/41	7/7	9/7	0/0	0/0	0/0	60/55	0.2
1982	180/165	23/22	15/14	1/1	0/0	0/0	219/202	0.6
1983	565/529	68/63	62/59	2/2	0/0	1/1	698/654	1.8
1984	1118/1058	112/102	131/118	8/8	0/0	2/2	1371/1288	3.5
1985	1941/1837	233/223	287/259	37/37	5/5	1/1	2504/2362	6.5
1986	3027/2811	406/370	453/411	53/47	10/10	9/7	3958/3656	10.2
1987	4058/3528	626/533	642/553	83/72	7/7	22/17	5438/4710	14.1
1988	4388/3411	847/642	882/680	77/67	12/8	11/7	6217/4815	16.1
1989	4722/3115	914/573	1041/678	130/91	18/13	17/6	6842/4476	17.7
1990	4502/2077	957/461	1097/513	121/54	21/10	41/8	6739/3123	17.4
1991 *	3034/662	651/137	807/200	76/17	10/4	25/0	4603/1020	11.9
Total	27586/19239	4846/3134	5428/3494	588/396	83/57	129/49	38660/26369	100.0
% of Total	71.4	12.5	14.0	1.5	0.2	0.3	100.0	
% Mortality	69.7	64.7	64.4	67.3	68.7	38.0	68.2	

TOTAL CASES: 38660/26369

Source: California Dept. of Health Services, Office of AIDS, December 1991

Annual Incidence of Los Angeles County AIDS Cases and Deaths 1981-1991
by Year of Diagnosis and Race/Ethnicity

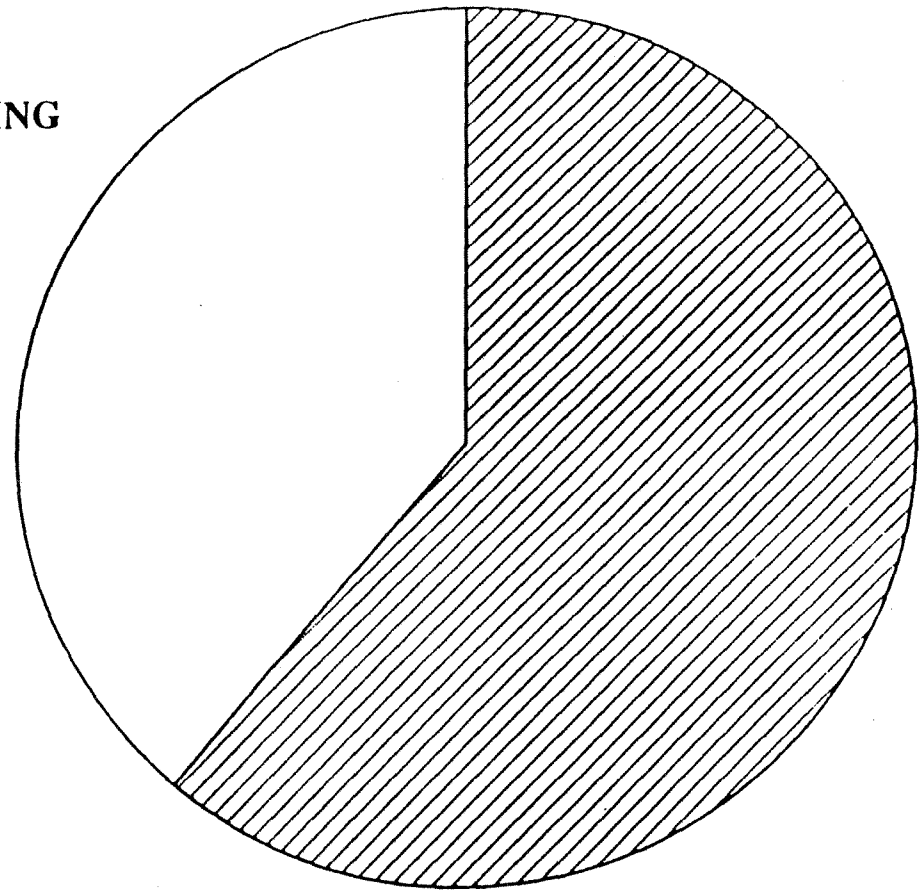
Format: Cases/Deaths

	White	Black	Hispanic	Asian	Native American	Unknown	Total	Percent of Total
Before 1981	3/1	0/0	1/1	0/0	0/0	0/0	4/2	0.0
1981	13/11	5/5	2/1	0/0	0/0	0/0	20/17	0.1
1982	59/51	12/12	8/8	0/0	0/0	0/0	79/71	0.6
1983	200/183	39/39	35/34	1/1	0/0	0/0	275/257	2.0
1984	355/335	69/64	60/52	1/1	0/0	2/2	487/454	3.6
1985	662/618	128/122	141/127	15/15	0/0	0/0	946/882	6.9
1986	1018/954	217/198	240/219	13/12	5/5	4/3	1497/1391	10.9
1987	1338/1143	292/263	320/274	23/19	0/0	16/12	1989/1711	14.5
1988	1328/1029	417/323	442/343	27/24	3/2	7/4	2224/1725	16.3
1989	1431/948	389/264	537/347	46/31	4/3	9/1	2416/1594	17.7
1990	1352/622	424/213	563/276	52/26	3/1	32/4	2426/1142	17.7
1991 *	710/176	228/59	333/90	18/5	1/0	19/0	1309/330	9.6
Total	8469/6071	2220/1562	2682/1772	196/134	16/11	89/26	13672/9576	100.0
% of Total	61.9	16.2	19.6	1.4	0.1	0.7	100.0	
% Mortality	71.7	70.4	66.1	68.4	68.8	29.2	70.0	

TOTAL CASES: 13672/9576

Source: California Dept. of Health Services, Office of AIDS, December 1991

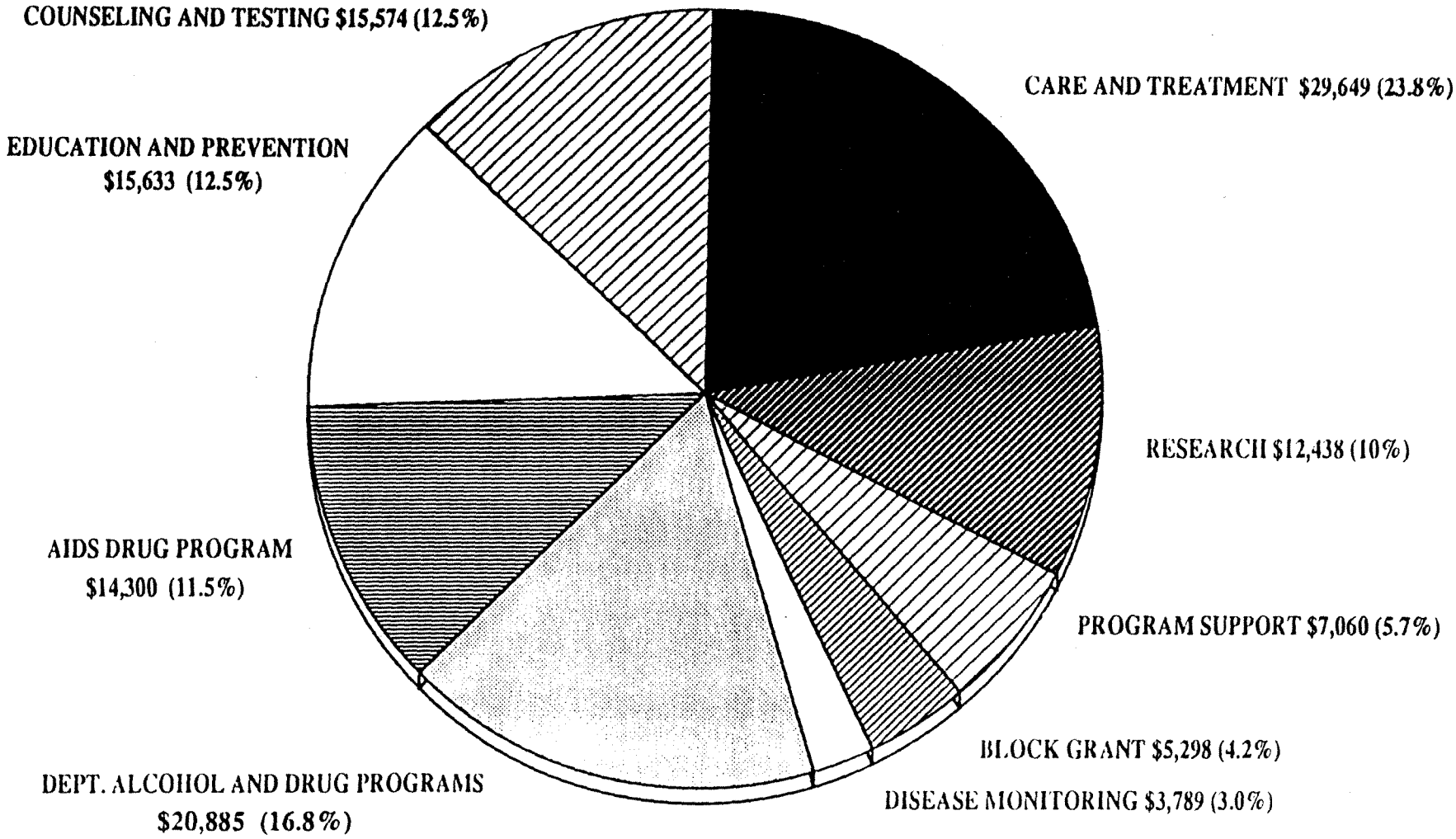
STATE OF CALIFORNIA
FISCAL YEAR 1991-92 AIDS FUNDING
(Federal Vs. State)



SOURCE: California Department of Health Services, Office of AIDS

ATTACHMENT V

STATE OF CALIFORNIA
FISCAL YEAR 1991-92 AIDS FUNDING
(In Thousands of Dollars)



Source: California Department of Health Services, Office of AIDS

ILOT CARE AND TREATMENT SERVICES SECTION, DHS/OA
GGREGATE TOTALS OF PROJECTS FUNDED IN LOS ANGELES COUNTY
ENDER AND RACE/ETHNICITY

	MALE	%	FEMALE	%	WHITE	%	BLACK	%	HISPANIC	%	ASIAN	%	AMIND	%	OTHER UNKNOWN	%	TOTAL	%
IP (1)	154	86.0	24	14.0	31	17.0	88	49.0	53	30.0	1	1.0	3	2.0	2	1.0	178	100.0
HC (2)	482	91.0	47	9.0	245	46.0	116	22.0	153	29.0	5	1.0	6	1.0	4	1.0	529	100.0
AS (3)	82	93.0	6	7.0	41	47.0	25	28.0	22	25.0	0	0.0	0	0.0	0	0.0	88	100.0
AIVER(4)	79	99.0	1	1.0	48	60.0	18	23.0	11	14.0	2	2.0	1	1.0	0	0.0	80	100.0
OTAL	797	91.0	78	9.0	365	91.0	247	91.0	239	91.0	8	91.0	10	91.0	6	91.0	875	91.0

1) Data for EIP is for a seven month period - Jan 91 thru July 91.
2) Data for CHC is for FY90/91.
3) Data for RAS is for the 1st QTR FY91/92 - Jul-Sep 91.
4) Data for Medi-Cal Waiver is for the a ten month period - Jan 91 thru Oct 91.

lote: All percents are rounded.

2/12/91
CH:rch

ATTACHMENT VII

TESTIMONY

SENATE HEALTH AND HUMAN SERVICES COMMITTEE

December 17, 1991

Good morning. I am Dr. Jim Kooler, Deputy Director of the Division of Alcohol and Drug Prevention at the California Department of Alcohol and Drug Programs. Senator Watson, thank you for inviting me to participate in today's hearing regarding HIV/AIDS. With me today is Eddie Yamamoto, Program Analyst for the Department's HIV/AIDS Counselor Program.

The Department's formal mission statement is based upon the principle that in order for alcohol and drug-related problems to be eliminated in California, a comprehensive, statewide effort must be made in partnership with county governments, private and public agencies, organizations, groups and individuals. The cornerstone of our efforts is the California Master Plan to Reduce Drug and Alcohol Abuse. The objective of the Master Plan is to foster the involvement of the community in the determination of local service policies. This emphasis reflects an awareness that effective policies require the commitment and involvement of local communities in determining their own priorities. It recognizes that the needs of one part of California may differ considerably from those of another, necessitating that governmental policies be tailored to appropriately and effectively address those local needs. Currently, 55 counties are participating in the Master Plan process, including Los Angeles County, which is a phase six

county (Master Plan due in June 1992). Thirty one counties are in phases one and two; one-third of them have identified HIV/IVDU populations as a priority for their county.

In regards to HIV/AIDS, the Department first formally addressed this issue in December 1986 when emergency regulations were passed authorizing exceptions to existing methadone program eligibility requirements for clients in response to the AIDS crisis. These exceptions improved treatment services by allowing programs to:

- exceed licensed capacity by ten percent when the need is documented;
- upon the Department's approval, waive the requirement that the client provide documented history of at least two years of narcotic addiction; and,
- also with the Department's approval, waive the requirement that the client provide documented history of two or more unsuccessful attempts in withdrawal treatment with subsequent relapse to regular narcotic use.

By the following year, the Department began allocating to counties federal Alcohol and Drug Abuse and Mental Health Services (ADMS) Block Grant funds, specifically to target intravenous drug users (IVDUs). These federal dollars are allocated by the Department via the county subvention process. This process reflects a state/county partnership in the field of alcohol and drug abuse services. The counties are given maximum flexibility in determining

their program priorities as long as federal requirements are met. In this manner, alcohol and drug abuse services are relevant to the needs of each community. During 1987-88, a total of five million dollars was allocated to the counties, of which, Los Angeles County received nearly two million dollars. Currently, 35% of the Department's total ADMS Block Grant Award is dedicated to drug programs, and half of that is "set-aside" for treatment programs for intravenous drug abuse as prescribed in the federal Public Health Service Act. For 1991-92, IVDU set-aside monies available to counties totaled over $23,000,000, a 360% increase from just four years prior. Of this, Los Angeles County will receive over $8,000,000, a 300% increase since 1987-88.

In addition to IVDU set-aside, other funds targeting IVDUs have become available to the Department over the past few years and are as follows.

- Augmentation of the Budget Act of 1988: Since 1988, general funds have been allocated to counties with the highest number of AIDS cases with a history of intravenous drug use. This increased treatment for IVDUs at risk of contracting and spreading HIV. Currently, over 1.2 million dollars is allocated to counties, of which, Los Angeles County receives nearly $400,000.

- HIV/AIDS Counselor Program: In late 1988, the federal Centers for Disease Control offered funding to state health departments to coordinate with state drug abuse authorities in establishing HIV counseling and testing services in drug

treatment programs. In response to this initiative, the Department of Health Services, Office of AIDS and the Department of Alcohol and Drug Programs collaborated to establish the HIV/AIDS Counselor Program. Approximately 1.8 million dollars was subvened to 20 counties throughout the state during 1991-92. Los Angeles County receives funds directly from the federal Centers for Disease Control to administer their own HIV/AIDS Counselor Program.

o Statewide AIDS, Alcohol and Drug Abuse Training: In September 1990, the Department convened a forum to develop a statewide AIDS, alcohol and drug abuse training system for program providers, administrators and staff. The primary purpose of the training is to ensure that HIV/AIDS training is available to all alcohol and drug service providers to minimize the risk of HIV infection among California's alcohol and drug using populations. County alcohol and drug program administrators, recovery and treatment providers and key experts on AIDS, substance abuse and training as well as recognized experts from other state agencies were in attendance. As a result, California was divided into twelve regions and local representatives were utilized to develop their own training curriculum based on their local needs. The Department used ADMS Block Grant funds to contract with Valley Community Counseling Services to coordinate and facilitate the training in each of the regions. The contract was in the amount of $100,000, expiring December 31, 1991. The Department is preparing a Request for Proposals to continue the training for the next three years.

- Continuation Waiting List Reduction Grant Programs: The intent of this grant program is to rapidly expand drug abuse treatment capacity in California. Expanding drug abuse treatment was one of the recommendations put forth by the National Commission on AIDS earlier this year. Approximately $13,000,000 in continuation funding is available for the Waiting List Reduction Grant Program for 1991-92, of which, $2,000,000 must be targeted to serve IVDUs. For 1991-92, Los Angeles County received 3.7 million dollars of continuation funding, of which, nearly $750,000 must be targeted to IVDUs.

In closing, the Department funds over $28,000,000 in programs targeting IVDUs throughout the state. Los Angeles County receives over $9,000,000 of this total. The state total represents a significant increase (460%) in resources dedicated to IVDUs since 1987-88 when $5,000,000 was committed. At this time, The Department looks forward to not only continue its existing efforts, but explore areas of potential collaboration with the State Department of Health Services to jointly focus on the twin epidemics of HIV and alcohol/drug abuse.

Testimony of Alan Harris: PHS AIDS Regional Coordinator

California Senate Committee on Health & Welfare
Interim Hearing on AIDS Funding in Ethnic Minority Communities
Los Angeles: December 17, 1991

I want to thank Senator Watson and her staff for the invitation to share with the Committee preliminary Public Health Service (PHS) Fiscal Year (FY) 1991 AIDS financial data for California recipient organizations. This information should be of some interest as the State government, local governments and local AIDS planning agencies prepare their budgets for 1992.

Based on preliminary data, for Federal FY 1991 (10/1/90 - 9/30/91) the PHS awarded nearly $191M to support AIDS program activities in 348 CA organizations. CA received slightly more than 10% of the $1.885B FY'91 national PHS AIDS appropriation. PHS support includes new financial and direct (personnel, equipment, supplies) assistance for a prospective 12 month budget to support AIDS/HIV and related activity. Assistance was provided through grants, cooperative agreements and contracts. In some cases, particularly for some research projects, the financial assistance includes program funding from appropriations other than AIDS. In all cases, the financial assistance does not include previously awarded and unused funds which PHS generally reauthorizes to support subsequent years of a 3 to 5 multi-year project.

I have prepared two exhibits that describe the preliminary PHS FY'91 CA AIDS funding:

* One exhibit indicates the PHS funding agency and general purpose;
* The other exhibit compares ~~funding levels in~~ PHS AIDS funding levels in CA for FY 1989, 1990 and 1991.

For the Committee, I am presenting copies of PHS computer printouts which detail all of the CA recipient organizations and their preliminary funding levels (Grants and Cooperative Agreements; Contracts). I am also sharing a separate printout of PHS AIDS grants and cooperative agreements awarded in Los Angeles County.

Of the three FY '89-'91 total $550M in CA PHS AIDS funding, $261M was awarded by the National Institutes of Health (NIH) in support of a wide range of biomedical and clinical AIDS research projects. Given the focus of the Committee's hearings today, I want to share the demographic statistics of the 3,466 adult and adolescent volunteers who have enrolled cumulatively in California's 5 AIDS Clinical Trials Groups (ACTG) and the 182 children who have enrolled cumulatively in California's Pediatric AIDS Clinical Trials Groups.

AIDS Clinical Trials Groups are University Medical School organized networks of hospitals and clinics whose participating physicians accept patient volunteers to enroll in clinical trials of

experimental therapies for HIV disease and opportunistic infections. Specific clinical trials of AIDS and HIV experimental therapies are sponsored and supported by the National Institute of Allergy and Infectious Disease, a major component of the NIH.

These statistics reflect that adult/adolescent volunteers enrolled in CA's 5 ACTGs were generally representative of California's cumulative AIDS cases with two exceptions: women at 2% vs. 3.5% and Blacks at 7% vs. 12% were underrepresented. California's total ACTG cumulative adult/adolescent enrollment represented 23% of nationwide ACTG enrollment. The children who were enrolled in California's 3 Pediatric ACTGs were fairly representative of the sex and racial composition of California's cumulative pediatric AIDS cases. These children represented 16% of the nationwide Pediatric ACTG enrollment.

I hope this information has been interesting and helpful. I look forward to answering any questions you may have now or later.

TESTIMONY TO THE CALIFORNIA SENATE

COMMITTEE ON HEALTH AND HUMAN SERVICES

Tuesday, December 17, 1991

Mr. Robert E. Frangenberg

Director, County of Los Angeles AIDS Program Office

"HIV/AIDS FUNDING IN LOS ANGELES COUNTY AND HIV/AIDS IN COMMUNITIES OF COLOR"

INTRODUCTION

- I am pleased to have the opportunity to address the Senate Health and Human Services Committee on the subjects of governmental funding for HIV/AIDS services in Los Angeles County and particularly in communities of color.

- Los Angeles County is the second-ranking metropolitan area in the United States in terms of both its present and cumulative AIDS caseloads.

- As of October 31, 1991, there were approximately 4,000 living individuals in the County with confirmed cases of AIDS and an estimated additional 36,000 HIV-infected. Our cumulative AIDS caseload was 13,647. Given these statistics, the County is facing enormous challenges on a variety of fronts.

THE STATUS OF HIV/AIDS IN LOS ANGELES COUNTY

CURRENT HIV/AIDS FUNDING

- The County Department of Health Services has two mechanisms through which funds are expended for HIV/AIDS-related public services: the AIDS Program Office and the Department's medical facilities.

- The AIDS Program Office is responsible for policy and program development for prevention and treatment services.

- The Department's medical facilities provide direct patient care to persons with HIV/AIDS. The majority of funding for these services falls under the budget of each individual facility; however, some funds for dedicated outpatient services are provided to certain facilities through the AIDS Program Office.

- Projected expenditures in Fiscal Year 1991-92 for AIDS Programs total $38 million. Of this, $14 million (37 percent) are County funds, $18 million (47 percent) are federal funds, and $6 million (16 percent) are State funds.

- County funds expended through the AIDS Program Office are spent in the following service categories:
    - HIV/AIDS education and prevention,
    - community-based outpatient clinical services and case management,
    - home health care,
    - residential care,
    - drug abuse treatment for persons with HIV,
    - day care, dental care, and

- The $18 million in federal funds will be spent in two broad programmatic categories:
    - $10 million in Centers for Disease Control funds have been allocated for HIV prevention and surveillance programs, and
    - nearly $8 million awarded through Title I of the Comprehensive AIDS Resources Emergency (CARE) Act of 1990 is supporting patient medical and support services.

- Seventy-one percent of the CARE Act funds is being expended on patient services through contracts with community-based organizations. Twenty-four percent is supporting HIV/AIDS medical services at County facilities, while the remaining five percent has been allocated for administrative oversight of the grant and the related contracts.

- We already know that our 1992 CARE Act Formula grant will increase from $3.9 million to $5.4 million. Our CARE Act budget will be augmented when the second-year CARE Act grants are awarded.

- The State Office of AIDS allocations to the County are being spent on the following activities:
    - $737,000 supports anonymous HIV testing and counseling at seven locations,
    - the AIDS drug program for low income persons in need of AZT and other HIV/AIDS drugs will receive approximately $4 million,
    - Martin Luther King/Drew Medical Center has been allocated $287,000 for primary care, and
    - the HIV/AIDS Block Grant of $1,123,000 will support epidemiological investigation of AIDS cases, counseling and HIV testing at juvenile halls, an HIV/AIDS prevention center at the Gay and Lesbian Community Services Center, and an outreach program for injection drug users operated by the Los Angeles Center for Alcohol and Drug Abuse.

- HIV/AIDS-related expenditures for inpatient and outpatient care at the County's medical facilities are supported by several revenue sources. The primary revenue supporting care is Medi-Cal, with smaller amounts coming from Medicare, patient revenues and insurance. During Fiscal Year 1990-91, the medical facilities spent a total of $34 million on HIV/AIDS-related care, with $9 million spent on inpatient care and $25 million spent on outpatient care. $16.0 million of the total expenditures were made at County cost.

- It is important to note that a trend toward greater reliance on outpatient medical services, rather than inpatient services, has been taking place in the County. This should inherently provide a more effective and efficient use of our financial resources, even though it provides lower reimbursement from MediCal.

HIV/AIDS IN COMMUNITIES OF COLOR

- Thirty-seven percent of the cumulative adult AIDS caseload in Los Angeles County is comprised of people of color. By race/ethnicity, this breaks down into 16% African-American, 20% Hispanic, and 2% "other peoples of color", which includes Asians, Pacific Islanders, and Native Americans.

- Compared with the 1990 U.S. Census data for the County, the percentages are as follows:

Race/Ethnicity	1990 Census	AIDS Cases
African American	11%	16%
Hispanic	38%	20%
Other non-white	11%	2%
White	40%	62%

- The behaviors which put adults and adolescents at risk in Los Angeles County are as follows for all races/ethnicities combined:

Male to male sexual contact	80%
Male to male sex and injection drug use	7%
Injection drug use	5%
Transfusion recipient	2%
Male to female sexual contact	2%
Hemophilia or coagulation disorder	<1%

- Los Angeles is significantly different from East Coast cities and somewhat different from other cities in California in the lower percentage of cases which are related to injection drug behaviors.

- Even when the behavior categories are examined within each racial/ethnic group, gay and bisexual men comprise the predominant group affected by the HIV/AIDS epidemic and at risk for HIV infection. For example, 66 percent of African-American adult/adolescent cases, 73 percent of Hispanic cases, and 80 percent of cases among other persons of color are attributable to male to male sex. An additional 10 percent of African-American cases, 6 percent of Hispanic cases and 3 percent of cases among other persons of color is attributable to the combined behaviors of male to male sex and injection drug use.

- These statistics are useful in targeting our prevention efforts. Particularly important are the trends in statistics over time. Although very slowly, the distribution of AIDS cases in the County by behavior category has been shifting as the epidemic has progressed.

- Prior to 1987, 83% of the adult caseload for all races were attributable to male homosexual or bisexual contact. This figure dropped to 77% in 1990.

- Conversely, the percentage of cases linked to injection drug use rose from 2% prior to 1987 to 6% in 1991.

- Over the same period, cases linked to injection drug use in combination with homosexual or bisexual contact dropped from 8% to 6%. The cases attributable to heterosexual contact rose from 1% of the total caseload prior to 1987 to 2% in 1990.

- Thus, though homosexual and bisexual contact may be viewed as the riskiest behavior for HIV transmission, injection drug use and heterosexual contact have increased in risk in recent years.

- The racial/ethnic distribution of new cases has also changed over time. Prior to 1987, 70% of new AIDS cases in the County were Caucasian cases. In 1990, only 56% of the new cases were diagnosed in Caucasians.

- These statistics for African-Americans are 14% prior to 198 and 18% of new cases in 1990. For Hispanics they are 15% prior to 1987 and 23% in 1990.

- Another way of looking at these trends is by incidence (the number of cases each year per 100,000 population).

  - The male Caucasian incidence in 1984 was 22/100,000. This figure rose to 89/100,000 in 1990;
  - For male African-Americans these statistics were 19/100,000 in 1984 and 122/100,000 in 1990;
  - The Hispanic figures are 7/100,000 in 1984 and 53/100,000 in 1990;
  - The "other" category incidence rates have changed from 0/100,000 in 1984 to 12/100,000 in 1990.

- The 1990 incidence rates for women in Los Angeles County were as follows:

  - 2/100,000 for Caucasian women,
  - 9/100,000 for African-American women,
  - 4/100,000 for Hispanic women, and
  - 1/100,000 for "other" women.

- Primary behaviors which put women at risk are heterosexual contact (33 percent of cases) and injection drug use (28 percent). Transfusion recipients constitute 23 percent of female cases, most for transfusions occurring prior to testing of the blood supply.

- As the local face of HIV/AIDS has changed, so has our approach to HIV/AIDS prevention and HIV/AIDS-related medical services. For instance, community-based organizations serving people of color and women now constitute the majority of our contractors for our HIV/AIDS education and risk reduction programs.

- We firmly believe that our preventive impact on high-risk persons of color will be maximized through the expertise of community-based organizations. These organizations have vast experience in targeting programs to their communities and in providing effective outreach in a culturally adept context.

FUNDING FOR COMMUNITIES OF COLOR IN FISCAL YEAR 1991-92

HIV/AIDS PREVENTION AND EDUCATIONAL OUTREACH PROGRAMS

- The County has contracts with the following community-based organizations for HIV/AIDS education and prevention programs for specified target groups:

•AIDS Healthcare Foundation/Gay Men of Color Consortium - Gay Men of Color - $255,286

•American Indian Free Clinic - Native Americans - $30,000

- Asian Pacific Lesbians & Gays - Asian and Pacific Island Lesbians and Gays - $28,500
- Avance Human Services Spanish Hotline - Hispanic Americans - $150,000
- The CORE Program Drop In Center - Hispanic Americans - $60,000
- The CORE Program Latino Gay Bar Project - Gay Latino Men - $50,000
- Drew University of Medicine and Science - Women of Color - $166,800
- El Centro Del Pueblo - Hispanic Americans - $104,186
- El Proyecto Del Barrio Latino Street Outreach - Hispanic Americans - $129,978
- Gay and Lesbian Latinos Unidos - Gay and Lesbian Latinos - $86,226
- Minority AIDS Project Men of Color Project - Gay Men of Color - $83,531
- Minority AIDS Project Say Sister Program - Women of Color - $100,000
- Southern California Youth and Family Center - Adolescent Women of Color - $100,000
- Special Service For Groups Youth and Men's Program - Asians and Pacific Islanders - $75,000
- Special Services For Groups Asian Community Outreach - Asians and Pacific Islanders - $144,706

- We also have contracts for programs which do not specifically target communities of color that do serve people of color, such as programs targeting high-risk adolescents.

- A total of approximately $1.5 million of HIV/AIDS education and prevention funding has been allocated specifically for communities of color. This is 65% of our total education and prevention budget ($2.3 million).

ANONYMOUS HIV COUNSELING AND TESTING

- The County provides anonymous HIV counseling and testing to its residents at these following locations:
    - The Edelman Health Center of the Gay and Lesbian Community Services Center in Hollywood,
    - The Roybal Health Center in Los Angeles,
    - The Valley community Clinic in North Hollywood,
    - The South Bay Free Clinic in both Manhattan Beach and Gardena,
    - The East Valley Community Health Center, and
    - The Minority AIDS Project in Los Angeles.

- Data from the month of October 1991 provide a picture of the racial distribution of anonymous testing and counseling services for all locations combined:
    - 67% of those receiving services were Caucasian,
    - 6% were African-American,
    - 20% were Hispanic,
    - 4% were Asians and Pacific Islanders,
    - 2% were Native Americans, and
    - 1% were classified as "other" or "unknown".

AIDS DRUG PROGRAM FOR LOW INCOME INDIVIDUALS

- HIV/AIDS Drugs are dispensed to qualifying persons with HIV/AIDS at seven locations in the County. Available data pertaining to AZT distribution for October and November 1991 demonstrate the following racial distributions of clientele by facility:

    - Los Angeles County + USC Medical Center
        - 35% of the doses were dispensed to Caucasians,
        - 47% were dispensed to African-Americans,
        - 12% were dispensed to Hispanics,
        - 1% were dispensed to Asians, and
        - 5% were dispensed in the "other" and "unknown" categories.

- Hudson Comprehensive Health Center
  - 60% were Caucasian,
  - 10% were African-American,
  - 27% were Hispanic, and
  - 3% were Asian.

- West Hollywood Clinic
  - 59% were Caucasian,
  - 7% were African-American,
  - 33% were Hispanic, and
  - 2% were Asian.

- Harbor/UCLA Medical Center
  - 37% were Caucasian,
  - 19% were African-American,
  - 40% were Hispanic,
  - 1% were Asian,
  - 1% were Native American, and
  - 2% were "other."

- Our allocation of CARE Act funds for outpatient services attempted to achieve an appropriate geographic balance of funding. CARE Act funding should thus have an impact on the racial distribution of outpatient services. Unfortunately, we do not have the necessary data to evaluate this at the present time.

- Similarly, our unmet needs projections for Fiscal Year 1992-93 account for needs in specific geographic areas, and hence by race/ethnicity.

PROJECTED UNMET NEEDS FOR FISCAL YEAR 1992-93

- The County Department of Health Services is facing Fiscal Year 1992-93 with projected unmet needs for HIV/AIDS-related services of approximately $29 million, at a minimum.

- This figure includes:
    - $3 million for HIV/AIDS educational outreach and prevention programs targeting high priority audiences,
    - $23 million for outpatient and inpatient medical services,
    - $2 million for HIV testing and counseling,
    - $900,000 for residential care for persons with HIV/AIDS,
    - $800,000 for dental care services, and

- We have stratified our projected unmet needs for HIV/AIDS educational outreach and prevention programs into priority groups. These groups are as follows:
    - Adolescents,
    - Women,
    - Substance Abusers,
    - Gay Men of Color, and
    - Gay White Men.

- These priority rankings were established through consideration of the current behaviors driving the HIV/AIDS epidemic in the County combination with the volume of HIV/AIDS education and prevention services each already allocated for each group.

- Our primary considerations in setting priorities are the behaviors which put persons at risk. Secondary considerations are the epidemiological data which associate certain demographic characteristics with the riskiest behaviors.

- The County's unmet needs for HIV testing and counseling may very well be approaching a critical status. The demand for anonymous HIV testing has been steadily rising during the past year.

- This can be attributed, to some extent, to a promotional campaign for HIV testing which was implemented locally by the State Department of Health Services.

- The demand for testing will surely rise during the upcoming year as well. CARE Act-funded contracts for programs promoting HIV testing are in the initial stages of implementation. We expect that these programs will cause more individuals to seek HIV testing.

- Furthermore, the public disclosure by Magic Johnson of his HIV-positive status is expected to have a increased impact on our HIV testing programs.

- The demand for publicly-funded HIV/AIDS outpatient and inpatient medical services has grown as this epidemic has progressed. Studies published in academic and professional journals have demonstrated that public health care programs serving the poverty-stricken are assuming an ever-increasing burden in the financing of AIDS care.

- Given this, the County's projected unmet needs figure of $23 million for outpatient and inpatient HIV/AIDS-related care is not surprising. It must be remembered that this figure is in addition to the current expenditure level in these service categories.

- Although we have made considerable progress in Los Angeles County in recent years both in terms of prevention and treatment for HIV/AIDS, particularly in communities of color, there are still extensive unmet needs for additional resources.

- Thank you for this opportunity to update you on these aspects of HIV/AIDS in the County of Los Angeles. I will be happy to answer any questions you may have.

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rev:12/16/91

PRELIMINARY

PUBLIC HEALTH SERVICE AIDS/HIV GRANTS, CONTRACTS & COOPERATIVE AGREEMENTS AWARDED TO CALIFORNIA ORGANIZATIONS IN FY 1991

PHS AWARDING AGENCY	General Purpose: Research	Risk Assessment & Prevention	Medical Care	Product Safety	TOTAL
ADAMHA (72)	33,830,998	-0-	-0-	-0-	33,830,998
AHCPR (2)	1,694,615	-0-	-0-	-0-	1,694,615
ATSDR (0)	-0-	-0-	-0-	-0-	0.00
CDC (82)	-0-	47,995,619	-0-	-0-	47,995,619
FDA (2)	-0-	-0-	-0-	41,045	41,045
HRSA (35)	-0-	-0-	44,900,948	-0-	44,900,948
IHS (1)	-0-	-0-	13,701	-0-	13,701
NIH (148)	62,093,314	-0-	-0-	-0-	62,093,314
OASH (6)	-0-	351,576	-0-	-0-	351,576
TOTAL (348)	97,618,927	48,347,195	44,914,649	41,045	190,921,816

Notes: (1) Number of projects are in parenthesis.
(2) $ reflects total PHS financial and direct assistance to identified AIDS/HIV projects. For some projects, total PHS support exceeds AIDS/HIV appropriations.

Sources: PHS Grants Management Information System: Report # GMSTAB8A; File # IPF91339.
PHS Contract Information System: Report # CISDISP4

Prepared by: Alan Harris; PHS Regional AIDS Coordinator; 12-9-91

PUBLIC HEALTH SERVICE AIDS/HIV GRANTS, CONTRACTS & COOPERATIVE AGREEMENTS
AWARDED TO CALIFORNIA ORGANIZATIONS
FY'89,'90, &'91 COMPARISON

PHS AWARDING AGENCY	FY 1989	FY 1990	FY 1991: PRELIMINARY
ADAMHA	$18,415,692 (46)	$29,115,371 (70)	$33,830,998 (72)
CDC	36,118,425 (52)	41,219,839 (72)	47,995,619 (82)
FDA	381,735 (2)	515,256 (4)	41,045 (2)
HRSA	11,405,456 (13)	18,132,239 (22)	44,900,948 (35)
NIH	92,041,359 (241)	106,773,161 (241)	62,093,314 (148)
IHS	N/A	439,941 (2)	13,701 (1)
OASH	225,493 (5)	270,389 (5)	351,576 (6)
AHCPR	2,067,953 (6)	2,402,099 (6)	1,694,615 (2)
TOTALS: CA	$160,656,103 (365)	$198,868,295 (417)	$190,921,816 (348)
US	$1,301,012,000	$1,589,756,000	$1,885,000,000
CA % of US	12.3%	12.5%	10.1%

Notes: (1) Numbers of projects are in parenthesis.
(2) $ represent total PHS financial and direct assistance to AIDS/HIV projects. For some projects, this may exceed the AIDS appropriated funding.

sources: FY'89: PHS/DHHS FY'92 Budget Justification to OMB
FY'90 & '91: PHS Grants Management Information System;
PHS Contract Information System

prepared by Alan Harris: PHS Regional AIDS Coordinator: 12-10-91

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CALIFORNIA AIDS CLINICAL TRIALS GROUP DEMOGRAPHICS: Adults & Adolescents

	Stanford	UCLA	UCSD	UCSF	USC	CA TOT.	CA %	US %	CA AIDS %
SEX: Male	504	611	737	721	798	3,371	0.97	.922	.965
Female	7	22	22	12	22	85	0.02	.078	.035
Unknown	0	0	3	1	6	10	0.00		
WHITE	457	456	652	627	469	2,661	0.77	.751	.720
BLACK	16	59	24	31	96	226	0.07	.114	.120
HISPANIC	32	107	68	67	242	516	0.15	.123	.140
OTHER	6	11	15	8	13	53	0.02	.012	.020
UNKNOWN	0	1	3	1	6	11	0.00		
IVDU: Never	479	559	670	612	750	3,070	0.89	.873	.850
Current	3	3	5	8	6	25	0.01	.007	
Previous	29	67	80	108	63	347	0.10	.120	.150
Unknown	0	4	7	6	7	24	0.01		
TOTAL	511	633	762	734	826	3,466	1.00		

NOTES: (1) Demographics reflect cumulative enrolled volunteers through 11-29-91.
(2) CA AIDS Statistics reflect cumulative adult & adolescent cases through 9-30-91.

SOURCE: AIDS Clinical Trials Information Service, NIAID/NIH/PHS
prepared by: Alan Harris: PHS Regional AIDS Coordinator 12-10-91.

CALIFORNIA AIDS CLINICAL TRIALS GROUP DEMOGRAPHICS: Children

	UCLA	UCSD	UCSF	CA TOT.	CA %	US %	CA AIDS %
SEX: Male	40	24	38	102	0.56	.548	.546
Female	28	13	39	80	0.44	.452	.454
Unknown	0	0	0	0	0.00		
WHITE	19	16	38	73	0.40	.249	.351
BLACK	18	5	22	45	0.25	.464	.295
HISPANIC	30	16	11	57	0.31	.326	.327
OTHER	1	6	6	13	0.07	.023	.027
UNKNOWN	0	0	0	0	0.00		
IVDU: Never	68	37	76	181	0.99	.991	
Current	0	0	0	0	0.00	.005	
Previous	0	0	1	1	0.01	.003	
Unknown	0	0	0	0	0.00		
TOTAL	68	37	77	182	1.00	1.00	

NOTES: (1) Demographics reflect cumulative enrolled volunteers through 11-29-91.
(2) CA AIDS Statistics reflect cumulative adult & adolescent cases through 9-30-91.

SOURCE: AIDS Clinical Trials Information Service, NIAID/NIH/PHS
prepared by: Alan Harris: PHS Regional AIDS Coordinator 12-10-91.

COUNTY OF LOS ANGELES • DEPARTMENT OF HEALTH SERVICES DHS

AIDS PROGRAMS

600 SOUTH COMMONWEALTH AVENUE, SIXTH FLOOR - LOS ANGELES, CALIFORNIA 90005

(213) 351-8000

August 8, 1991

TO: CARE Act HIV Planning Council

FROM: Robert E. Frangenberg

SUBJECT: **ESTIMATE OF UNSPENT CARE ACT FUNDS**

At the last meeting of the CARE Act HIV Planning Council, AIDS Programs was requested to prepare an estimate of funds which will be unspent in the CARE Act Formula and Supplemental grants this year. This is the response to that request.

When all of the contracts which are being developed are approved by the Board of Supervisors, all of the CARE Act Formula and Supplemental grant funds will be encumbered. Funds are encumbered in one of three ways: contracts, purchase orders, and County departmental service orders. Funds which are encumbered by the end of the budget period (January 31, 1992 and April 3, 1992 for the Formula and Supplemental grants respectively) are considered as "spent" by the Health Resources and Services Administration, even though actual expenditures under the contract continue into the second budget year. Therefore, if each contractor or program spends 100 percent of its contract budget, there will be no unspent funds.

However, since many contract agencies are starting new programs and may not have full staff on the payroll from the beginning of the contract, potential savings will be generated in some contracts. At this time it is too early to calculate savings based on actual cost reports from the contractors. Therefore, we have estimated these savings by using 15 percent of contracts, with several exceptions. Savings were not projected in currently operating outpatient clinics and hospitals, dental, residential, and detoxification programs, and administration.

Attached is a schedule of projected savings by category and contract. Until we have a longer history of experience with each contractor, it will be difficult to determine a more reliable estimate. Specific savings must be demonstrated before we can contract for these savings. The earliest date by which we will have reliable expenditure data to demonstrate savings is October.

We will continue to monitor CARE spending and as soon as savings are demonstrated, we will propose contract modifications in accordance with the Planning Council's priorities. Augmentation of existing contracts using savings will be expedited by a new contract provision which authorizes the Director of Health Services to augment contracts by 10 percent without going back to the Board for a contract amendment.

If you have any questions or need additional information, please let me know.

REF:rbf
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Attachment

PRIORITIZING FOR UNSPENT FUNDS

Analysis of Supplemental Funding

CATEGORY	APPLICATION ALLOCATION	ACTUAL ALLOCATION	DIFFERENCE	PERCENTAGE FUNDED
Early Intervention & Outpatient Medical				
South Central	$100,000	$75,000	$25,000	75%
Hollywood, WH, WLA	$400,000	$344,000	$56,000	86%
Long Beach, South Bay	$100,000	$175,000	($75,000)	175%
San Fernando Valley	$200,000	$150,000	$50,000	75%
East Los Angeles	$250,000	$215,000	$35,000	86%
Central LA	0	$315,000	($315,000)	
Special Populations				
Outpatient	$700,000	$415,949	$284,051	59%
Support Services	$100,000	$86,000	$14,000	86%
Mental Health (RFP)	$100,000	$75,000	$25,000	75%
Promotion of Services (RFP)	$100,000	$75,000	$25,000	75%
Access to Alternative Therapies	$250,000	0		
Drug Abuse Treatment				
Residential Detox	$300,000	$258,000	$42,000	86%
Outpatient Detox	$150,000	$129,000	$21,000	86%
Primary Care to Substance Abusers	$150,000	$129,000	$21,000	86%
Case Management	$450,000	$337,500	$112,500	75%
Mental Health/Psychosocial Support	$500,000	$375,000	$125,000	75%
Residential Care	$500,000	$375,000	$125,000	75%
Recruitment/Retention	$100,000	$86,000	$14,000	86%
Transportation	$50,000	$37,500	$12,500	75%
Outreach for Testing	$100,000	$75,000	$25,000	75%
Administration	$242,105	$196,208	$45,897	81%
	$4,842,105	$3,924,157		

Note: Central LA monies derived from Special Populations ($200,000) and Access to Alternative Therapies ($115,000). Long Beach received additional $100,000 from Access to Alternative Therapies.

COUNTY OF LOS ANGELES - AIDS PROGRAMS
ESTIMATE OF UNSPENT CARE ACT FUNDS - PROJECT BUDGET YEAR ONE

Service	Provider	Allocation	Projected Savings
FORMULA GRANT			
Outpatient/South Central	King/Drew	765,000	114,750
Outpatient/San Gabriel	Pasadena AIDS Coord.	239,000	35,850
Outpatient/San Fernando V	Northeast Valley	189,000	28,350
	Olive View	50,000	0
Outpatient/Long Beach	Long Beach Comp. Ctr	382,000	57,300
CBO CARE to Relieve 5P21	AIDS Healthcare Foun	287,000	0
	Alta-Med	287,000	43,050
Case Management	Various CBOs	382,000	57,300
Mental Health	Various CBOs	191,000	28,650
Dental Care	APLA	96,000	0
Residential/Emerg. Relief	Various CBOs	239,000	0
Cross-Training	Various CBOs	191,000	28,650
Transportation	Various	143,000	21,450
Outreach/Promotion	Various CBOs	191,000	28,650
Regional Consortia	AIDS Regional Board	96,000	0
Administration	AIDS Programs	196,157	0
TOTAL FORMULA GRANT		3,924,157	444,000
SUPPLEMENTAL GRANT			
Outpatient/South Central	King/Drew	75,000	11,250
Outpatient/West	AIDS Healthcare Foun	219,000	0
	Gay & Lesbian CSC	75,000	0
	UCLA	50,000	0
Outpatient/Long B, So.Bay	Harbor/UCLA	175,000	0
Outpatient/San Fernando V	Northeast Valley	150,000	22,500
Outpatient/East L.A.	AltaMed	215,000	32,250
Outpatient/Central	Hudson Comp. Ctr.	315,000	47,250
Special Pop.			
Outpatient	Various CBOs	415,949	62,392
Support Svcs.	Various CBOs	86,000	12,900
Promotion of Svcs.	Various CBOs	75,000	11,250
Mental Health	Various CBOs	75,000	11,250
Mental Health	Various CBOs	375,000	56,250
Outreach for Testing	Various CBOs	75,000	11,250
Case Management	Various CBOs	337,500	50,625
Residential	Various CBOs	375,000	0
Recruitment/Retention	Various	86,000	12,900
Transportation	Various	37,500	5,625
Residential Detox	Tarzana Treat. Ctr.	258,000	0
Outpatient Detox.	BAART	129,000	0
HIV Primary Care/Subst.	El Proyecto del Barr	129,000	19,350
Administration	AIDS Programs	196,208	0
TOTAL SUPPLEMENTAL GRANT		3,924,157	367,042
TOTAL BOTH GRANTS		7,848,314	811,042

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LOS ANGELES COUNTY - DEPARTMENT OF MENTAL HEALTH

HIV MENTAL HEALTH NEEDS IN ETHNIC MINORITY COMMUNITIES

Testimony Presented to the
State Senate Committee on Health and Human Resources

by Elsie Go Lu, Ph. D.
Deputy Director

I. Lack of funding for:

   A. HIV mental health services

      1. State Department of Mental Health - $476,000
      2. L.A. County Department of Health Services - $100,000

   B. Services for ethnic minority communities

II. Special HIV mental health needs of ethnic minority communities

   A. Geographic accessibility
   B. Providers familiar to the community (e.g. established agencies)
   C. Providers familiar with the community (e.g. acculturated/culturally sensitive)
   D. Stigma associated with mental health treatment
   E. Sensitivity to cultural norms re: sexuality and drug use
   F. Child care

III. Ethnicity of HIV mental health consumers

   A. Program H.O.P.E.
   B. AIDS Project Los Angeles

LOS ANGELES COUNTY

HIV STRATEGIC PLAN

Fiscal Years 1990/91 - 1992/93

Prepared by

The County-Community HIV Planning Council

and the

County of Los Angeles

Department of Health Services AIDS Programs

March 1990

Mental Health Services

Mental health services for HIV impacted persons are a critical need throughout the continuum of the illness, from immediately after testing seropositive to the most advanced stages of AIDS. They may also be required by those who are HIV negative, including significant others, families, and the "worried well." Early psychological evaluation and intervention are of the utmost importance in order to deal with the many emotional, physical, behavioral, and psychological impacts of HIV disease. Currently, community-based organizations are providing the majority of mental health services. These agencies are able to reach and effectively serve the community via a non-threatening environment.

Agencies handle clients with a perplexing range of emotional and psychosocial issues associated with HIV, including: denial, depression, stress, anxiety, the impact of discrimination, and suicidal ideation. Persons not infected with the virus, but still impacted by the disease, may share some of these same issues. HIV brain disease, in varying degrees and often more severe in the latter stages of the illness, also affects many HIV+ individuals.

This section of the plan will discuss the general mental health needs of the HIV impacted population as well as the unique needs of special populations. The services currently being offered are outlined, and the barriers to receiving these services are described. The Mental Health section also defines specific needs and offers recommendations for a comprehensive system of HIV-related mental health care. Lastly, projections of service utilization and capacity are presented. These projections demonstrate that additional funding and resources are necessary if we are to provide psychosocial support to all those who require it.

Description of Affected Population

Those infected with HIV are by no means a homogeneous population. They may be anywhere along the HIV continuum, from asymptomatic to full-blown AIDS. Different stages of the disease present varying needs and may require different modes of treatment or assistance. In addition to the dimension of illness severity, the personal history and background of the individual must be taken into account. As discussed in the Prevention section of the plan, service providers must recognize the needs of individuals with diverse ethnic/racial backgrounds, cultural values, sexual orientation, etc.

For mental health planning purposes, HIV affected populations may be categorized in the following manner:

- individuals with severe psychiatric complications as a result of the disease, i.e., advanced HIV brain disease (commonly referred to as HIV dementia complex);

- those with pre-existing psychiatric conditions, i.e., the chronically mentally ill;

- persons with multiple diagnoses, i.e., persons with several primary problems, such as addictive behaviors and a psychiatric complication; and

- persons with the significant emotional reactions to severe stressors, such as a diagnosis with a chronic, life-threatening illness or the illness or death of a loved one.

Advanced HIV Brain Disease

HIV brain disease is a direct result of infection of the brain by HIV. The complex is characterized by a host of cognitive, motor, and behavioral symptomatology. The impact of dementia ranges from the functional impairment of early cognitive loss to the profound effects of its severe form in which patients are rendered nearly vegetative and require full-time institutional care. Neuropsychological impairments appear to affect those with AIDS, particularly those at an advanced stage of the disease (Tross, et al., 1988). The prevalence of HIV brain disease in otherwise asymptomatic HIV+ persons is very low.

Clinical experience indicates that HIV brain disease is common and imposes significant morbidity in the late stages of HIV infection. At least two-thirds of patients eventually develop dementia before the terminal phase of the disease, and additional numbers exhibit subclinical evidence of neurological dysfunction (Price and Brew, 1988).

Chronically Mentally Ill

The severely/chronically mentally ill are especially difficult to reach in terms of HIV services. Education and behavior change can be especially difficult for this population. Mental illness may interfere with their ability to hear, process, and integrate information. Lack of ability to control behavior or delay gratification may prevent safer behaviors, even if educational material is understood or remembered.

Whether the mentally ill population can be mainstreamed into the HIV health care system or not depends on the severity of their mental illness. If their physical ailments are too severe, the psychiatric wards, concerned about infection control and the ability to provide needed medical services, will not admit them. Special protocols and close communication must be developed between the mental health and HIV health care systems to avoid "bouncing" the patient back and forth between facilities.

Persons with Multiple Diagnoses

Persons with multiple diagnoses are dealing with many of the same issues as the chronically mentally ill. Mental health professionals find working with this population especially difficult. They may have character disorders and drug abuse problems that adversely affect attempts at behavioral change. Unfortunately, HIV service agencies are seeing a high number of

individuals in this category.

Persons with Significant Reactions to Stressors

The persons in the last category do not fall into the other three. They have no pre-existing mental health conditions and are not experiencing advanced HIV brain disease, but they are seeking psychosocial support in order to cope with their illness. Upon learning of their seropositive status, many individuals may seek short-term counseling in the form of crisis intervention. Later, they may attend group therapy and remain with this modality for the long term. Others seek individual psychotherapy and/or therapy involving loved ones.

Universal Mental Health Needs

The impact of HIV often results in similar or universal reactions among all populations. General psychosocial issues are presented to mental health and other professionals by those affected by HIV. These issues become important when an individual learns that he/she or a loved one is seropositive, and cannot wait to be addressed until symptoms appear or an AIDS diagnosis is made.

These psychosocial issues include: an increase in suicidal ideation; inadequate social supports; lack of resources; social isolation; stigmatization; anxiety; depression; negotiations surrounding implementation of safe behaviors; and factors concerning the grief and loss process. This list is by no means an exhaustive one, but it does present several of the common problems that HIV affected persons face.

Suicidal ideation is an especially common presentation among persons with HIV. Recent data have revealed that the relative risk of suicide in men with AIDS ages 20 to 59 years was 36.3 times that of men without the diagnosis, and 66.15 times that of the general population (Marzuk, et al., 1988). Health professionals who serve such clients must be constantly alert to the risk of suicide.

Mental Health Needs of Special Populations

The needs of special populations, often overlooked or unmet, are important to recognize in the continuum of HIV-related services. Special populations include, among others: gays and bisexuals, women, intravenous drug users, ethnic/racial minorities, adolescents, and the incarcerated. The unique needs of these populations have been discussed extensively in the Prevention section under "Guiding Principles and Selection of Target Groups" and "Health Education/Risk Reduction Programs." In addition to the items discussed under these sections (e.g., cultural norms, unique needs, specialized interventions, etc.), providers must recognize that mental health services for these groups may require a specialized approach. In all cases, providers must be sensitive to the needs of these special populations. Language, culture, social support, and sexual orientation are some of the variables that must be taken into account in the provision of HIV-related mental health care.

Access for special populations is an especially crucial issue. These communities are often unwilling or unable to access any health services, let alone mental health services. Some populations may see a stigma associated with accessing mental health care, e.g., a service only for "crazy people." Often cultural values do not encourage the focus on self that mental health care traditionally requires. They may be helped more by group support than traditional individual psychotherapy.

One confounding factor in attempting to service the HIV impacted population is the number of individuals who live by themselves and/or do not have close family or other support networks. Populations engaging in high risk behavior, such as IVDUs, prostitutes, street youth, and undocumented persons, are often those without the stable support network or help-seeking skills needed to attempt behavior change. Most of these individuals experience feelings of isolation and abandonment, but may not have the knowledge, skills, or financial ability to seek out mental health care.

Minority populations are most often comfortable receiving care from a member of their own community, someone who is seen as sensitive to their needs. The level of trust that must be developed between therapist and client is often more intense in these communities than in the mainstream population. Without that trust and sense of caring, the individual may not continue to utilize the needed services. Consequently, mental health professionals may need to adapt traditional techniques to make them effective with special groups.

The following outline is a brief synopsis of some of the unique needs of special populations:

- **Gays/Bisexuals:** This population is often facing issues of homophobia and the "coming out" process. The nature of HIV disease may also lead to feelings, originating from themselves and/or others, of blame or responsibility for the epidemic. They are also facing multiple losses of friends and loved ones. Those who have tested negative may experience the trauma of "survivor's guilt." When accessing services, this population encounters social service providers who are often not accepting of gays and bisexuals because of their sexual orientation.

- **Women:** Issues surrounding pregnancy and/or children are common among women facing HIV disease. Parents must face how their children will be cared for during illness and after death. They may be losing their support system at a time when they need it the most. The risky behaviors of a spouse or significant other may be at the forefront for the first time. Many issues, including financial dependence upon a man, contribute to the woman's fear of changing behaviors. She may also require assertiveness training and psychosocial support to handle negotiations around safe sex. Few programs exist that are designed specifically for women,

many of whom are uncomfortable with male-dominated settings.

- **IVDUs:** The issues faced by drug abusers are only exacerbated by the presence of the virus. These persons, if they are in recovery, may relapse upon learning of a seropositive status. Their sense of isolation may increase as they are shunned from their drug culture. The number one priority may be to take care of their drug habit, and the motivation to change behaviors is often low. The IVDUs' reactions to the disease are quite dependent on their initial psychosocial standing, i.e., the less stable before the positive test result, the more intensive assistance they will need in facing the disease. Matters are further complicated by the fact that some residential drug treatment programs still will not accept HIV+ persons, especially if they are symptomatic.

- **Ethnic/Racial Communities:** As discussed throughout this plan, the needs of people of color may differ according to language, culture, and religion. Bicultural and bilingual providers are necessary to deal with clients' deeper social isolation, rejection, and fear. Many Asians, for example, feel shame and experience a loss of status for themselves and their entire families. The risk of suicide may be even greater than in other populations. Differing approaches may have to be taken with immigrants versus native-born persons. Undocumented persons face a host of complications surrounding their immigration status, including fear of accessing public systems of care. In some cases, Blacks and other racial/ethnic minorities are in denial regarding how they acquired the virus, and are internalizing feelings of homophobia.

- **Adolescents:** Young adults at high risk (homeless/runaway) may be resistant to accessing health services; many come from homes which are dysfunctional and abusive. The behavior that is appropriate for their age group may be in conflict with the demands of adult decisions necessitated by HIV. Alcohol and drug use are especially prevalent. Adolescents are a particularly difficult population to educate and produce behavior change because of their impulsivity, experimentation with their emerging sexuality, and a belief in their own immortality.

- **Incarcerated:** Those in the jail and prison systems may fear the consequences of their HIV diagnosis. They may have well-entrenched character disorders that, similarly to the severely chronically mentally ill, interfere with the ability to integrate information and change behaviors. Severe and chronic mental illness may also be a factor in their HIV-related care. Also, the prison system lacks the resources to provide comprehensive mental health care for

HIV-related issues. Once the inmate is released, networking or "discharge planning" among the prison system and other agencies rarely exists.

Range of Services

Mental health services may be discussed via several categories. These categories include inpatient care, residential care, day treatment, and outpatient services. The following outline of these services provides a useful understanding of the mental health care needs of HIV-affected persons in Los Angeles County.

Inpatient Care

- **24-hour acute hospital care:** This care is defined as hospital beds for: (1) HIV+ mentally ill patients, (2) HIV brain disease patients with or without medical complications, and (3) patients experiencing psychiatric crises in response to the severe stressors attendant with HIV. Current facilities are already completely overwhelmed and very few beds exist in the private sector.

- **Sub-acute care:** This category of mental health care refers to locked/unlocked skilled nursing facilities with increased nursing components, rehabilitative staffing, and mental health services. Sub-acute care is a high priority because of current and expected future demand from HIV impacted patients. Currently, no such facilities accept HIV-infected clients.

Residential Care

- **Board and care facility:** A residential site of this type offers structure and access to mental health services while allowing clients to remain in the community. Medications are distributed by staff. Frequently, a family and several staff members are administrators for a small number of beds.

- **Residential psychiatric facility:** While similar to board and care facilities in terms of programmatic structure, residential psychiatric facilities are larger with perhaps one hundred or more beds.

- **"Our House" model:** The AIDS Project Los Angeles' Our House is an important and unique model of a residential facility for the multiply diagnosed. The 14-bed facility is designed to accommodate ambulatory HIV+ clients who have a pre-existing mental illness, HIV brain disease, and/or a history of drug/alcohol abuse.

Day Treatment

- **Day treatment programs:** This program involves a structured environment that is an avenue for providing mental health treatment and socialization for clients, as well as respite for caregivers. This alternative is more cost-effective than an inpatient situation or homecare for all affected individuals. A program in this category should provide integrated services that are responsive to the psychosocial and spiritual needs of the client. Life skills improvement, which gives structure to daily living, and compensatory strategy development, which helps clients cope with memory loss, are important components of the program.

Outpatient Care

- **Professional services:** This category encompasses a wide range of programs and modalities, including: crisis intervention; early counseling; support groups; individual, couple, and family psychotherapy; case management; and psychiatric medication evaluation. Providers must be able to treat and refer multiply diagnosed clients in a sensitive and competent manner. They must understand both the medical and psychological aspects of HIV disease, to satisfy client needs.

  Crisis intervention may be provided for such crises as a clients' deteriorating medical condition, loss of loved ones, and others' reaction to the client's illness (i.e., rejection, discrimination).

  Early counseling is delivered as soon as possible following post-test counseling. This period is a crucial time to educate, offer support, initiate behavior change, provide information and referral, initiate/support secondary prevention efforts and, support positive coping strategies.

  Support groups (on-going and drop-in) provide peer emotional support on both an as-needed, flexible basis without regular attendance requirements and on a more structured, weekly basis.

  Case management provided by mental health professionals involves referrals to needed resources, psychosocial assessments, and, often, some form of crisis intervention.

  Psychiatric medication evaluations are crucial and a high priority. The evaluations are designed to determine whether the client needs to be placed on psychotropic drugs. Evaluation may reduce the need for inpatient care as the clients' needs are more clearly defined.

- **Paraprofessional/Volunteer Programs** (mental health specific): These programs include the successful "buddy" programs and peer counseling. Programs may be provided to individuals, couples, and/or families. Providers must deal with the training of volunteers, matching volunteers and clients, and burnout.

Training and Professional Support

- **Training, Consultation, and Education:** These programs are targeted to specific disciplines or providers, e.g., board and care operators, psychiatrists, and students/interns in different mental health disciplines. Providers cannot be equipped to handle HIV-related clients without HIV-specific training. The HIV+ patient presents issues that differ from the providers' traditional clients. Emphasis on culturally/linguistically appropriate client needs is necessary.

- **Emotional Support Services to HIV Service Providers:** Support groups and burnout prevention workshops provide emotional support to HIV service providers. Providers are often coping with the deaths of clients and loved ones, and may feel a sense of isolation from their colleagues.

Barriers to Meeting Needs

The single greatest barrier to meeting the mental health needs of the HIV-impacted population is, of course, financial. Patients often do not have the personal funds to access care, thus placing the onus on the public sector to provide care. The existing public mental health system is so limited and so underfunded that the Department of Mental Health cannot serve populations beyond one target population, the chronically mentally ill.

Unfortunately, HIV mental health care is multiply stigmatized--not only does the public associate a stigma with mental health, but also with HIV disease. Consequently, mental health services, especially for HIV-related issues, are not seen as a priority by the public or public funding sources. Neither the funding nor the pressure to acquire the funding are sufficient to meet the current demand for services.

Another significant limitation involves staff resources. The staff fear the possibility of themselves becoming infected. Emotional burnout among HIV service providers is prevalent, and retaining staff can be difficult. The demands of working exclusively with severely ill and dying patients are quite high. This burnout is also due, in part, to the inability to find support from colleagues who do not see HIV impacted clients. Also, the environment of long hours, high caseloads, and low pay makes retaining and recruiting staff especially difficult.

The lack of HIV-related training and information provided to mental health professionals and the inadequate reimbursement

rates for the care are the major reasons for inadequate numbers of appropriately trained staff. Providers are often resistant to receiving this education because of their reluctance to care for HIV impacted persons. They are not well-compensated financially and may not be able to deliver the ethnic and culturally specificity required. Space in which to provide services is also an issue. Community organizations do not have the space or rent to hold all the support groups and offer the peer counseling that is required.

Access to and development of resources is also hindered by the discrimination that exists against those who require services. Potential clients are stigmatized because of their mental illness, seropositive status, sexual orientation, and/or substance abusing history. This tendency to "blame the victim" creates a difficult environment in which to design, develop, and support HIV-related mental health services.

A serious lack of coordination also exists. Networking is necessary among and within County departments and between these departments and the community. Effective referral and case management cannot take place without formal mechanisms to link inpatient facilities, CBOs, and other sites. Agencies recognize this deficiency and many are attempting to correct it through more open communication, but much work remains to be done.

Needs and Recommendations

Particularly crucial categories that require expansion are: medical-psychiatric hospital beds for acute care, sub-acute care facilities, residential facilities, and day care mental health programs. Further funding for outpatient services is also urgently needed to meet both current and projected needs. Training and education to professionals and paraprofessionals is necessary in all programs.

Other needs arise from the fragmentation of the health care system among the various organizations, including the Department of Mental Health, the Department of Health Services (e.g. AIDS Programs, Alcohol and Drug Programs), and community-based organizations, which especially adversely affects the treatment of the multiply diagnosed patient. Coordination between these systems must be a priority if clients are to be effectively served. For example, attempts at early counseling will not work if improved connections are not made between post-test counseling and other follow-up services.

Multi-level Facility: Sub-acute, Residential, and Day Care

Ideally, sub-acute care should be offered in a single, multi-level facility. The best situation provides for sensitive staff in one location to meet the demanding needs of the mentally ill client. The facility could provide a continuum of mental health care through the combination of a locked ward with a skilled nursing component, residential care, transportation, and day treatment at both the intensive (crisis resolution) and habilitative (maintenance) levels. If a single facility is not

established, strong and formal ties must be made with the several sites providing these services. A patch funding program is needed to pay sub-acute care facilities for extra services provided to HIV mental health patients.

Case management coordination between mental health and community-based providers becomes critical when placement of an HIV-positive chronically and severely mentally ill person in a community residential setting is necessary. Few facility operations (from board and care homes to SNFs) are willing to or comfortable with caring for an HIV-positive/chronically mentally ill individual who could place other residents at risk of exposure to HIV. Additionally, residential facility operators must be educated to deal with issues related to HIV/AIDS.

Acute Care

Too often inpatient facilities are not accepting HIV+ patients in direct violation of anti-discrimination ordinances of the Cities of Los Angeles and West Hollywood and the County of Los Angeles. These violations should be reported and appropriate action taken. This situation highlights the need for training and education to decrease fear and sensitize providers to the psychosocial need of HIV patients.

Professional Services

Professional services such as crisis intervention, counseling, and support groups require further staff training and expanded availability. Greater geographic distribution of programs and services provided in languages other than English are needed. Development of new models that are culturally appropriate, based upon what people perceive they want and need, is necessary. New and innovative models should outreach to clients and educate them on the benefits of mental health services. Services should also incorporate the provision of messages to prevent transmission of the virus and the development of acute mental health conditions.

A major priority includes the need to increase the availability of case managers. Increased communication is necessary between DMH, CBOs, and DHS (e.g., AIDS Programs, Drug Abuse Program Office, Alcohol Programs) to decrease overlapping services and multiple case managers. Some mental health professionals believe that creative and culturally sensitive mental health counseling may be provided by mental health professional case managers, rather than through a more traditional, formal setting. Clients may feel more comfortable with this one-on-one relationship in which they have already developed a level of trust and security.

Medication Evaluations

Medication evaluations are an integral part of mental health care. Unfortunately, very few private providers agree to do evaluations on a long-term basis or at low cost. Monitoring and follow-up are important, but most psychiatrists are unwilling or

unable to devote the intensity of effort required. Resources should be developed in this area through active recruitment and education.

Psychosocial Support for Providers

The need to develop more support groups and burnout prevention workshops for mental health providers is acute. Bereavement intervention is also a very real need. These services should be part of an overall resource development program that seeks to recruit and retain HIV providers throughout the various delivery systems.

Projections

The projections of psychosocial services needed by HIV+ adults (Table 18) are made with the use of the estimates described below. All estimates are derived from the experiences of the County Department of Mental Health and community-based organizations providing HIV care.

By definition, the chronically mentally ill and persons with multiple diagnoses (categories 2 and 3) are not mutually exclusive. However, the overlap between the two categories is insignificant given the uncertainty of the seroprevalence estimate. All numbers have been rounded to the nearest fifty.

Table 18

Mental Health Service Projections
1990/91 - 1992/93

Category	Estimates 90/91	91/92	92/93
Persons with HIV brain disease needing mental health intervention (1)	2,900	3,500	4,050
Chronically mentally ill (2)	1,700	1,700	1,700
Persons with multiple diagnoses (3)	2,500	2,500	2,500
Persons with significant emotional reactions seeking mental health intervention (4)	22,400	22,400	22,400

Table 18 Notes

(1) It is estimated that 66 percent of patients develop significant symptomatology related to HIV brain disease before the terminal stages of the disease. However, approximately half of these individuals (33 percent) will need mental health intervention. The estimates use AIDS cases per year plus 10 percent to capture the severely symptomatic. 90/91: (8,845)(.33) = 2,918; 91/92: (10,678)(.33) = 3,523; 92/93: (12,293)(.33) = 4,056

(2) It is estimated that one and one-half percent of the general population is chronically mentally ill. Those with a chronically mentally ill diagnosis prior to HIV infection are estimated as 1.5 percent of the 112,000 infected. (112,000)(.015) = 1,680

(3) This estimate is the number of HIV infected persons who are also diagnosed with several primary problems, such as a psychiatric complication and addictive behaviors. The total number of infected persons is multiplied by 15 percent (the estimated proportion of infected who are IVDUs) and by another 15 percent to estimate the total number of HIV+ IVDUs with a psychiatric disorder. (112,000)(.15)(.15) = 2,520

(4) This estimate is based on the APLA figure of 66 percent of new clients receiving counseling and group therapy services. The number is reduced to 58 percent when categories 1, 2, and 3 are excluded. Approximately one-third of these individuals who might need mental health intervention actually seek the care. The bulk of this care is group therapy. Therefore, 20 percent of the HIV-infected were placed in category 4. (112,000)(.20) = 22,400

Acute Hospital Care

Approximately five percent of mentally ill patients (categories 1-3) need acute inpatient care, according to Department of Mental Health statistics. This figure may be applied to the HIV+ population to determine the number of hospital psychiatric beds needed for their care. Five percent of categories 1-3, and 5 percent of half of category 4 (they are not considered mentally ill, but half may be suicidal) require such care each year. Average length of stay is two weeks.

Sub-acute Care

In order to determine the number of beds in a locked mental health skilled nursing facility (SNF) that are required by HIV+ individuals, only categories 1, 2, and 3 are considered. Fifty

percent of those entering an acute hospital setting will be discharged into sub-acute care. Five percent of persons from categories 1-3 will enter the locked SNF directly from the community. Average length of stay is two months.

Residential Care

Board and care facilities experience a six-month length of stay for their patients. Only categories 1 and 2 are considered. Eighty percent of those entering a sub-acute care setting will be discharged into board and care. Five percent of persons from categories 1-3 will enter from other sources.

Category 3 utilizes the "Our House" model of care. Individuals with multiple diagnoses remain at Our House about six months before being discharged into hospice or other care. It is estimated that 8 percent of persons with multiple diagnoses require an Our House facility. That is, 200 HIV+ persons per year need 100 "Our House" beds. This figure reflects seven times as many beds as currently exist.

Day Treatment

Individuals with HIV brain disease and those who are chronically mentally ill are the most appropriate clients for a day treatment program. Approximately 15 percent of categories 1 and 2 require such care. Five percent of those with multiple diagnoses would benefit from day treatment. Currently, DMH's Program H.O.P.E. can handle a case load of twenty-five, significantly less than what is needed.

Outpatient Care

For outpatient care, projections are made for four professional services: individual therapy, group therapy, case management, and medication evaluation. The percentages described below are estimates provided by a working group comprised of Los Angeles County mental health professionals.

HIV-infected persons require individual therapy at the following percentages: 7 percent of category 1; 66 percent of category 2; 60 percent of category 3; and 33 percent of category 4. The chronically mentally ill utilize long term individual psychotherapy while persons with multiple diagnoses are more likely to seek intervention intermittently, during times of crisis.

Group therapy is the most utilized mental health intervention, especially by persons in category 4. However, chronically mentally ill patients are not placed in group therapy settings. Persons with multiple diagnoses are often disruptive in group settings, but they will seek such care on a drop-in basis for crisis resolution. Approximately 7 percent of category 1, 25 percent of category 3, and 66 percent of category 4 seek these services.

Case management projections consider those individuals who need this service within the mental health system. The Case Management section of the Plan captures the HIV+ population

receiving non-mental health specific case management in community-based agencies. One hundred percent of the chronically mentally ill and 25 percent of those with multiple diagnoses should receive case management in the mental health sector.

Medication evaluation for psychotropic drugs is required by a large number of individuals in our categories. One-hundred percent of the chronically mentally ill patients, 50 percent of persons with multiple diagnoses, and 6 percent of category 4 require such services.

Mental Health Services Cost Projections
1990/91

Category of service	Amount needed	Total Costs
Acute Hospital Care	35 psych beds	$ 6,591,900
Sub-acute care	86 SNF beds	$ 2,511,200
Residential care	240 board and care beds	$ 1,752,000
	100 "Our House" beds	$ 1,785,714
Day Treatment	815 HIV+ individuals/year	$10,866,664
Outpatient Care		
Individual counseling	10,200 HIV+ individuals/year	$14,203,800
Group counseling	15,600 HIV+ individuals/year	$28,315,832
Case management	2,325 HIV+ individuals/year	$ 1,453,000
Medication evaluation	4,300 HIV+ individuals/year	$ 378,400
TOTAL:		$67,858,510

1991/92

Category of service	Amount needed	Total Costs
Acute Hospital Care	36 psych beds	$ 6,826,680
Sub-acute care	93 SNF beds	$ 2,715,600
Residential care	268 board and care beds	$ 1,956,400
	100 "Our House" beds	$ 1,785,714
Day Treatment	905 HIV+ individuals/year	$12,066,664
Outpatient Care		
Individual counseling	10,260 HIV+ individuals/year	$14,400,360
Group counseling	15,654 HIV+ individuals/year	$28,442,504
Case management	2,325 HIV+ individuals/year	$ 1,453,000
Medication evaluation	4,300 HIV+ individuals/year	$ 378,400
TOTAL:		$70,025,322

1992/93

Category of service	Amount needed	Total Costs
Acute Hospital Care	37 psych beds	$ 7,043,916
Sub-acute care	100 SNF beds	$ 2,920,000
Residential care	297 board and care beds	$ 2,168,100
	100 "Our House" beds	$ 1,785,714
Day Treatment	988 HIV+ individuals/year	$13,166,338
Outpatient Care		
Individual counseling	10,297 HIV+ individuals/year	$14,582,880
Group counseling	15,693 HIV+ individuals/year	$28,560,128
Case management	2,325 HIV+ individuals/year	$ 1,453,000
Medication evaluation	4,300 HIV+ individuals/year	$ 378,400
TOTAL:		$72,058,476

1991 CARE/CDC REQUESTS FOR PROPOSALS FACT SHEET

TOTAL NUMBER OF PROPOSALS RECEIVED: 47

RFP MENTAL HEALTH & PSYCHOSOCIAL SUPPORT SERVICES (#91-003)

RECOMMENDED FOR FUNDING:	**AMOUNT**
AIDS PROJECT LOS ANGELES	$93,000
EAST VALLEY COMMUNITY HEALTH CENTER	75,000
PACIFIC CENTER FOR COUNSELING	55,000
MINORITY AIDS PROJECT	111,000
HOLLYWOOD-SUNSET COMMUNITY CLINIC	66,000
*GAY AND LESBIAN COMMUNITY SERVICES CENTER	133,000
TARZANA TREATMENT CENTER	108,000

TOTAL NUMBER OF AGENCIES RESPONDING: 20
TOTAL AMOUNT OF FUNDING REQUESTED: $2,517,958
TOTAL FUNDING AVAILABLE:

CARE Supplemental	$450,000
CARE Formula	191,000
TOTAL	$641,000

RFP HIV OUTREACH AND PROMOTION OF SERVICES (#91-004)

RECOMMENDED FOR FUNDING:	**AMOUNT**
JWCH INSTITUTE, INC.	$42,538
THE LOS ANGELES FREE CLINIC	40,000
CITY OF LONG BEACH DEPT. OF HEALTH	35,000
CALIFORNIA DRUG CONSULTANTS, INC.	42,000
*AIDS HEALTHCARE FOUNDATION/ GAY MEN OF COLOR CONSORTIUM	255,286

NUMBER OF AGENCIES RESPONDING: 18
TOTAL AMOUNT OF FUNDING REQUESTED: $1,845,610
TOTAL FUNDING AVAILABLE:

CDC (Supplemental)	$ 73,824
CARE Formula	191,000
CARE Supplemental	150,000
TOTAL	$414,824

RFP TRAINING & CROSS-TRAINING (#91-005)

RECOMMENDED FOR FUNDING:	**AMOUNT**
*PROTOTYPES/W.A.R.N.	$235,700
LOS ANGELES HOMELESS HEALTH CARE PROJECT	93,127
*AIDS HEALTHCARE FOUNDATION/ GAY MEN OF COLOR CONSORTIUM	106,300

NUMBER OF AGENCIES RESPONDING: 9
TOTAL AMOUNT OF FUNDING REQUESTED: $1,046,087
TOTAL FUNDING AVAILABLE:

CDC	$244,127
CARE Formula	191,000
TOTAL	$435,127

* Represents group/consortium proposals

team2:ma:again

California Statewide Interim Hearing
Senate Health and Human Services Committee
State Senator Diane E. Watson, Ph.D., Chair
Exposition Park
December 17, 1991 9:30 a.m. - 4:30 p.m.

PUBLIC TESTIMONY

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INTRODUCTION

My name is Cynthia Davis and I am the Program Director of two HIV/AIDS education, prevention and risk reduction programs being implemented under the auspices of the Center for Community and Preventive Medicine of the Charles R. Drew University of Medicine and Science, the National Organization of Black County Officials, Inc. (NOBCO) and the Centers for Disease Control. The purpose of the projects are twofold:

1) to develop a model HIV/AIDS risk reduction program targeting school-age, out-of-school and college-age youth which can be replicated in the African American community on a national basis and

2) to increase the HIV/AIDS-related knowledge and awareness of Black elected and appointed county officials so that they can more effectively advocate for increased and/or enhance HIV/AIDS-related services targeting the African American community on a national basis.

I have been involved in developing, implementing and evaluating family life education (FLE) and HIV/AIDS education and risk reduction programs targeting ethnic majority youth and young adults in Los Angeles County since 1984.

My testimony will focus on the overall HIV/AIDS-related educational needs of African American youth on a national as well as local level.

BACKGROUND

As of October 1991, on a national level there have been approximately 758 cases of AIDS among 13-19 year olds reported to the Centers for Disease Control (CDC). Of these 758 cases, 42% are White (322), 37% are Black (280) and 19% are Hispanic (142).

Of those cases reported among Black youth, 59% are male (166) and 41% are female (114). The exposure categories that have been reported for all youth aged 13-19, irrespective of race, indicate that 26% were infected due to homosexual/bisexual contact, 30% were infected due to hemophilia/coagulation disorders; 14% due to heterosexual contact, 12% due to IVDU, 7% due to receipt of contaminated blood products; for 7% their exposure category is unknown and 4% due to the multiple risk factor of homosexual/bisexual contact and IVDU.

Out of a cumulative total of 199,406 cases reported to date, the number of 13-19 year olds reported with AIDS accounts for less than 1% (.38%) of the total cases. However, this fact should not give one the false notion that "teens aren't at risk" for HIV infection.

In Los Angeles County, to date (September 1991) there have been a total of 30 AIDS cases reported among youth aged 13-19: 9 among Blacks (30%), 11 among Hispanics (37%) and 10 among whites. (33%)

While adolescents (age 13-19) account for less than 1% of the total number of AIDS cases, both nationally and locally, 20% of all reported AIDS cases are among persons 20-29 years of age. Given the extended latency period from the time of initial infection with HIV until manifestation of symptoms which result in an AIDS diagnosis, usually from one to ten years, it can be concluded that most of the individuals in the 20-29 age category were infected with HIV during their teen age years.

For far too long HIV infection and AIDS has been viewed as a "gay/bisexual white male disease". This myth still prevails. In lieu of the fact that the incidence and prevalence of HIV infection and AIDS is relatively low among the adolescent population, adolescents are at serious risk for HIV infections.

The number of reported cases of AIDS among adolescents does not accurately reflect the risk that this deadly virus poses to youth in this nation. To understand the full impact of AIDS among adolescents we must look beyond these seemingly low statistics to other sources which suggest that adolescents are at high risk for contracting HIV because of their behaviors.

WHY ARE YOUTH AT RISK FOR HIV INFECTION?

Adolescents and young adults are at increased risk for HIV infection due to numerous factors. These factors include:

1) increased sexual experimentation (heterosexual, as well as homosexual) among youth,

2) youth's increased experimentation with licit and/or illicit drugs,

3) youth engaging in casual sex or sex with more than one partner, and

4) youth failing to utilize "barriers" methods of birth control (i.e. latex condoms)

According to the 1980 Census, there are 10.5 million Black youth under the age of 19 in the U.S. with nearly 3 million aged 15-19 and 3 million aged 20-24. This under 24 age group comprises approximately 50% of the total U.S. Black population. Thus, we have a whole generation at increased risk for HIV infection.

Blacks and Hispanics currently account for approximately 44% of all patients diagnosed with AIDS, 73% of women, and 75% of all children with perinatal acquired infection. The overwhelming majority of minorities who have contracted AIDS are inner city residents of low socioeconomic status.

Numerous health and related social problems negatively affect the health and well being of significant numbers of Black and other ethnic minority adolescents and young adults across the U.S. The following statistics present a general overview of the seriousness of the problems:

Nationally,

LOW LITERACY - 1981, 15.4% of Black youth aged 16-24 were high school dropouts; another survey estimated that over 20% of Black males aged 12-17 could not read at a fourth grade reading level.

UNEMPLOYED - In 1983, 48.3% of Black youth aged 16-19 were unemployed, more than twice the 21.6% rate for all teens.

INCARCERATED - In 1979, 15% of all Black youth (456,633) aged 15-19 had an arrest record. In addition, 26% of all juvenile offenders in public or private residential facilities were Black.

DRUG USE AND ABUSE - In 1979, a National Institute on Drug Abuse (NIDA) survey indicated that non-white youth aged 18-25 have higher or equal rates of drug abuse than white youth in every major drug category except for inhalants and hallucinogens. Whereas a decreasing trend in marijuana use has been noted among white youth aged 12-17 and 18-25, this trend is not paralleled by a decreasing trend among minority youth in the same age categories. Another NIDA study predicts an increase in drug abuse among Black and

Hispanic youth through 1995 because they constitute the fastest growing segment of the U.S. population and because of their drug use patterns. A conservative estimate is that 200,000 adolescents have used drugs intravenously.

UNINTENDED PREGNANCIES- Over one million teenage girls become pregnant annually in the U.S. The rates of teenage pregnancy for Black and Hispanic teens in Los Angeles County are 3-4 times greater than for White teens. A 1981 report of the Population Council indicated that 83% of babies born to Black teens were born out-of-wedlock, compared to 33% born to white teens.

EARLY SEXUAL EXPERIMENTATION -By age 15, 16% of boys and 5% of girls in the U.S. have engaged in sexual intercourse at lease once. By age 17, these rates are almost three times nigher for boys and five times higher for girls. The rates of sexual activity for Black youth living in urban, inner cities are estimated to be higher than for white youth and studies indicate that Black youth begin engaging in sexual intercourse at earlier ages than white youth.

SEXUALLY TRANSMITTED DISEASES -Sexually transmitted diseases (STDs) have reached epidemic proportions in the U.S. In 1985, the Centers for Disease Control (CDC) reported that 25% of all individuals infected with gonorrhea or syphilis were aged 10-19 and 37% of individuals infected were aged 20-24. The rates of STDs for non-whites in Los Angeles County have been at epidemic proportions for several years.

On a local level, California leads the nation in the number of teenage pregnancies. In 1981, there were a total of 143,730 teen pregnancies of 15 to 19 year olds in the State, for a rate of 145 births per 1,000 teenagers age 15-19. In Los Angeles County this rate was 148 birth per 1,000 teenaged girl age 15-19 or 47,091 pregnancies.

In 1988 in California, there were 284 births to Black girls less than 15 year olds; 3,804 births to Black girls aged 15-17, and 5,832 for Black girls aged 18-19. Los Angeles County had, a total of 6,859 births for all ethnic groups who were less than 20 years old and who were unwed teens.

These high rates of teenage pregnancy and STDs indicate that preadolescent, adolescents and young adults are not using barrier methods of birth control when engaging in sexual intercourse. It's obvious that many teens and young adults are having sex; but unsafe sex.

CURRENT STATUS OF HIV/AIDS EDUCATION IN THE AFRICAN AMERICAN COUNTY IN LOS ANGELES COUNTY

Los Angeles Unified School District (LAUSD) which is the second largest school district in the nation with over 600,000 students has been involved in HIV/AIDS education since 1984. The district received limited funding from the public and private sector for Family Life Education which included HIV/AIDS education beginning in 1984. In 1987, the district was 1 of 16 school districts nationally to receive CDC funding to expand and ennance their HIV/AIDS education programs for teacher training and curriculum development.

Currently, the district implements a comprehensive health education curriculum which includes a component on STDs/HIV. This curriculum is targeted to the upper elementary (5th-6th) grades and secondary grades (7-12). Beginning in 5th and 6th grades student receive Family Life Education and HIV/AIDS education within the comprehensive health education curriculum. STDs/AIDS covers 8-10 lesson and can be implemented over a 3-6 week period depending upon the needs of class.

Parental consent is required for both the elementary and secondary school students.

LAUSD is currently updating its STDs/AIDS curriculum. The district for the past several years has been looking at changes in knowledge and attitudes concerning HIV/AIDS; and not behaviors.

For gay identified youth there are special peer counseling programs offered by the district's psychological services department at each school. And at Fairfax High, Project 10, a program for gay identified youth has been implemented for approximately 10 years. Youth can be referred to this program from other schools. The district is currently developing a Senior Exit program for 17-18 year olds. Prior to graduation, they will receive additional HIV/AIDS related information.

This past fiscal year over 1,662 secondary teachers were trained to use the STD/HIV curriculum. A staff of three persons coordinates the program and the program is in its 5th year of 5 years of funding. The district also works with local CBOs to train their staff in the use of its HIV/AIDS curriculum. (Urban League, Asia Pacific Project, AVANCE, and WARN Project)

There are several local CBO's targeting school-age and out-of-school population in South Central Los Angeles:

NOBCO AIDS Information and Education Project
Drew University Information and Education Project
Watts Health Foundation
Youth and Family Center of Inglewood
People Who Care
FAME Project
Minority AIDS Project

Funding for these projects is primarily from the public and private sector (LACDHS-APO, State Office of AIDS and CDC)

HIV/AIDS-related funding targeting African American women, youth and young adults has been nominal.

Los Angeles County AIDS Program Office 1990-91

Prevention/Education Contracts $279,651
El Centro del Pueblo - Central/Echo Park, Silverlake

El Proyecto del Barrio - Northeast San Fernando Valley

AIDS Awareness Campaign - Countywide

Gay & Lesbian Community Service Center - STOP AIDS Project
Valley Community Clinic

Health Education/Risk Reduction $1,493,560
(APO contract with local CBOs)

CORE Program -Outreach to gay/bisexual males

Children's Hospital -Homeless/Runaway Youth HIV/AIDS

AVANCE -Spanish Language Hotline

Minority Initiative $96,700
(Targeted Education/Prevention)
Asian, Latino and Black Community Outreach

Los Angeles City AIDS Coordinators Office funding for education, prevention and risk reduction totals $70,000; $17,500 of these dollars are targeted for South Central Los Angeles.

Incarcerated Populations (Juvenile Court Health Services)
Individuals who traditionally have been underserved are homeless, incarcerated and street youth.
Approximately 20-25,000 minors are in some form of custody in the Juvenile Halls and Camps in Los Angeles County annually. A majority of these youth are Hispanics and Blacks.

During 1990, approximately 1,754 minors received HIV antibody testing and pre/posttest counseling for HIV. Of the 1,754 tested, 2 were HIV +.

DHSJCHS provides HIV/AIDS education for these youth:

State AIDS Program - 1987
CDC HIV detection program - 1989
CDC/State AIDS Video Project - 1989

A survey of risk behaviors of these youth determined that:

97% are sexually active (16% use condoms frequently)

73.8% use drugs (6% use IV drugs)
56% "get drunk"

Since 1986, JCHS has had 21 cases of HIV + minors.

Of the 250 females tested, 21 were pregnant upon admission; 80 had a previous pregnancy; 30 had children and 94 had reported history of STDs.

Of the 1504 males tested, 120 had a partner who was pregnant, 372 had a partner with a previous pregnancy; 221 had children and 268 had a history of STDs.

Of the 1,754 surveyed, 51% were Hispanic; 35% were African American; 7% were White; 3% Multiethnic; 1.5% Asian; 1.5% Other; .22% Native American and .05% Undetermined.
Of the 1,754 minors tested, 31 females and 135 males reported zip codes in South Central Los Angeles as well as other areas of the city/county populated by ethnic majority populations.

EFFECTIVE STRATEGIES

The key issues we have had to address in developing effective and culturally relevant and sensitive programs include the following:

1) Developing culturally relevant programs; 2) gaining widespread community involvement and acceptance; 3) target group accessibility; 4) developing program legitimacy; and 5) having adequate resources. On another level, we still have to deal with a great deal of fear, denial, ignorance and apathy in our community. Early on, in our educational outreach efforts, women adolescents and young adults verbalized that they were immune to AIDS and HIV infection. They repeatedly stated, "It can't happen to me", I don't know anyone with AIDS", and "Only prostitutes and drug users have AIDS." Many of them believed that AIDS was only a "gay/bisexual White male disease." However, after repeatedly

exposing community residents to accurate information on AIDS and HIV infection, as well as focusing on the fact that it's not risk groups but one's behavior that places one at increased risk for HIV infection, many individuals overcame their initial denial, fear and apathy.

One cannot overlook the impact of poverty, illiteracy, lack of access to medical/social health care, and a general sense of hopeless, powerlessness and lowered self-esteem and self-worth that comes into play when considering people's knowledge levels concerning AIDS and HIV, as well as their attitudes, beliefs and values concerning maintenance of good health and mental and spiritual wellbeing in general. In addition, community norms, mores and values play a key role in what is commonly "acceptable" versus "non-acceptable" behavior. Thus, educating individuals and the community-at-large alone is not enough and will never be enough. There has to be a concerted effort to change the social norms, values and mores of a community if we are to have a lasting effect in reducing risk taking behaviors for AIDS and HIV, as well as reducing the incidence and prevalence of adolescent pregnancy, STD, IV drug use, alcohol and cocaine abuse, and a host of other health and socially related problems that have for generations plagued our communities.

STRATEGIES

It has only been within the last four years that there has been a national and local effort to educate ethnic minority communities about HIV and how to stop its spread. Los Angeles County as well as the rest of the nation is 5-8 years behind the gay community in developing and implementing effective and successful education and risk reduction campaigns. We need to learn from the gay community's success in reducing the incidence of HIV infection among gay/bisexual men. However, models developed in the gay community may not be replicable in minority communities. Until recently, the vast majority of educational programs being developed and implemented were not targeting ethnic minority communities nor were they culturally relevant or sensitive in their approach.

We have found, to insure greater efficacy, it is incumbent that HIV/AIDS educational/informational campaigns focus on community development. Effective programs are comprehensive and multidisciplinary in their approach and focus on prevention, are skills and values based, are peer mediated and work towards community empowerment.

We have been very successful in using the model of community development. In the area of program development, utilizing this model, the following steps should be taken:

1) formation of a broad-based community advisory council which will provide ongoing input concerning the planning, implementation and evaluation of the project.

2) developing models that include skills building, enhancement of social competency and development of problem-solving skills.

3) administration of a comprehensive community needs assessment survey of the target groups, as well as the local service providers, in order to identify unmet needs, bridge gaps in services and avoid duplication of services.

4) development of a process for evaluation that includes a formative, as well as summative evaluation of the program.

5) incorporation of HIV/AIDS education into existing family life education and/or sex education programs which are school or community-based.

6) working in concert and collaboration with public and private sector organizations such as schools, youth service agencies, probation departments, children's services, county health and social service departments, county drug abuse programs, colleges, civic and business organizations, the media, religious institutions, the gay/bisexual community and parent groups.

RECOMMENDATIONS

These recommendations are based upon the Women and HIV/AIDS Public Hearing held on February 28, 1991 at Exposition Park in Los Angeles, California. What held true ten months ago, still holds true today.

HIV/AIDS affected women, youth and young adults are in dire need of the following services and programs in Los Angeles County and in Metro South Health Area (South Central) in particular.

1. Comprehensive and multidisciplinary Early Intervention Programs (EIP) which provide culturally specific, gender sensitive and linguistically appropriate services including case management, mental health, social support, respite, child care and public benefits counseling and advocacy. These services are needed immediately.

2. Specialized Women's Clinics based on the West Hollywood model, need to be developed. These clinics would provide care rom initial diagnosis to full blown AIDS. Further development of the adolescent clinic in the Oasis program at Martin Luther King Jr. Hospital. This clinic provides medical services to HIV + youth and young adults.

3. A well coordinated and integrated residential and shelter program for HIV infected women and their children is needed immediately. The type of housing needed includes: emergency shelter, and long term residential programs. All of these programs should be geared to promote independent living for the women and their children. Child care and respite services need to be incorporated into all of these programs.

4. Women and youth with dual diagnoses, HIV infection and having mental health and/or addiction problems, have unique special needs. These women, youth and their children and families require specialized case management services to insure that they receive the full range of EIP, mental health, substance abuse and rehabilitative services.

5. Many women and adolescents at risk for HIV infection can be characterized as being of low income, low SES, low educational attainment, illiterate and single heads of households. These women and adolescents are generally in deep denial concerning their risk for HIV infection. A client advocate (ombudsman) needs to be integrated into the existing system of care. He/She would play a key role in advocating for the personal and legal rights of HIV infected and affected woman.

6. Existing HIV/AIDS resources throughout L.A. County are inadequate and do not fully address the health (mental, physical and spiritual) of HIV affected women, youth and their children and families. A standardized and comprehensive community needs assessment to identify unmet service and client needs must be developed and administered on an ongoing basis.

7. HIV positive women and youth recently released from an incarcerated setting and gay/bisexual women and youth need to receive targeted outreach in order to educate them about their risk for infection as well as the benefits of EIP programs.

8. Primary prevention programs need to be developed and expanded to reach pre-adolescent, adolescent and adult women in order to stop the spread of HIV infection among women of childbearing age and their sexual partners. According to the most recent data from the State Office of AIDS, in Los Angeles County, in a recent HIV seroprevelance study of women of childbearing age (14-44) 1 in 174 African American women of childbearing age in the study was found to be infected with HIV (N=5,403).

9. A comprehensive educational campaign targeting local African American churches, radio stations, social organizations, the business community and elected officials needs to be implemented and maintained to ensure that the public and private sectors are aware of the problem and can work

collaboratively to develop solutions to solving the problem of HIV infection in the African American community. The issue of HIV/AIDS and women/youth needs to be a priority and addressed in the form of public hearings and community forums on an ongoing basis.

10. Continued lobbying at the state and federal levels to mandate HIV/AIDS education in grades k-12 and for increased funding for primary prevention funding.

There are no simple solutions for combating the spread of HIV in multiethnic communities nationally or locally. Combating the spread of HIV will require complex multidisciplinary approaches and strategies, as well as greater collaboration between public and private sector organizations throughout the nation. AIDS and HIV have to be looked at in terms of the interconnecting links between one's biological, social and psychological environment. It can't be looked upon in isolation and in a vacuum. In lieu of the fact that presently, the majority of cases are concentrated among homosexual and bisexual men and IV drug users, AIDS and HIV infection are related to behavior, not risk groups, and we in the Black community currently have an entire community of men, women, children and adolescents at increased risk for infection.

DATE: November 9, 1991

LOCATION: UCLA Faculty Center

PRESENTER: Cynthia C. Davis, MPH, CHES
Program Director
NOBCO AIDS Education Projects
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"HIV/AIDS-Related Service Needs of HIV Affected and Infected Women in Los Angeles County.

In February of 1991, the first public hearing in Los Angeles County on Women and HIV/AIDS was held at Exposition Park under the sponsorship of the Los Angeles Commission on the Status of Women, former Los Angeles City Councilman Robert Farrell, and numerous community-based organizations which serve and advocate on behalf of HIV affected and infected women, children and adolescents who are the most medically underserved and under represented constituencies in Los Angeles County, the state and nation. A summary report of the public hearing was presented to the Los Angeles City Council in June of 1991 outlining the numerous gaps in services and the need for immediate resources for women. To date, nine months after the public hearing there has been no response from city government to address the crisis situation that HIV infected and affected women, children and adolescents have to deal with. There has been token response from local County government, vis-a-vis the nominal allocation of Ryan White Care Act funds to enhance and/or develop specialized services for women. As we begin to assess the need for comprehensive services for women, we must also look to the unmet needs of the preadolescent and adolescent females (aged 13-19) who are at just as great a risk for HIV infection, if not more, than their adult female counterparts. And lastly, we cannot overlook the infants and children that are apart of the lives of most women in this society, whether they be married or single, straight or gay, young or old, of childbearing age or post menopausal, drug free or drug addicted.

The purpose of this presentation is to focus on existing HIV/AIDS-related services being provided by community-based organizations throughout Los Angeles County. Los Angeles County is a very large county covering over square 4,000 miles and with a total population over 9 million. Currently, there are over 300 HIV/AIDS-related service providers in Los Angeles County. These providers make available a full spectrum of services ranging from primary prevention (education) services, testing, counseling, direct medical/clinical services, social support, mental health, extended care, residential, hospice, transportation, food, clothing, and legal.

Because one of the primary the purposes of this conference was to target HIV infected women, I'll be highlighting those few agencies having specialized services for women.

In looking at the "health" needs of HIV infected women, I feel it is imperative that we define their health in a wholist manner - with health being one's physical, mental and spiritual well being, not merely the absence of disease or infirmity. Thus, we must begin to look at addressing the overall health care needs of HIV infected women in a comprehensive fashion and it must encompass a full range of services.

At a minimum, HIV infected women's physical health service needs would include:

- direct medical/clinical care (inpatient and outpatient)
- ongoing education regarding risk reduction
- fulfilling necessities of life needs (i.e. food, clothing and shelter)
- residential care (long term and short term; in home or free standing)
- emergency shelter; drop-in center; crash houses, transitional housing, permanent housing
- hospice care (6 months or less to live); transportation
- drug treatment and rehabilitation

Mental Health service needs would encompass:

- direct medical/clinical services (counseling/treatment - individual and family)
- support care for: HIV symptomatic and HIV asymptomatic women and their affected families, and care givers; and counseling to couples, individuals and the community.
- comprehensive case management; vocational; legal; respite; buddy/support programs; volunteers; stress reduction; counseling referral; financial/benefits counseling; self-employment programs; and having cultural competent staff and multilingual staff

Spiritual Health service needs would include:

- bereavement counseling; spiritual counseling; education concerning alternative/wholist treatment modalities; burial counseling; grief resolution

Having a well coordinated and integrated system of care encompassing all of the aforementioned services will go a long way towards adequately addressing the needs of HIV infected women.

There are numerous agencies which provide a full range of services to all individuals impacted by HIV. No agency can legally discriminate solely on the basis of one's sexual preference or one's gender. Thus, for the HIV infected woman, there are numerous agencies throughout the County which could provide a wide range of

services as well as make appropriate referral for services.

Geographically these agencies are located as follows:

Westside	APLA	Pacific Ctr	Tuesday's Child
	AHF	Being Alive	Project Angle Food
	GLCSC	Act-up LA/Women's Caucus	
	LAPAN		
	JWCH Institute		
	Hollywood/Sunset Ctr. (Cara-a Cara)		
	Caring for Babies with AIDS		
Eastside	ADVANCE		
	Milagros AIDS Project		
	Altamed/Buenacare		
	El Project del Barro		
	Calif State University Los Angeles		
Downtown	HOP		
	Weingant Center		
	L.A. Bar Association-Hospice Project		
	Salvation Army		
	Chris Brownlie Hospice		
Northside/Valley	All Saints AIDS Service Center		
	Northeast Valley Health Center		
	Tarzana Treatment Center		
	Foothill AIDS Project		
Southside	MAP	Youth & Family Center	
	WARN Project		
	WHF		
	King/Drew Medical Center		
	THE Clinic		
	NOBCO/Drew I & E Projects		
	Drew Women's Outreach Project/LA Southwest College		
Southbay/Long Beach	Southbay Free Clinic		
	Long Beach Minority AIDS Project		
	Calif State University Long Beach		

Los Angeles County Comprehensive Health Centers.

Los Angeles County Hospitals
UCLA/Harbor
MLK
County/USC (5P21 and the outpatient clinic)/Maternal/Child
HIV Research Clinic

Private Hospitals
- Cedar's Sinai
- UCLA
- St. Francis Medical Center
- St. Mary's Medical Center

Euchemenical Agencies
- FAME Church
- St. Brigid's Catholic Church
- Unity Fellowship Church
- Unitarian Church

Gay/Lesbian Organizations
- Asian
- Hispanic
- Black

Clinical Trials
- USC/UCLA
- Search Alliance (Community-based trials)

Residential Facilities
- Rue's House
- St. Francis House
- Group One
- Dignity House

Hospices (6 months or less to live)
- Chris Bronlie (AHF)
- City of Angles
- West Hollywood (AHF)
- Our House (APLA)

Its only been within the last year that there has been a "popular" interest in the impact that the HIV epidemic is having among women. As a result of this interest and the rising number of women (adult and adolescent females) becoming infected, there has been greater lobbying to involve women in clinical trails as well as changing the CDC case definition to reflect manifestations commonly found among women, as well as, the demand for more specialized services for women.

The Women's Caucus of Act-Up (National chapters & LA Chapter) have been instrumented in advocating for more comprehensive and gender specific services for women. As a direct outcome of their advocacy role, women serving in the HIV/AIDS arena have mobilized to lobby and advocate on a local, statewide and national basis to insure that comprehensive HIV related services targeted for women are developed and/or enhanced. All of these advocates for women who are affected/infected by HIV are to be commended.

Currently, in Los Angeles County there are a few programs

which have or are developing gender specific programs for women. One joint project is being developed in collaboration with the Women's Caucus of the Los Angeles AIDS Regional Board and THE Clinic for Women.

A full time OB-GYN and a mid-level Nurse Practitioner are being identified to provide Level I & II treatment to symptomatic and asymptomatic women, using a community-based model. Two satellite clinics where the Staff will rotate to on a weekly basis have been identified (Polanco Clinic & Altamed/Buenacare). These women will receive a baseline assessment of their HIV status and be case managed to insure that they receive adequate follow-up care and treatment. Another program is the AHF's Palanco Clinic. This Clinic which provides EIP services and medical treatment to HIV positive individuals recently developed a specialized program to treat women. They have a case load of over 60 women that they have been treating and following for the pass several months. At County USC there is a program for women who deliver at USC and test positive to receive ongoing treatment and care by staff at the Maternal and Child HIV Research Project. These women and their families receive comprehensive care and support services.

Concerning the extended care needs of women, there are women's support groups being implemented at ACT-Up Women's Caucus, WARN Project, Gathering Place, APLA and the GLCSC. Plans are in the making to develop a women's support group at Minority AIDS Project and the new Oasis Project at Martin Luther King Hospital will be having a specialized clinic for women and a specialized clinic for transvestites.

Search Alliance which is involved in community-based clinical trials is currently recruiting women to participate in those trials.

Tarzana Treatment Center which is headquartered in the valley has two residential detox programs. One program is not specialized for women, but does take women clients. It is a 6-9 month residential drug detoxification program which is comprehensive in its scope (case management, education, therapy/support groups) and then a non-residential detoxification program provides the same services as well as nursing and home health care and case management. Tarzana's residential treatment center in Long Beach primarily targets women and their children. This program can take up to 85 women, not including their children. It is a long term residential program for drug addicted women. They will take pregnant women and their children up to 3 years of age. The program includes parenting classes, a cooperative nursery; AIDS education on site, HIV testing and counseling, a back to school program and vocational programs. The ultimate goal is to help the women to develop the skills to live independently in a supportive environment. The women are court referred, physician and self-referred. They don't have to have insurance to become enrolled;

they only have to pay a $100.00 admission fee. This program also has two transitional houses that their clients can graduate to and they have bilingual and bicultural staff.

Rue's House is the only residential AIDS Shelter program targeting only women located in the Black community.

These agencies are reflective of the need to develop and identify more resources for HIV affected and infected women.

The remainder of my presentation will focus on filling in the gaps in services.

Follow-up Recommendations:

These recommendations are based upon the Women and HIV/AIDS Public Hearing held on February 28, 1991 at Exposition Park in Los Angeles, California. What held true nine months ago, still holds true today.

HIV/AIDS affected women are in dire need of the following services and programs in Los Angeles County.

1. Comprehensive and multidisciplinary Early Intervention Programs (EIP) which provide culturally specific gender sensitive and linguistically appropriate services including case management, mental health, social support, respite, child care and public benefits counseling and advocacy. These services are needed immediately.

2. Specialized Women's Clinics based on the West Hollywood model, need to be developed. These clinics would provide care from initial diagnosis to full blown AIDS.

3. A well coordinated and integrated residential and shelter program for HIV infected women and their children is needed immediately. The type of housing needed includes: emergency shelter, and long term residential programs. All of these programs should be geared to promote independent living for the women and their children. Child care and respite services need to be incorporated into all of these programs.

4. Women with dual diagnoses, HIV infection and having mental health and/or addiction problems, have unique special needs. These women and their children and families require specialized case management services to insure that they receive the full range of EIP, mental health, substance abuse and rehabilitative services.

5. Many women and adolescents at risk for HIV infection can be characterized as being of low income, low SES, low educational attainment, illiterate and single heads of households. These women and adolescents are generally in deep denial concerning

their risk for HIV infection. A client advocate (ombudsman) needs to be integrated into the existing system of care. He/She would play a key role in advocating for the personal and legal rights of the HIV infected and affected woman.

6. Existing HIV/AIDS resources throughout L.A. County are inadequate and do not fully address the health (mental, physical and spiritual) of HIV affected women and their children and families. A standardized and comprehensive community needs assessment to identify unmet service and client needs must be developed and administered on an ongoing basis.

7. HIV positive women recently released from an incarcerated setting and gay/bisexual women need to receive targeted outreach in order to educate them about their risk for infection as well as the benefits of EIP programs.

8. Primary prevention programs need to be developed and expanded to reach pre-adolescent, adolescent and adult women in order to stop the spread of HIV infection among women of childbearing age and their sexual partners. According to the most recent data from the State Office of AIDS, in Los Angeles County, 1 in 300 African-American women of childbearing age (14- 44) is projected to be infected with HIV.

9. A comprehensive educational campaign targeting local African American churches, radio stations, social organizations, the business community and elected officials needs to be implemented and maintained to ensure that the public and private sectors are aware of the problem and can work collaboratively to develop solutions to solving the problem of HIV infection in the African American community. The issue of HIV/AIDS and Women needs to a priority and in the form of public hearings and community forums on an ongoing basis.

AIDS Regional Board Title II Public Hearings
Hubert Humphrey Comprehensive Health Center
August 21, 1991 1-3 p.m.

PUBLIC TESTIMONY

My name is Cynthia Davis and I work for the Charles R. Drew University of Medicine and Science. I have been extensively involved in HIV/AIDS-related education and prevention programs targeting the Black community on a local level since 1984 and on a national level since 1987. I currently chair the Minority AIDS Consortium which was established in February of 1989 to address the HIV/AIDS-related needs of medically underserved communities throughout Los Angeles County and in the South Health Area (South Central Los Angeles) in particular.

The South Health Area of Los Angeles County continues to lag behind other Health Areas of the County in terms of health, support and extended care services for individuals with HIV disease and their families and significant others. Several months ago the membership of the Consortium identified several priority target populations for program development and/or enhancement. These target populations were identified as women, adolescents and children, gay men of color, the homeless and undocumented.

The consensus of the Consortium was to develop programs that would complement and/or augment the existing programs being operated by the AIDS Clinic at Martin Luther King Hospital. The Consortium plans to work in collaboration with Martin Luther King Hospital to ensure that an infrastructure of needed outpatient and support services for HIV positive individuals and their families is developed in the South Health Area. The Consortium sees these services as being comprehensive in their scope. These services include:

-Early Intervention Programs
-Mental Health Services and Services for the Dual Diagnosed
-Residential Care Programs (Emergency and Long Term)
-Case Management and Referral Services
-Support/Advocacy Services
-Transportation Services

Level I, II and III services are provided by the EIP and AIDS Clinic at Martin Luther King Hospital. There is a need to provide EIP services at local CBO's which have a track record for providing services to HIV infected individuals. Currently, Minority AIDS Project is the only local CBO in the region providing a full complement of EIP and CAse Management services to HIV infected individuals in the area. People who test positive for HIV need services such as: benefits counseling, legal aid, support services, case management, mental health (drug counseling, respite care, residential care (emergency and long term), transportation, clothing and food banks and rental assistance.

Title II funding will allow several local CBO's within the region to expand and enhance their existing HIV/AIDS related services. For example:

-THE Clinic for women which currently operates a CTS is proposing to expand its services to include early intervention services targeting women of color aged 14-44.

-The Gathering Place which currently provides support and respite care is proposing to become an ATS as well as to expand its benefits counseling and outreach and promotion of EIPs.

-The WARN Project is proposing to provide transportation to the HIV infected women they work with.

-The Minority AIDS Project is proposing to develop a residential program for dual diagnosed individuals.

-The Watts Health Foundation is proposing to augment its case management services with an EIP.

-The Drew University I&E Project is proposing to provide food baskets to HIV infected individuals during the holidays (i.e. Thanksgiving, Christmas and Easter).

All of the aforementioned services are needed and currently are not being provided by CBOs in South Central Los Angeles. There will be no duplication or over lap of services because all of the providers are geographically dispersed throughout the region and enhancing service in one region will create greater accessibility to services throughout the entire region.

Long range program plans of some of the providers of the thirty-seven member Consortium include:

-development of a mobile unit targeting adolescents for outreach and promotion of EIP services.

-increase in the number of residential housing sites for HIV infected women and their children.

-targeted case management at geographically dispersed sites (i.e. Watts Health Foundation, Minority AIDS Project, T.H.E. Clinic, Gathering Place) throughout the region.

-development of additional ATS in the region.
-development of a regional transportation network to serve HIV+ individuals and their families

Allocation of Title II funds to local CBOs in the South Health Area of Los Angeles County will go a long way toward ameliorating not only the serious gaps in HIV/AIDS outpatient and support services for the targeted populations, but for the community-at-large.

I have attached copies of additional public testimony presented to the Ryan White Care Council (Title I) as well as other relevant documentation concerning the need for HIV/AIDS-related services in the Metro South Health District of Los Angeles County.

Thank you.

Senate Health and Human Services Committee

Diane E. Watson

Chairperson

Statewide Interim Hearing

December 17, 1991

"HIV/AIDS in Ethnic Minority Communities"

Presented by: Suzi Rodriguez
Director, Drug Abuse Programming
AltaMed Health Services Corporation

First and foremost, I would like to thank the Committee for inviting me here to present before you today. On behalf of AltaMed Health Services Corporation, we welcome the opportunity to share what we have learned, thus far, in our attempt to provide HIV/AIDS services to the predominantly Latino population of East Los Angeles.

Background:

AltaMed Health Services Corporation began providing primary health care services in the East Los Angeles Community over twenty years ago. We were originally known as the "East Los Angeles Barrio Free Clinic". We are a community based, multi-service organization with diverse programming. Currently, we operate Four Primary Health Care sites, a Teen Pregnancy Program (which provides case

management to over 150 pregnant and/or parenting teens), an Adult Day Health Care Center (which evolved from a National Model we developed that targets specifically Latino Elderly), a Methadone Maintenance and Detoxification program, and a community-based HIV Early Intervention program that includes pre and post test counseling, HIV Testing, T-Cell Testing, Case Management, and access to appropriate therapies for HIV+ clients.

Our funding sources, for our Drug Treatment and HIV/AIDS Services come from the Los Angeles County Drug Abuse Program Office, the Federal Office for Treatment Improvement, the Federal Bureau of Health Care Delivery and Assistance, and the Federal Ryan White CARE Act.

The focus of AltaMed has, historically, been on providing access to quality health care to Latino populations who have systematically been disenfranchised from access to these types of services. When publicity regarding the AIDS epidemic and its impact on the Latino populations of New York hit the local press back in the early 80s, AltaMed decided we had an obligation to take a proactive position in regards to this disease within our own community.

Because the initial reports linked HIV positivity with IV Drug Use within the Latino population, we agreed to accept a sole source contract with the County of Los Angeles to provide methadone maintenance and detoxification services to injecting drug users in the East Los Angeles Community. Although we do not see methadone as the panacea to all drug abuse problems, we did see its

connection to the HIV epidemic and believed that it would provide us with an avenue by which to reach and educate this very at-risk population (the community of East Los Angeles has more injecting drug users than anywhere else in the County...conservative estimates place the number at well over 10,000).

Our initial efforts were met with resistance on the part of the Community. We fell victims to the "NIMBY (Not In My BackYard) Syndrome" and were forced to abandon two different identified sites before, with the help and support of Councilman Edmund Edelman, we were finally able to open our program on the grounds of the County USC Medical Center. The availability of additional resources, through the aforementioned Federal entities, allowed us to pursue the development of HIV specific programming.

Although fairly new to this arena on the direct service delivery side, we have learned some lessons we feel may be of value to others who have a desire to provide like-services.

<u>What we have learned:</u>

Although we have operated our program for a short time, we can discern some pattern in our population:

* Most of our patients are of Mexican origin.
* Most are undocumented.
* They have a relatively low level of formal education/schooling.
* They are alone in the United States.
* All were infected by sharing needles or by having sex with

an infected man.

* There is a definite gap in culturally appropriate services for gay and bisexual Latinos, especially those with drug problems/treatment needs.
* Clinic staff must be culturally appropriate to the population they are serving.

Recommendations:

Given our experience, we feel the following steps should be taken:

* Linkages must be made with historically Gay HIV/AIDS programs in order to provide appropriate staffing, training, and service provision for Gay and bisexual clients.
* There must be continuous and on-going education for/to the Community.
* The Church must be accessed.
* Intensive training in pre and post test counseling should be required for all case managers.
* Clinic personnel should be reflective of the population they are serving.
* HIV testing should be encouraged to all program participants.
* A system of comprehensive care should be instituted that includes:
  - Pre-test Counseling
  - HIV Testing

- Post test counseling when delivering any results. If positive, there should be an expeditious way to admit patient into a medically managed program where one case manager will follow the patient during the course of the disease.

* Increased outreach must be done to the injecting drug using population (we believe the sero-positivity rates remain low for this population only because the data being gathered is reflective only of those IDUs who are accessing treatment. Additionally, consideration should be given to the legalization of needle-exchange programs tied directly to increased treatment availability).
* Staffing should include a financial analyst to assist patients with accessing appropriate programs (MediCal, MediCare, etc.)

Homeless Outreach Program

901 East Sixth Street
Los Angeles, California 90021

HOP/SSG
MIKE NEELY
DIRECTOR

Tel: (213) 683-8304
Fax: (213) 683-0753

SENATE COMMITTEE

on Health and Human Services

TESTIMONY:

"AIDS AND THE HOMELESS COMMUNITY"

PRESENTED BY:

MIKE NEELY

DIRECTOR, HOMELESS OUTREACH PROGRAM

DECEMBER 17, 1991

Good afternoon Senator Watson, Ladies and Gentlemen, I am very pleased to be able to present testimony on the subject of AIDS and the impacts on the homeless community.

I am sure that your have heard much testimony on the HIV Virus and the AIDS epidemic therefore I would like to focus my testimony on the unique problem of AIDS and the homeless community. By definition a homeless individual has no resources except public resources., however the majority of the public health resources have gone to communities which are not poor, are not undereducated or are not underrepresented. We must reverse the trend because society will pay a much greaater price in the long run.

In Los Angeles county the Central Health District (which contains the highest concentration of homeless people in the county) has the second highest rate of infection in the entire county, however we do not receive monies proportionate to the severit of our problem. We also do not receive any consideration for the complexity of the problem. You have probably heard how AIDS is considered a chronic disorder that is not true in the homeless community. We have found tht homeless people generally have 18-24 months life expectancy from diagnosis to demise. The present county system is overloaded with individuals who would not normally be in that system and

leaves no room for homeless people who have no other health system.

A person infected by the HIV virus who is homeless is practically without care in the state of California. The current care system is not designed to deal with the multiplicity of problems a homeless person presents. The current system is designed to either take care of the persons medical problem or to deal with the persons survival needs generally not both. In a system of this nature conflicts arise and the person who suffers is the one we say we are helping an example is a person goes to the clinic and receives medication, he/she then returns to a shelter the shelter takes the medication and gives it to the personas their schedule or time permits. The person has night sweats and cannot sleep the next morning the person is tired however shelter rules say everyone must be out of bed by seven O'clock therefore that person must get up. the person takes his/her medication but experiences side effects there is nothing for that person. The person makes a decision not to take his/her medication because it makes life too difficult. I have tried to portray this scenario as realistically as possible and not to portray any party as wrong because no one is wrong we merely have a system not able to deal with the problem.

We no longer have the luxury of hoping that AIDS will

somehow go away, we must recognize the clear and present danger among us. We must also expand our vision of the problem for the minority community. We must also recognize that the majority of the homeless community are minority. I realize tht this is difficult to believe, because in most cases when you see someone advocating on behalf of the homeless they are mostly white and mostly middle class, believe me that although they may speak for the homeless they do not represent the homeless community, because unless you share a common bond with your constituency it is difficult to represent them. We need special consideraion because more than any group you may have heard from today we have the least and have the most to have to overcome. We do not have the money to lobby you, we do not have the political sophistication to defeat candidates, We do not have the ability to impact the planning process, however we do have the ability ot impact negatively on our entire society. We want to make contributions but we do not have the opportunity. We want some help in changing our destinies that is what we are denied. Our needs are very simple, we need the type of assistance that other communities currently receive but we need them designed for homeless people specifically. We need specialized treatment programs, we need peer-based counseling, we need specialized housing , we need a strong political advocate to make changes in public benefits on federal , state and county levels to force the bureaucrats

to declare an individual who is homeless and HIV positive as an emergency case and afford them certain considerations.

Finally, I am personally a strong advocate of categorical funding to solve problesm that are unique or so longstanding that special efforts are needed to protect the common good. Homeless persons with AIDS are a problem which has serious impacts on all of us.

In order to understand the need for categorical funding we need to analyze L.A. county's allocation of C.A.R.E. ACT formula and supplement grants. The county received $7.8 million in total allocation for year one. (See attachment one) Total monies allocated for homeless persons is $127,238, this represents less than 2% of the county funds, and of that amount 2/3 of the money goes into cross-training of staff. (See Attachment II)

Further, no monies were allocated for early intervientionOutpatient care. (see Attachment III) The only clinics which provide early intervention/outpatient care are not located where there are concentrations of homeless persons.

Ladies and gentlemen this is the reason why a homeless person is 100 times more likely to contract HIV than a

homed person. The rate of infection in the homeless community is about 1 in 5. This is an emergency of the greatest magnitude. I have spotlighted Los Angeles county but in my travels around the state I have found similar situations in other large urban counties.

I appreciate your time and will be happy to answer any questions.

Thank You.

COUNTY OF LOS ANGELES - AIDS PROGRAMS

ESTIMATE OF UNSPENT CARE ACT FUNDS - PROJECT BUDGET YEAR ONE

Service	Provider	Allocation	Projected Savings
FORMULA GRANT			
Outpatient/South Central	King/Drew	765,000	114,750
Outpatient/San Gabriel	Pasadena AIDS Coord.	239,000	35,850
Outpatient/San Fernando V.	Northeast Valley	189,000	28,350
	Olive View	50,000	0
Outpatient/Long Beach	Long Beach Comp. Ctr.	382,000	57,300
CBO CARE to Relieve 5P21	AIDS Healthcare Foun.	287,000	0
	Alta-Med	287,000	43,050
Case Management	Various CBOs	382,000	57,300
Mental Health	Various CBOs	191,000	28,650
Dental Care	APLA	96,000	0
Residential/Emerg. Relief	Various CBOs	239,000	0
Cross-Training	Various CBOs	191,000	28,650
Transportation	Various	143,000	21,450
Outreach/Promotion	Various CBOs	191,000	28,650
Regional Consortia	AIDS Regional Board	96,000	0
Administration	AIDS Programs	196,157	0
TOTAL FORMULA GRANT		3,924,157	444,000
SUPPLEMENTAL GRANT			
Outpatient/South Central	King/Drew	75,000	11,250
Outpatient/West	AIDS Healthcare Foun.	219,000	0
	Gay & Lesbian CSC	75,000	0
	UCLA	50,000	0
Outpatient/Long B, So.Bay	Harbor/UCLA	175,000	0
Outpatient/San Fernando V.	Northeast Valley	150,000	22,500
Outpatient/East L.A.	AltaMed	215,000	32,250
Outpatient/Central	Hudson Comp. Ctr.	315,000	47,250
Special Pop.			
Outpatient	Various CBOs	415,949	62,392
Support Svcs.	Various CBOs	86,000	12,900
Promotion of Svcs.	Various CBOs	75,000	11,250
Mental Health	Various CBOs	75,000	11,250
Mental Health	Various CBOs	375,000	56,250
Outreach for Testing	Various CBOs	75,000	11,250
Case Management	Various CBOs	337,500	50,625
Residential	Various CBOs	375,000	0
Recruitment/Retention	Various	86,000	12,900
Transportation	Various	37,500	5,625
Residential Detox	Tarzana Treat. Ctr.	258,000	0
Outpatient Detox.	BAART	129,000	0
HIV Primary Care/Subst.	El Proyecto del Barr.	129,000	19,350
Administration	AIDS Programs	196,208	0
TOTAL SUPPLEMENTAL GRANT		3,924,157	367,042
TOTAL BOTH GRANTS		[illegible]	811,042

unspfund.wk1/rev. 5/91

ALLOCATION OF CARE ACT FUNDS BY MODE OF SERVICE & TARGET POPULATION

	Adolescents/young adults	Hearing Impaired	Gay Men of Color	Pediatrics	People of Color	Substance Abusers	Homeless	Women
Prevention and Education								
Counseling/Testing								
Outreach for Testing/Promotion of Services Total = $341,000	L.A. Free Clinic $40,000 (S) CA Drug Consultants $42,000 (S)		Gay Men of Color Consortium $181,462 (F)		City of Long Beach $35,000 (F)		JWCH, Inc. $42,538 (S)	
Residential Detoxification Services Total = $258,000						Tarzana Treatment Center $258,000 (S)		
Outpatient Detoxification Services Total = $129,000						BAART $129,000 (S)		
Early Intervention/ Outpatient Care Total = $4,018,000	Childrens Hospital $212,000 (S)			L.A. Pediatric AIDS Network $66,000 (S)		El Proyecto del Barrio $129,000 (S)		HIV Program for Women $138,000 (S)
Dental Care	$96,000 allocated to all populations							
Recruitment/ Retention	$86,000 allocated to all populations							
Cross-training of Staff Total = $191,000			Gay Men of Color Consortium $106,300 (F)				L.A. Homeless Healthcare Project $84,700 (F)	
Transportation Services	$138,500 allocated to all populations.							
Case Management	$719,500 allocated to all populations.							
Mental Health/ Psychosocial Support Total = $641,000			Minority AIDS Project $111,000 (S) East Valley Comm. Hlth. Ctr. $75,000 (F) Hollywood Sunset Comm. Clinic $66,000 (F)		GLCSC $66,500 Pacific Cntr. for Counseling $55,000 (F/S) APLA $46,500 (S)	Tarzana Treatment Center $108,000 (S)		APLA $46,500 (S) GLCSC $66,500 (S)

ATTACHMENT III

	Adolescents/young adults	Hearing Impaired	Gay Men of Color	Pediatrics	People of Color	Substance Abusers	Homeless	Women
Support Services Total = $86,000		AIDS Education for the Deaf $25,000 (S)	Gay Men of Color Consortium $36,000 (S)		Asian Pacific AIDS Education Project $25,000 (S)			
Residential Care (CLHF & RAS)	$613,969 allocated to all populations.							
TOTAL:	$294,000	$25,000	$575,762	$66,000	$228,000	$624,000	$127,238	$251,000

* NOTE: CARE Act funds cannot be utilized for prevention and testing services. The agencies placed within this table include only those programs specifically charged with serving a particular target population(s) and does not include programs that serve all communities. This table addresses only the special populations as defined by the CARE Act Planning Council. This does not exclude the fact that all other programs not listed are responsible for serving all populations.

8UP

DEC 11 1991

COMPREHENSIVE AIDS RESOURCES EMERGENCY (CARE) ACT
HIV HEALTH SERVICES PLANNING COUNCIL

600 S. Commonwealth Ave., 6th Floor, Los Angeles, CA 90005

December 9, 1991

TO: CARE Act Interim HIV Health Services Planning Council Members

FROM: Suzi Rodriguez, Co-Chair
Phill Wilson, Co-Chair

SUBJECT: **MEETING DATE**

DATE:	Thursday, December 19, 1991 1:00 p.m. - 4:00 p.m.
LOCATION:	American Red Cross **Fredrick G. Larkin Board Room** **Mezzanine 2** **2700 Wilshire Blvd.** **Los Angeles**

The building is located at the corner of Wilshire Blvd. and Rampart Blvd.

Parking is limited. If the Red Cross lot is full, park on the street or at the Sheraton Town House Automate lot at 6th and Commonwealth.

If you have any questions or need additional information, please contact Cherie Orilonise at (213) 351-8130.

COMPREHENSIVE AIDS RESOURCES EMERGENCY (CARE) ACT
HIV HEALTH SERVICES PLANNING COUNCIL

600 S. Commonwealth Ave., 6th Floor, Los Angeles, CA 90005

AGENDA
December 19, 1991
1:00 p.m. - 4:00 p.m.
American Red Cross
Fredrick G. Larkin Board Room
Mezzanine 2
2700 Wilshire Blvd.

I.	Review of Handouts and Pre-meeting (15 min.)	Council
II.	Opening and Roll Call (5 min.)	Suzi Rodriguez Phill Wilson
III.	*Approval of Agenda & Minutes (5 min.)	Council
IV.	*Priorities for Unspent County Funds (60 min.)	Council
V.	*Report on Council Priorities (45 min.)	Suzi Rodriguez Phill Wilson
VI.	Adjournment	Suzi Rodriguez Phill Wilson

* Handout

NEXT MEETING: January 8, 1992
Orthopaedic Hospital
1:00 - 4:00 p.m.
Crowe Seminar Room

DEC19.AGN

PRIORITIES FOR UNSPENT CARE ACT TITLE I FUNDS
Total = $1,000,000

NOTE: This document reflects changes agreed upon at the November 13, 1991 meeting of the CARE Act Planning Council.

If actual unspent funds total less than $500,000, then APO will perform budget modifications, budget augmentations, and contract extensions.

If actual unspent funds exceed $1 million, 50% of the amount over $1 million will go to priorities which received zero funding on this sheet (#5-10). The remaining 50% over $1 million will be divided proportionally among priorities on this list which have been allocated unspent funds (#1-4). If unspent funds exceed $2 million, the Council will meet again to allocate those funds over $2 million.

1) Level III HIV Outpatient Care / Specialty Consults **$300,000**

- Level III care is required by HIV infected patients who have reached a level less than 200 CD4+ cells or who have developed HIV related symptoms, and who may receive medical and/or psychological services in non hospital based outpatient clinics.

2) AIDS Drugs **$300,000**

- Currently, the State has allocated $12 million state-wide this year for AIDS drugs. APO is billing the State at a rate of 300,000 per month. With the CARE Act, additional centers will be billing to the State AIDS drug program through the County. Also, more drugs have been added to the program.

NOTE: Due to the increase in State dollars for AIDS drugs, should this category remain #2 on this list?

3) Residential Detox Slots **$300,000**

- L.A. County has an estimated 190,000 IDUs and 35 residential detox slots. With an estimated seroprevalence rate of as much as 10%, 19,000 HIV+ IDUs need drug treatment. The Council allocated $258,000 to Tarzana Treatment, which only pays for 3.5 beds or 90-100 persons per year (10-day average stay). 50% of this money will go to Residential Detox, with the other 50% going to rehabilitation facilities.

4) Primary HIV Care for Undocumented **$100,000**

- Of the originally prioritized populations, the undocumented is the only group not directly receiving funds. Providers can no longer rely on the IRCA/SLIAG funding.

5) Primary HIV Care to Special Populations $ 0

- Special populations include women, pediatrics, and adolescents.

6) Counseling/Testing in County STD and TB Clinics $ 0

- The need to make testing available to all persons entering County STD and TB clinics has long been a priority. Individuals being treated at STD clinics have already placed themselves at high risk. Experience in TB clinics shows that a high proportion are HIV-infected. Currently, resources do not allow this service to be universally available.

7) Outreach/Promotion of Services to Gay Men of Color $ 0

- The HIV Strategic Plan names this group as a priority for outreach services. Gay men of color are not always reached in effective or culturally specific ways. More than three-quarters of AIDS cases among men of color are transmitted through gay/bisexual contact.

8) Residential Care $ 0

- The Planning Council passed a motion on May 15 to consider residential care a priority for unexpended funds.

9) Adult Day Health Care -- City of West Hollywood $ 0

- The City of West Hollywood requested funds from the Planning Council for an adult day health care program for persons with AIDS. It is scheduled to open January of 1992 at the L.A. Free Clinic.

10) Case Management $ 0

- If unspent funds are available, the Case Management Consortium will meet and recommend allocations.

snprior.uns
November 19, 1991

LOS ANGELES COUNTY CARE ACT PLANNING COUNCIL
PRIORITIES

Priorities for Planning Council Funding Decisions

- Programs and services must focus on underserved and indigent populations with little access to health care.
- Program and service staff must be linguistically competent and culturally sensitive to ethnic populations, gay and bisexual communities, and other special populations.
- Consortia are encouraged and given priority in funding allocation decisions.
- Programs and services must be provided by indigenous community-based organizations whenever possible prior to the County providing such programs and services.
- Programs, services, and agencies with existing infrastructure(s) must be given preference.

Priorities for the Contractors in the Provision of Care

- Programs must have advisory committees comprised of clients, providers, and persons with HIV.
- Providers and programs must have internal HIV workplace policies for staff and volunteers.
- For those contractors providing training on human sexuality, the training will attempt to present human sexuality as a normal, positive aspect of the human experience.
- Contractors must rely on paid professional staff for program administration, direction and guidance, and services; trained volunteers may be used to supplement services provided by paid staff.
- Programs and services must meet the community standard of care provided to HIV-infected individuals.

Priorities for the Planning Council and the Contractors

- Programmatic, service, and staffing information on the needs of women and how they will be met must be detailed in each program and service recommended, unless women are not an appropriate target group for the contractor or if women are not included in the specific target population(s) under the Agreement.

- Programs and services must have specific linkages to other service sectors, i.e., homeless and substance abuse services, with cross-training of staff.

- Contractors must coordinate services with other service providers of the same service(s) and other providers of any AIDS/HIV services located in the same geographic region, and must participate in regional consortia.

care\snprior.lst
10-29-91

DRAFT DRAFT

PRIORITIES FOR UNSPENT NET COUNTY COST FUNDS
Total = $2,000,000

NOTE: Based on approved decisions at the December 4, 1991 meeting, dollars were allocated to 1 and 3 which totaled $750,000. Decisions are pending for 2 and 4 through 10. The total available is $1,250,000.

Previous Formula: If actual unspent funds exceed $1 million, 50% of the amount over $1 million will go to priorities which previously received zero funding (#5-10). The remaining 50% over $1 million will be divided proportionally among priorities on this list which have been allocated unspent funds (#1-4).

$450,000 1) Level III HIV Outpatient Care/Specialty Consults

2) Primary HIV Care for Homeless/Skid Row Area

$300,000 3) Residential Detox and Residential Rehabilitation Slots (funds split 50-50 between these slots)

4) Primary HIV Care for Undocumented Persons

5) Primary HIV Care for Special Populations (women, pediatrics, adolescents)

6) Counseling/Testing in County STD and TB Clinics

7) Outreach/Promotion of Services to Gay Men of Color

8) Residential Care

9) Adult Day Health Care (City of West Hollywood/L.A. Free Clinic)

10) Case Management

snunspen.ncc
12-9-91

NATIONAL ORGANIZATION OF BLACK COUNTY OFFICIALS INC

NOBCO

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Science

February 16, 1990

This project is part of a national grant from CDC. Its purpose is to increase the availability of HIV/AIDS education and information to Black and minority youth in urban and rural communities. It is a national project, and it will be managed out of our office in Washington, D.C. Project technical focus will be provided at the Charles R. Drew University of Medicine and Science located at the King/Drew Medical Center in Los Angeles County, Los Angeles California.

NOBCO PROJECT OPERATIONS GROUP

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NATIONAL AIDS TASK FORCE

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Commissioner Mary McAllister - Cumberland County, NC
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Paul Simms, Deputy Director Physical Health Services, San Diego County, CA
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Commissioner El Franco Lee - Harris County, Texas
Commissioner Virgil Brown - Cuyahoga County, Ohio

NATIONAL LIAISON TEAM*

National Medical Association (NMA)
National Conference of Black Mayors (NCBM)
National Forum for Black Public Administrators (NFBPA)
National Black Caucus of State Legislators (NBCSL)
National Black Caucus of Local Elected Officials (NBC-LEO)

*Partial Listing

Corinne Tanon, M.S.H., C.A., Health Educator

The American Indian Clinic, Inc.

9500 Artesia Blvd., Bellflower, CA 90706

P.O. Box 4068 • 330 South Long Beach Blvd. • Compton, CA 90221

Phone (213) 537-0183 920-7227

A. Agency Background

1. Briefly describe the scope of services your agency provides.

The American Indian Clinic is located in Compton, California, in a building that once was a motel. The American Indian Clinic, Inc. was founded in 1969 to serve the health and social needs of American Indians in the Los Angeles area. It has provided continuous care to the community for over twenty years and is the oldest American Indian, service agency in the Los Angeles area. The clinic department are medical, dental, WIC, family planning, pre-natal, outreach, health education, two alcohol recovery programs and a food box program.

B. Community Demographics

According to 1980 census, California has the largest Indian population. There are approximately 225,000 American Indians from 200 different tribal affiliations. In Los Angeles County alone there are over 90,000 Urban American Indians. And is the largest Urban Indian community in the nation. The American Indian community is well dispersed and 54,000 of the American Indians live below poverty level. Metropolitan Los Angeles Indian unemployment is 45%.

The Indian population is a young population. Nationwide the average age is 20.4. The average age of Indians in Los Angeels is 17.3. Sixty-seven percent of the Indian population are 25 years old or younger. Indians are 3 times more likely to die young (between ages 24 and 40) than non Indians. Average life expectancy for Indians is 44 (this is lower than the average life expectancy for migrant farm workers).

According to the Los Angeles Unified School District, Indian High School drop out rate is 23%. This figure increases when you include those that never enrolled in high school. Average age of Indians living in Los Angeles is 17.3 vs 20.4 for Indians nationwide. Sixty seven percent of Urban Indian adolescents drink or use drugs moderately to heavy; whereas the non-Indian urban adolescent rate is 23%.

Health Issues

Indian suicide rate is 7 times that of the national rate. Indians have the highest rate of heart disease and diabetes. 20-25 percent of all American Indian children suffer from mental illness. Adjusted alcoholism mortality rate for Indians is 41.3 deaths/100,000 vs 17.4 deaths/100,000 for Afro Americans and 6.4 deaths/100,000 for Whites or 2.3 times that of Black population and 6.5 times that of White population.

Gaps in Health Care

Health care is expensive to nearly all segments of the community but especially to many Indian people. They may not be able to afford health care due to lack of insurance or other needs that are more pressing. They will go to a health care facility only when the need is acute. Therefore, they might hear the message about AIDS, Diabetes, Hypertension prevention at a health facility. There is a pressing need for outreach at those places where they may congregate; community functions, pow wows, sports events.

With the high rates of sexually transmitted diseases and alcohol and IV drug use among American Indians, hopefully, ~~Indian Health Service~~ State of Calif may understand the importance of ~~a continue~~d funding as a preventative measure.

We are the only peoples who have a treaty, or trust relationship with the United States Government. That is, we have a contractual agreement whereby the Government is to provide free and "Adequate" health care as ratified by the Snyder Act of 1921 to Indian people regardless of location-this is not being done!

Since the Indian Health Service (IHS) cannot be counted on to provide adequate health services we must continually seek out other funding sources.

The source of continued funding is always contingent upon the outcome of census, demographics, and socioeconomic and political strategies.

Because we are a small population of 90,000 American Indians in Los Angeles County, we are sometimes mistaken for hispanics, filipino, white, and Afro American. The community is well dispersed and this may contribute to the political underrepresentation and social misrepresentation in the communities. We are poorly represented in every segment of society. I can only speak for myself-we have no political clout, and our voices aren't being heard. This theme is reflected in the decision making of our city fathers and government.

Source: Kathy Grandstaff, American Indian Counseling Center

The original American Indian Free Clinic Established 1969

The American Indian Clinic, Inc.

P.O. Box 4068 • 1330 South Long Beach Blvd. • Compton, Calif. 90221
Phone: (213) 537-0103

According to the HIV-AIDS and American Indians handbook for Tribal Leaders stated the following:

"Since September, 1991 the Center for Disease Control has approximated 305 American Indians diagnosed with AIDS. Dr. Emmett Chase AIDS coordinator for Indian Health Service estimates that there are 12 to 13 new Indian AIDS cases identified each month. The fact is the annual rate of increase of new AIDS diagnosis is greater for Indian people than for any other racial group. The number of Indians diagnosed with AIDS grew by 91% from 1989 to 1990. While other racial groups have a higher number of individuals with AIDS, the number of Indians with AIDS is rising at a rate proportionately faster than for other groups.

PERCENTAGE INCREASE IN AIDS CASES FROM 1989-1990

Whites	**8%**
African Americans	**13%**
Hispanics	**5%**
Asian/Pacific Islander	**17%**
Indian/Alaska Native	**91%**

The time of **PREVENTION IS NOW.** Indian people can benefit from the experiences of other populations which have dealt with the AIDS virus for the past eight years. We must **ACT** now, before the virus wipes us out like the **smallpox epidemic** disease of the early 1800's.

According to the study for the Centers for Disease Control found that Indians and Alaskan Natives experienced higher rate of gonorrhea and syphilis than did non-Indians from 1984 to 1988 in 13 selected states with large Indian populations. **This study indicates that we are at risk.**
The transmission categories for these cases are **54% homosexual/bisexual transmission, and the rest by blood or blood product transmission.** This contrasts with White Transmission which is 76% homosexual/bisexual and **15%** shared needle and 2% heterosexual..The percentage of Alaska Native and American Indian women with AIDS is 13% of the total number of American Indian and Alaska Native cases, in contrast to 4% of White women. According to CDC has been working with IHS to evaluate the HIV in the American Indian population. It is estimated that for every 1 million American Indians and Alaskan Natives approximately 1,000 individuals are currently HIV infected. Then it could be estimated that over 85% of these individuals do not know they are HIV infected.