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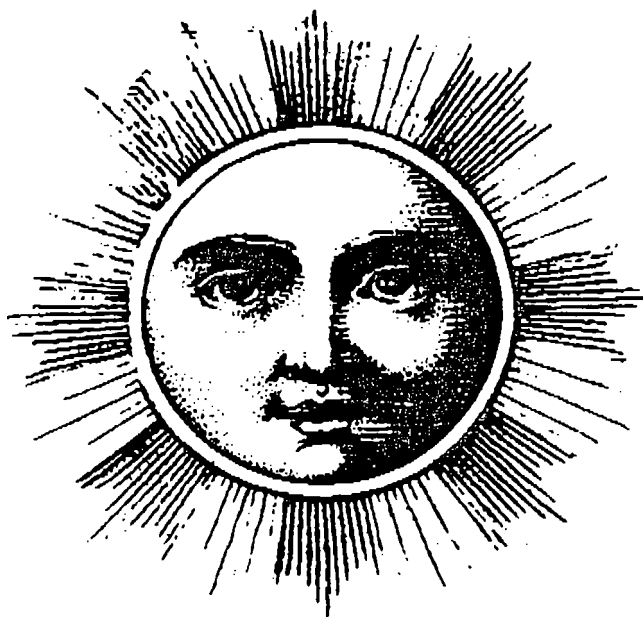
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Second Annual HIV/AIDS Forum

Kansas City Marriott Downtown

October 27-28, 1995

1995 CONFERENCE REPORT



"Strengthening Community--Partners Against AIDS"
"Fortaleciendo a la Comunidad--Aliados En Contra del SIDA"

Presented by:

Hispanic AIDS Coalition of Greater Kansas City

Sponsored by:

U.S. Public Health Service Region VII,

Regional Minority Health Program

Midwest Hispanic AIDS Coalition, Chicago, IL

Office of Minority Health, Washington, D.C.

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Office of Minority Health, Washington, D.C.

March 1996

The 1995 Conference Report was developed by Fuenzalida & Associates, with guidance from HACGKC, the Midwest Hispanic AIDS Coalition, the Federal Office of Minority Health, and the Office of Minority Health's Region VII Coordinator. The report was written by Mizzette Fuenzalida, president of Fuenzalida & Associates (Minority Health Consultants), with graphic layout and editing by Carol J. Cohan, Ph.D., vice president of Fuenzalida & Associates, 11017 Cone Lane, Silver Spring, MD 20902. Phone: 301-949-3696; fax: 301-949-6544.

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I. EXECUTIVE SUMMARY:

The Second Annual HIV/AIDS Forum, *"Strengthening Community—Partners Against AIDS," "Fortaleciendo a la Comunidad—Aliados En Contra del SIDA,"* held at the Kansas City Marriott Downtown October 27-28, 1995 was presented by the Hispanic AIDS Coalition of Greater Kansas City (HACGKC). The forum was sponsored by the Midwest Hispanic AIDS Coalition (MHAC), U.S. Public Health Service Region VII, Regional Minority Health Program, and the Office of Minority Health, Department of Health and Human Services. More than 100 community health workers, program managers, executive directors, medical doctors and nurses, state and regional health directors, federal public health representatives, health consultants, and volunteers came together to revisit their goals and strategies in working with Latino/as and the impact of the HIV/AIDS epidemic. A cultural celebration was held for "EL día de los Muertos" with an "Altar" for remembrances of those who have passed on from HIV/AIDS in the Latino communities.

The keynote address, ***Prevention Revisited - "Moving Ahead While Looking Back"*** presented by Eunice Diaz, Ph.D. M.P.H., helped set the tone of the conference and provided an historical perspective in the work that is currently being done as well as the work that still needs to be done. Her message: *"A vision is needed to help form a renewed dedication to a higher degree of commitment to excel and stay in the fight for the survival of Latinos and Latinas. If it is not done by us, who will do it?"*

Dr. Diaz presented the following recommendations to form the vision and rededication: increased: 1) advocacy, 2) funding, 3) prevention, 4) education, 5) research, 6) data, and 7) technical assistance. In addition, special attention to legal and ethical issues and the proper identification and strategies to incorporate Latino/a-specific cultures and languages (dialects) in program planning and implementation were also recommended.

NASADAD, NASTAD, ASTHO and NACCHO, national agencies and groups, must begin to address the specific needs of Latino/as locally, regionally and nationally by providing funding, culturally appropriate technical assistance, and representation at their meetings that deal with strategic planning for communities of color.

Increased advocacy activities and strategies were recommended in each workshop for Hispanic/Latino leaders and community persons around the issue of HIV/AIDS. The Latino Caucus revised and added issues to the **National Hispanic/Latino AIDS Agenda** (NHLA) document of 1994. Advocacy areas included recommendations for national, regional and local levels to: 1) educate Congress and targeted agencies to the NHLA document; 2) enlarge the circle of information-sharing from AIDS service organizations currently in Latino/a networks to bring in agencies outside of AIDS for a more comprehensive sign-off campaign in 1996; 3) get and keep younger Latino/as involved in the policy-setting process to carry on the work; and 4) become proactive politically by exercising their right to vote in all elections.

Specific recommendations include 1) educate the media on the impact of HIV/AIDS regionally, locally; 2) involve Latino business leaders in partnerships with local/state/regional agencies; 3) hold Latino leaders and business leaders accountable to their response to AIDS; 4) increase awareness of HIV/AIDS volunteer workers in Mexico and the Midwest region through media coverage; 5) forward the revised 1996 NHLA document to federal PHS agencies **Substance Abuse Mental Health Services Administration (SAMHSA)**, **Human Resources Services Administration (HRSA)**, **Centers for Disease Control (CDC)**, **Office of Minority Health (OMH)** for inclusion in their policy and programs targeted to Latino/as; and 6) forward the revised 1996 NHLA document to national associations **National AIDS State and Territorial AIDS Directors (NASTAD)**, **NASADAD**, **ASTHO** and **NACCHO** for inclusion in their policy and programs targeted to Latinos and Latinas.

Increased advocacy: Specific local recommendations centered on metro-Kansas City area and the work of the HACGKC that has been done since April 1995. It was noted that the Coalition by itself cannot make the changes happen. The changes must take place as a community-driven partnership with the Coalition in cooperation with 1) the local health department; 2) Hispanic leaders of the metro area such as elected officials, business, school, religious, health agencies and others; and 3) the state health departments of Kansas and Missouri.

Other recommendations included 1) an increase in voter registration immediately for the local level; 2) to hold voter registration drives in conjunction with other agencies for more visibility; 3) in order to increase accountability, citizenship drives must begin immediately in each locality; 4) contact state and federal representatives to explain the implications of PPGs for people of color locally; 5) contact Dr. Stoiber's office at the Department of Health and Human Services to request filing specific names of people of color as invitees to the upcoming regional meetings; and 6) contact state health departments to request filing specific names of people of color as invitees to the upcoming regional meetings.

Specific areas for clarification on advocacy could revolve around the following questions: 1) what is the public health rationale in the PPG proposed document? 2) what is the public health rationale for the formula? 3) how will the PPG and its formula improve the public health? Recommendations included activities to oppose the block grant approach in lumping STD/TB/HIV together due to incompatible public health data collection techniques (partner notification for STDs or HIV compromise confidentiality, whereas TB partner notification has been mandated); and instead of PPG being mandated legislatively, the proposed process of block-granting health care/services could be accomplished administratively. It was pointed out that SAMHSA funding streams have been block-granted successfully.

Community advocates must address a broad spectrum of groups and individuals and engage them in dialog to assist in identifying the specific health needs of Latinos and Latinas in HIV/AIDS. These dialogs should lead to partnerships where

all parties are engaged in the development of the appropriate policies and programs to meet the concerns of HIV/AIDS in the Hispanic/Latino Community. Advocates should seek to create partners from every level and sector of the community:

- Local politicians and city officials
- State legislators and Congress persons
- Administrators of city, county, and state departments of Health
- Immigrant, migrant and seasonal worker advocates and service agency representatives.
- Youth program managers and counselors Law enforcement officials.
- Drug treatment counselors and substance abuse program directors.
- Teachers and school administrators.
- Hispanic/Latino civic group directors and members.
- Federal HIV/AIDS program directors and minority health advocates throughout the departments of Health and Human Services.

Other recommendations: 1) gather support from other racial/ethnic minority groups involved with HIV/AIDS and ask them to support the needs of Hispanic/Latino communities; 2) develop a community plan; 3) convene representatives of city/county health departments, elected officials, educators, civic organizations, religious leaders, media, employers, health professionals and Hispanic/Latino community advocates who know the needs and are able to express them. The community planning sessions must have members who are dedicated to a re-education and re-alert of the Hispanic/Latino community about the AIDS epidemic; 4) develop a position statement that all community planning members can sign to demonstrate support for AIDS prevention and services with the Hispanic/Latino community; 5) use the position statement, local data and support from allies to educate the mayor, city council, health administrators, elected officials and others; and 6) establish a network of supportive allies from the community.

Increased funding recommendations included: 1) local attention to the impact of AIDS funding in block grant format on minorities and on Latino/as in particular; 2) acknowledgment of historical perspective on collaborative efforts and their success/failure; and 3) support of those collaborative efforts currently underway and those that may be beneficial in the future as funding changes. 4) Latino community leaders, CBO directors and board chairs, and prevention program managers must play an active role in advocacy to increase funding for Latino AIDS service and prevention programs. 5) Latino CBOs should explore the possible partnership with universities to conduct service, care, and program evaluations. A grievance procedure is required to provide for the future accountability of states receiving Performance Partnership Grants (PPG). It should be required that states work in partnership with their citizens to arrive at a reasonable and equitable process. This is an issue which must be resolved as the states move to PPG funding; an issue especially critical for Latinos and for all other racial and ethnic minorities. At the minimum, funding for a regional/local needs assessment of health practices,

knowledge and behavior of gay Latinos, MSMs, and Latinas lesbians is desperately needed. Ideally, the assessment would include all Hispanic/Latino persons. Latino community leaders must play an active role in advocacy to increase funding for Latino AIDS services and prevention programs.

Specific recommendations were: 1) increase the availability of housing for persons living with HIV and AIDS; 2) provide for case management in a linguistically and culturally appropriate manner; 3) institutionalize counseling and preparation loss for the Latino family and children of affected mothers; 4) provide training and technical assistance to Latino community based organizations to gather, access, and analyze data; 5) increase the number of Spanish language public service announcements on Spanish-speaking radio programs and provide Spanish subtitles for English language PSA's on television; 6) provide technical assistance to members of school, church, and community groups which want to provide better targeted prevention messages about alcohol/substance abuse, teen pregnancy, and STD's including HIV/AIDS incorporating the use of protection for younger Latino/latina youth; 7) increase the number of Latino CBO's involved in drug treatment and substance abuse prevention.

Additional recommendations were: 1) convene focus groups with the purpose of seeking solutions to, and identifying improved health/prevention interventions for Latino gay men, MSM, and Latina lesbians and youth.

Increased prevention recommendations included: 1) to build in regional meetings to discuss and explore the current CPP and future PPG processes, outcome and direction for developing plans which will enhance prevention initiatives and service delivery for all persons of color; 2) increase hiring Latino/a paraprofessionals and use of volunteers. In formalizing agreements between and among partners to do prevention, it was recommended to put all agreements in writing, and bring all diverse community persons to the "table", including persons living with AIDS.

Increased education areas were recommended in education seminars to health care providers on Latino/a language and culture issues, possibly as an immersion program for language proficiency. Continued communication with the community by Hispanic/Latino leaders is absolutely necessary on the topic of HIV/AIDS. Educational efforts must be directed to the leaders of Hispanic/Latino churches, community-based organizations (CBOs) and other agencies to make them more knowledgeable of the communities' needs surrounding HIV/AIDS.

Increased research activity recommendations included partnerships be formed with local university researchers and schools of health to assist Latino CBOs document the connection between HIV/AIDS and substance abuse. The

partnerships must be equal and long term with all data collected and analyzed, and the recommendations shared with the community.

Increased data activity recommendations indicated a need to provide data on Latino/a health by NCLR, COSSMHO, OMH and CDC to the media. Until such time as a national needs assessment can be designed, implemented, and analyzed, the anecdotal information on Latino/Latina health would indicate: 1) a distressed and non-use of the medical community in services, prevention, treatment, and research; 2) misperceptions of health care providers; 3) higher percentage of dually diagnosed HIV/AIDS and substance abuse. The anecdotal information of Latin lesbian's health would indicate: 1) misdiagnosis of infectious diseases; 2) economic and employment barriers to spousal health insurance benefits; 3) lack of research and clinical trials specifically designed for Latina lesbians; 4) higher percentage of diagnosed terminal illness when the health system is accessed.

Anecdotal information pertaining to health issues of Latino gay men and MSM would suggest that 1) bisexual behavior often increases the risk of all sexually transmitted disease infections to their female partners; 2) lack of social support is a contributing factor to the higher incidence of suicide for young, gay Latino males; 3) internalized homophobia is a barrier to the reception of prevention messages by Latino, gay males and MSM; 4) poor self worth and group peer pressure contribute to a higher percentage of Latino men who abuse alcohol and/or drugs; 5) gay males have an increased risk being victims of violent behavior, suffering broken limbs and, in many cases, even death. The beating of gay men has occurred with such frequency that a phrase, "gay bashing", was coined; 6) an implicit part of the Machismo attitude is the denial of personal risk even when engaged in high risk, sexual activities. These and other indicators must have equal consideration by the medical institutions, public health, and policy makers of this country. A long history of ignorance and dismissal of particular segments of the population cannot continue.

Recommendations:

Conduct comprehensive health assessment for the local Latino/Hispanic community.

- Use existing data, if it is available; from reports of research organizations, Health Departments and AIDS planning groups to enhance data on Latino HIV/AIDS and other health needs.
- Coordinate research/data networks to continue data gathering on Latinos/Latinas and their specific health issues.
- Provide training and technical assistance to Latino community based organizations to enhance their capacity to create, access and analyze data.

- Use data to support and justify work of Latino Community Based Organizations.

Increased technical assistance recommendations centered around the need for NCLR and its affiliates to: 1) provide technical assistance to the region on press conferences, media relations and marketing; 2) provide open forums (workshops/seminars) for dialogue on the impact of and identification of appropriate solutions to discrimination based on race, ethnicity and sexual orientation; and 3) design, develop and disseminate a directory of Mexican CBOs, NOGS, volunteers and care givers serving HIV/AIDS Latino/as to assist and identify adequate care providers for those patients who are living with AIDS in the Midwest and may wish to return to Mexico.

Special attention to legal and ethical issues were recommended to institute grievance procedures for the future Performance Partnership Grants (PPG) processes. The State should be responsible for disseminating this information. Emphasis should be placed on the resolution of grievances for persons living with AIDS within a timely manner.

Specific areas the Office of Civil Rights (OCR) of Region VII recommended and suggested that future activities include their willingness to enter into joint training sessions concerning civil rights and discrimination with Latino and other limited-English proficient communities, on request of those communities. OCR recommended review by the community that institutions that receive Federal funds must provide translators/interpreters for all patients who are of limited-English proficiency at the time health services are needed. Institutions and health providers who receive Federal financial assistance cannot ask for documentation pertaining to legal status from any patient, at any time, and OCR recommended that community groups get the word out. If discrimination is found, anyone (either as a complainant or on behalf of) can file a complaint with OCR for alleged discrimination.

Latino/Latina-specific cultures and languages areas of recommendation included: 1) regional issues to address the differences and difficulties of language, culture, health access, immigration, and types of service delivery and care for those persons who speak different dialects of Spanish and have different cultures (i.e., migrant and seasonal workers); 2) to address the special needs of providing HIV/AIDS prevention messages to rural communities; and 3) to provide targeted prevention messages for newly arrived immigrants, refugees, and the undocumented.

Specific recommendations included: 1) provide increased bilingual case

management services; 2) bilingual home health care services; 3) maintain cultural and language differences intact for the families of the afflicted; 4) hire medically trained interpreters familiar with OBI's and implement a standardization process for licensing interpreters; 5) develop specific programs, research, and evaluation components that reflect differences in culture, language, assimilation and acculturation; and 6) design and develop specific consumer health materials for Latino/Latina ethnic differences to be acknowledged by providers.

With reference to health materials that are in languages other than English, recommendations included: 1) they must be pre-tested with local community members who speak and read the language for accuracy of terminology, understanding health messages, cultural accuracy, and syntax; 2) don't expect that all non-English health materials have been tested; 3) development of original health materials must include date of publication and local agency address/phone or space to be provided; 4) all health materials must be reviewed for accuracy and changes incorporated before copies are disseminated; and 5) use a health materials evaluation form to begin assessment of currently used health materials.

Medical updates and recommendations around the use of HIV RNA testing and its implication for anti-retroviral therapy with HIV as a manageable, chronic illness indicated a possible immune restoration by IL-2 infusion, stem cell expansion, and lymphocyte transplantation along with prophylaxis for opportunistic infections and early antiretroviral therapy to slow the progressive deterioration of the immune system. Within nutritional areas, updates suggest a routine BIA and dietary intake assessment, treatment of hormonal or digestive disorders, appropriate vitamin supplementation, aggressive use of nutrition supplementation and aggressive treatment of malnutrition and wasting syndrome. Within psychological aspects, indications are for honest, open assessment of psychological skills, professional guidance through psychological wellness programs, treatment of depression and anxiety disorders and a goal to improve one's psychological skills prior to a crisis rather than during the crisis.

Conference Report Overview:

The HACGKC HIV/AIDS Forum 1995 conference report is presented in four major sections: the keynote address (pages 1 to 8); summary of four major workshops (pages 9 to 21); summary of five additional workshops (pages 23 to 29); and, a summary of the Mesa Redonda I (pages 31 to 32). Report addenda include names and addresses of conference speakers (pages 35 to 36) and advisory group members (pages 37 to 39) with a listing of HACGKC board members (page 41). Attachments start on page 43 and reflect pertinent handouts from presenters including other regional recommendations for the NHLA document, fact sheets, and order forms.

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- The conference report was developed and written by Mizzette Fuenzalida, president of Fuenzalida & Associates (Minority Health Consultant) with guidance from HACGKC, the Midwest Hispanic AIDS Coalition, the federal Office of Minority Health's regional minority health coordinator and the national Office of Minority Health. Any opinions expressed within the report are those of individual or agency presenters and not of the Office of Minority Health.

On behalf of the Hispanic AIDS Coalition of Greater Kansas City, I wish to express our sincere appreciation to each of the twenty seven members of the advisory planning group of the Second Annual HIV/AIDS Forum. Their enthusiastic assistance and commitment contributed largely to the overall success of the conference.

Tom Valverde, Coordinator
Second Annual HIV/AIDS Forum

SECOND ANNUAL HIV/AIDS FORUM ADVISORY GROUP

Roberto Archuleta
Hispanic AIDS Coalition of Kansas
1333 So. 27th St.
Kansas City, KS 66106
Phone: 816-231-1960
Fax: 913-362-8250

Maureen Blair KC Free Health Clinic
2 East 39th St. 2nd Floor
Kansas City, MO 64111
Phone: 816-753-6144
Fax: 816-753-0804

Wade Freeman
El Centro, Inc.
1333 So. 27th St.
Kansas City, KS 66106
Phone: 913-677-0100
Fax: 913-362-8250

Mizzette Fuenzalida, President
Fuenzalida & Associates
Minority Health Consultants
11017 Cone Lane
Silver Spring, MD 20902
Phone: 301-949-3696
Fax: 301-949-6544

Barbara Garcia, Assoc. Admin. for AIDS
DHHS/SAMHSA
5600 Fishers Lane
Parklawn Bldg. #12-95
Rockville, MD 20857
Phone: 301-443-5305
Fax: 301-443-3817

Shirley Hoskins, President
Native American AIDS Coalition
5119 E. 24th St.
Kansas City, MO 64127
Phone: 816-231-8895
Fax: 816-231-4481

Richard Kellogg, M.A.
Case Manager
Samuel U. Rodgers Health Center
825 Euclid
Kansas City, MO 64124
Phone: 816-474-4920
Fax: 816-474-6475

Ceceila Olivarez Huerta, Administrative Assistant
Mexican-American Commission
State Capitol
P.O. Box 94965
Lincoln, NE 68509
Phone: 402-471-2791
Fax: 402-471-4381

Gary Johnson, Administrative Director
Kansas City AIDS Research Consortium
4050 Pennsylvania # 230
Kansas City, MO 64111
Phone: 816-756-5116
Fax: 816-756-5121

Deborah L. Kyea, LPN, Educational Coordinator
Native American AIDS Coalition
5119 E. 24th St.
Kansas City, MO 64127
Phone: 816-231-8895
Fax: 816-231-4481

Adolfo Mata, Acting Branch Chief, HIV Linkage Division of Clinical Programs
SAMHSA/CSAT
Division of Clinical Programs
Rockwall II
5600 Fishers Lane
Rockville, MD 20857
Phone: 301-443-8435
Fax: 301-443-3543

William G. Mayfield, Regional Minority Health Coordinator
USPHS Region VII
601 E. 12th St. Room 210
Kansas City, MO 64106
Phone: 816-426-3291
Fax: 816-426-2178

Monica Medina, Executive Director
Midwest Hispanic AIDS Coalition
PO Box 470859
Chicago, IL 60647
Phone: 312-772-8195
Fax: 312-772-8484

Matthew Murguia, Deputy Director
Division of Policy and Data
DHHS/Office of Minority Health
Rockwall II
5515 Security Lane, Ste. 1000
Rockville, MD 20852
Phone: 301-443-9923
Fax: 301-443-8280

Lorenzo Olivas, Program Manager
New Mexico Department of Health
HIV Prevention Program
1190 St. Francis Drive
Santa Fe, NM 87502
Phone: 505-476-8475
Fax: 505-476-8527

Henry Pacheco, M.D., Director
National Council La Raza
Center for Health Promotion
1111 19th St. NW Suite 1000
Washington, DC 20036
Phone: 202-785-1711
Fax: 202-785-0851

Teresa Pacheco, Chairperson
El Centro, Inc.
1333 S. 27th St.
Kansas City, KS 66106
Phone: 913-677-0100
Fax: 913-362-8250

Eva Pereira, Executive Director
Kansas Advisory Committee on Hispanic
Affairs
117 S.W. 10th Ave.
Topeka, KS 66612
Phone: 913-296-3465
Fax: 913-296-8118

Regena Polk, Visiting Fellow
Centers for Disease Control and Prevention
Division of HIV and AIDS
1600 Clifton Road MSD 21
Atlanta, GA 30333
Phone: 404-639-0906
Fax: 404-639-0910

Maria Reyes, HIV/AIDS Educator
Guadalupe Center, Inc.
2641 Belleview
Kansas City, MO 64108
Phone: 816-561-6885
Fax: 816-561-7009

Brian Riegel, HIV/AIDS Educator
Condom Crusaders
706 W. 42nd St.
Kansas City, MO 64111
Phone: 816-561-9717
Fax: 816-753-1088

Angel Rizo, Health Educator
Harvest America Corporation
14th and Metropolitan
Kansas City, KS 66103
Phone: 913-342-2121
Fax: 913-342-2861

Irene Salazar, Minority Health
Kansas City MO Health Department
301 E. Armour Blvd. Suite 430
Kansas City, MO 64111
Phone: 816-561-1044
Fax: 816-561-6384

Larry Simmons, HIV Specialist
Visiting Nurse Association
527 W. 39th St.
Kansas City, MO 64111
Phone: 816-531-1200
Fax: 816-531-8231

James Stanford, M.D., Clinical Director
Kansas City AIDS Resource Consortium
4050 Pennsylvania # 230
Kansas City, MO 64111
Phone: 816-756-5226
Fax: 816-756-5121

Betsy Topper, Executive Director
The AIDS Council of Greater Kansas City
2801 Wyandotte Suite 167
Kansas City, MO 64108
Phone: 816-751-5166
Fax: 816-756-5121

Dorothy Triplett, Assistant Director
Minority and Other Special Populations
OD-HIV/AIDS
USPHS/CDC & Prevention
1600 Clifton Rd. MSD 21
Atlanta, GA 30333
Phone: 404-639-0906
Fax: 404-639-0910

Tom Valverde
President, Hispanic AIDS Coalition
1319 South 28th St.
Kansas City, KS 66106
Phone: 913-831-4710
Fax: 913-362-82560

II. KEYNOTE ADDRESS: Prevention Revisited - "Moving Ahead While Looking Back"
Presenter: Eunice Diaz, Ph.D. M.P.H., Health Care Consultant

We must have a VISION which moves us AHEAD - "For without vision, the people perish". This cannot be our plight. Today, as we look back, let us learn from the past, our successes and failures, our under achievements. We must dedicate ourselves to a higher degree of commitment to excel and to stay in this fight for the survival of our people. If we don't do it - who will?

Background: I appreciate the opportunity afforded me by your planning committee to attend this important conference and to address you with these opening remarks.

Since 1981, I began to work at the Los Angeles County Health Department with a handful of early cases of what we today know as HIV/AIDS; but at that early stage it was a strange and unknown illness, sapping the lives of heretofore healthy gay white men in three major cities: New York, San Francisco and Los Angeles.

Today we come together to look at where we've been, and to determine how we need to move ahead in forcefully combating the HIV/AIDS epidemic in our Hispanic community. With all due respect to the talented, knowledgeable, experienced, and highly dedicated people I see in this room today, I need for you and me to reflect on some very basic issues. There are some important questions and concerns that strike at the very core of our ability to move ahead at this critical time in our community in regards to HIV prevention. There is a strong possibility that we can make a significant impact in stemming the tide of this epidemic in our midst.

After 14 years of working in this field, attending conferences, seminars, and lectures on HIV/AIDS, as probably many of you also have done through the years, I must be perfectly honest with you. I don't want to see any more slides, read any more statistics, look at another pamphlet or look at anymore videos or fill out another questionnaire. Some of you may still appreciate these activities, and I respect that. However for me, I truly can tell you that with the audiences I work with, these activities at this point have limited value. Simply put, information giving is just not moving any of us ahead. What are the Hispanic community concerns that we need to deal with if we are to move ahead in combating the HIV/AIDS epidemic?

As many of you know, I had the privilege of serving for four years on the National Commission on AIDS from 1989 to 1993. During those years, in numerous hearings, and site visits throughout this country and in Puerto Rico, we undertook a careful process of documentation of the various communities' concerns regarding the rapid spread of HIV in the Latino community.

Common concerns of Hispanics/Latinos:

Although many of you may have seen a copy of our report on the Hispanic community, within the section on the Hispanic/Latino community in the report, ***The Challenge of HIV/AIDS in Communities of Color***, we found a high degree of consensus about the following concerns: community diversity; community empowerment; drug users; education; families; Hispanic/Latino gay men; immigration; language; leadership; migrant workers; orphans; prevention; research; and women.

For us to be able to move ahead, we must clearly understand and hear the views, perceptions and misperceptions of our people. We must also carefully look at the barriers that prevent us from moving ahead, and be able to address these.

The National Commission on AIDS' Hispanic/Latino identified barriers:

The general barriers that were identified include: 1) **denial** - it won't happen to me and my family; 2) **fatalism** - "whatever happens is simply my fate or destiny"; 3) **inertia** - "hard for us to take decisive action and meet with resistance"; 4) **lack of unity and resolve** - "we just can't come together on this;" and 5) **"AIDS is a punishment"**. God is punishing some sinful or immoral behavior and these people deserve it".

The barriers identified as **cultural norms** include: 1) **communication about sex** (conservatism vs. traditionalism); 2) **concern for appearance** - "Que diran" when going for counseling or testing; 3) **less apt to trust mainstream** organizations and providers; 4) **homophobia** - fear of homosexuality; poverty - Hispanics have disproportionate lack of health insurance over any other group; 5) **concern for survival** - day to day, AIDS is not the top priority; stigma and fear associated with having AIDS or taking "the test" and discrimination; 6) **hopelessness** - "if you have AIDS you will die and nothing can be done"; 7) **machismo** - who is in control is overpowering in importance for gender, relationship, power; and 8) **marianismo** - what makes a good wife/partner.

Group barriers that have been identified include: 1) **differences in national origins**; 2) **gay and bisexual behaviors**; 3) **drug users**; 4) **teenagers**; 5) **women in general**; 6) **migrants**; and 7) **prison inmates**.

A living document that will be updated at this conference is the ***National Hispanic/Latino AIDS Agenda (NHLA)***:

Some of the same concerns are found in the April 1993 NHLA document, stated as challenges to HIV prevention and care. The NHLA document lists the following reasons for difficulty in providing effective, culturally appropriate HIV/AIDS education, prevention and health care services to Hispanics/Latinos. Among them are:

1. The lack of access to health insurance;
2. The lack of Hispanic/Latino physicians, nurses and other health care providers, especially those with expertise in HIV/AIDS;
3. The lack of information on HIV/AIDS treatments which are culturally appropriate and at appropriate literacy levels for Hispanic/Latino populations;
4. The lack of adequate and continuing funding to establish and operate community-based HIV/AIDS prevention programs;
5. The dearth of drug treatment programs designed to meet the needs of Hispanics/Latinos, especially women with children and gay-identified men;
6. A perception among many Hispanics/Latinos that HIV/AIDS is a "White Gay Male" disease or is primarily a disease of injecting drug users;
7. Social and cultural stigma associated with behaviors such as injecting drug use, "promiscuous" sexual practice and homosexual sex;
8. The opposition by many churches and religious entities to safer sex practices and to prevention messages that promote safer sex;
9. The correct assumption that all Hispanics/Latinos share the same risk factors and cultural values, which lead to the misconception that those prevention programs that work for one Hispanic/Latino group will work for all groups;
10. Public information campaigns directed at Hispanic/Latino communities that do not consider language, class, and cultural differences;
11. The dearth of Spanish-language prevention programs and of Spanish-speaking staff at both public health and social service facilities and organizations serving Hispanic/Latino communities, including drug treatment and prevention programs;
12. The lack of coordinated prevention and services targeting Hispanics/Latinos who commute or migrate between the United States, Mexico and Puerto Rico; and
13. The lack of research on sexual knowledge, attitudes, beliefs, behavior and practices of Hispanics/Latinos, and on drug use/abuse among Hispanics/Latinos.

What have we, as Hispanics/Latinos, done? - our accomplishments are small:

Data and national information gathering on Hispanics/Latinos on HIV/AIDS has been minimal and reports have been under represented in comparison to the rising numbers of infected persons within our communities. Los Angeles was the site for two important meetings: in 1988 the first National Strategy Symposium on Latinos and AIDS was held and the First National Hispanic Teleconference on HIV/AIDS was held in 1989. There was a National Health Interview Survey in 1990 that included Hispanics, as well as a study conducted by the Northeast Hispanic AIDS Consortium in the same year. In 1993 the US Surgeon General's report on Hispanics/Latinos was published and the National Hispanic/Latino Health Agenda, coordinated by Dr. Antonia Novello, was begun.

Exemplary Hispanics/Latinos who represent all of us at the federal level are Dr. Antonia Novello, who was the previous U.S. Surgeon General, Dr. Ciro Sumayo, who heads HRSA, and Dr. Nelba Chavez, the head of SAMHSA. We now have Hispanic

researchers who regularly are included in NIDA's advice lines, and currently there are more Hispanic reviewers on the federal RFP process committees and serve as grant reviewers.

Publications from COSSMHO and NCLR specific to Hispanics/Latinos about HIV/AIDS continue to be updated and are available to assist local groups. More Hispanic/Latino CBOs have been funded and some skills building and technical assistance has been provided by Latinos, for Latinos.

Recommendations for action: For this conference, there are nineteen NHLA agenda recommendations for action that are appropriate. These are in the areas of: 1) **leadership**; 2) **CBOs**; 3) **care**; 4) **education and prevention**; 5) **research**; 6) **data**; and 7) **legal and ethical concerns**.

LEADERSHIP:

1. Make Hispanic/Latino HIV/AIDS issues a top priority of elected and appointed officials at the federal, regional, state and local levels.
2. Involve Hispanic/Latino leadership, at all levels, as part of the community response to the HIV/AIDS epidemic.
3. Include Hispanic/Latino communities in the development of HIV/AIDS policies and programs.

COMMUNITY-BASED ORGANIZATIONS (CBOs):

4. Increase public and private funding and technical assistance for Hispanic/Latino CBOs that provide prevention and services to the Hispanic/Latino community.
5. Increase funding for Hispanic/Latino CBOs providing services to the Latino gay, bisexual, and lesbian communities.

CARE:

6. Emphasize and strengthen the linkage between HIV/AIDS and primary care needs in the Hispanic/Latino community.
7. Increase the number of and access to available substance abuse treatment slots for Hispanics/Latinos.
8. Increase culturally and linguistically appropriate mental health services to provide support for persons with HIV infection and AIDS, their partners, families, friends and others who might be providing care services.
9. Focus attention on the needs of Hispanic/Latina women with HIV/AIDS and their families.
10. Develop consumer protection materials and include them as part of the counseling to educate Hispanics/Latinos on how to recognize and avoid fraudulent HIV/AIDS treatments and "cures" and guard against unscrupulous providers.

EDUCATION AND PREVENTION:

11. Institute a federal comprehensive AIDS prevention strategy that will provide culturally based and linguistically appropriate prevention messages to Hispanic/Latino groups, especially those most at risk for HIV infection - gay/bisexual men, injecting drug users, sexual partners of injecting drug users, women, youth, incarcerated populations, immigrant and migrant populations and persons with TB;
12. Provide incentives to state and local governments, the private sector and religious organizations to provide both financial and technical support to prevention efforts conducted by Hispanic/Latino CBOs within their communities.

RESEARCH:

13. Increase Hispanic/Latino participation in clinical trials, particularly the participation of Hispanic/Latina women, children and adolescents.
14. Provide funding for research on the sexual attitudes, beliefs and practices in the Hispanic/Latino population.
15. Conduct additional research on the effects on the continuity of care and prevention efforts for Puerto Ricans who travel between the mainland and the island.
16. Increase incentives to recruit Hispanic/Latino researchers in order to develop a community-based HIV research effort by and within the Hispanic/Latino community.

DATA:

17. Break down Hispanic HIV/STD data by subgroups to enable more effective planning.

LEGAL AND ETHICAL CONCERNS:

18. Eliminate HIV infection as grounds for excluding immigrants to the US.
19. Educate the Hispanic/Latino communities about the provisions of national, state and local anti-discrimination laws, build adequate mechanisms for the enforcement of these laws, and facilitate the filing of complaints.

What do we need to do to make the above happen?

As a top priority, we need to revisit the whole concept of HIV prevention for our communities. We need, as a people, to give more than "lip service" to the concept of prevention. We need to:

1. Believe in prevention and form partnerships and coalitions.
2. Plan for prevention in coordinating programs and strategies.
3. Commit the necessary resources and dollars to prevention.
4. Commit to evaluation and research of prevention.
5. Review current prevention messages.

6. Look carefully at the messengers of prevention.
7. Make a careful analysis of where and how prevention is being delivered and communicated to our people (churches, schools, social circle, workplace, home).
8. Look carefully at who may be our allies.
9. Lay aside our misperceptions, distortions and mixed messages (i.e., dangers of anal sex, no nonoxynol 9, heterosexual risks, cleaning needles, safety of condoms, length of time between initial infection and symptoms at onset).
10. Focus on primary and secondary prevention for the whole family since few Latina women understand the past sexual practices/behaviors of husband or partners can put them at risk today, and few Latino men can understand that casual past drug using behavior or casual sex of years ago can place their family at risk today.

How do we move ahead in order to make it happen?

Let's come together on a point of critical analysis here. With no vaccine or cure at this time, do we continue to join the chorus of voices singing the same tune "Our only sure arm of defense against HIV/AIDS in our communities is prevention" or, do we commit to some type of analysis of what we mean by prevention and why our efforts might be somewhat ineffectual or limited? And then, how can we give these efforts a renewed "shot in the arm", or booster, at such a critical time as this?

We cannot and must not allow the continual increase of AIDS and HIV infection in our community. Nine percent of the population, representing 18 percent of the cases is at this point an urgent matter of survival!

What areas do we focus on to be most effective in order to move ahead?

Where can we move ahead on this while we look back in a positive sense? Let me share a few ideas, as I see it.

1. **Prevention needs advocates and advocacy.** Advocacy skills, strategies, and process must be taught and learned by many of us here. Advocacy is not a bad word and we should not shy away from this type of work at all levels in our community - federal advocates, state advocates, local advocates, and grassroots advocates.
2. **Prevention of HIV/AIDS for the Hispanic/Latino community** deserves its "own day in court" **with a planned, well executed forum or think tank for consideration.** Give it priority and sell it to our constituents and get their support. I personally do not believe that our issues and concerns can be fairly dealt with at this early time of community prevention planning process and with the shifts of attention from federal agencies to the states.

3. Many prevention models in newer CBOs were just getting started when funding streams dried up or bureaucracies changed regulations, processes, and people. **Increase the funding streams to assist our Hispanic/Latino CBOs do their work and provide them with technical assistance to make their organizations stronger and better able to compete.**
4. We, in the Latino community, do not know enough from the research perspective as to what works best in HIV/AIDS prevention and education to apply the science of technology transfer and knowledge dissemination to make our efforts most effective. **New research and scientific technology breakthroughs that center around Hispanic/Latino HIV/AIDS prevention and education successes must be disseminated to our communities in a manner that is easily understood. The information sharing must be made available on a regular basis with periodic updates to assist the effectiveness of our local efforts.**
5. We have “locked” ourselves within an artificial compartment separating prevention and care and services. **We and our funders cannot ignore the value of looking at prevention in its broadest definition of primary, secondary, and tertiary linkage with care and services.**
6. We are afraid to understand, and probably subscribe to in a very limited way, the program evaluation process. The fear of evaluation probably is founded in the perception that it (evaluation) takes away from services or education. Most of us are really “flying by the seat of our pants” on this one. If we were asked to describe the scientific basis of our interventions and the formative research, process, or outcome evaluation, we might be hard pressed. **Assistance on evaluation and techniques of analysis, processes and implementation must be an integral part of future funding package to our CBOs with the purpose of incorporating evaluation in all facets of organizational functions to assure ongoing organizational capacity building.**
7. There is a body of prevention research and individuals who do that prevention research in the Latino community. **The researchers and community scribes who co-exist out there doing prevention research need to be sought out, nourished, coordinated, and their work be continually built by consensus.**
8. **To work effectively on behalf of the Hispanic/Latino population you must know the population and language, its leadership, people, culture, norms and values, barriers to communication, social and organizational structure, concerns, research, data and researchers .**

We must have a VISION which moves us AHEAD - "For without vision, the people perish". This cannot be our plight. Today, as we look back, let us learn from the past, our successes and failures, our under achievements. We must dedicate ourselves to a higher degree of commitment to excel and to stay in this fight for the survival of our people. If we don't do it - who will?"

III. SUMMARIES OF MAJOR WORKSHOPS

1. Latino Caucus – the National Hispanic/Latino AIDS Agenda.

Facilitators: Monica Medina, Acting Executive Director of MHAC; Martin Ornelas-Quintero, Director of AIDS Programs for National LLEGO; Barbara Garcia, Associate Administrator for AIDS for SAMHSA; Matthew Murguia, Deputy Director, Division of Policy and Data for OMH.

Background: The Latino Caucus was held on two consecutive days, facilitated the first day by Ms. Medina and Mr. Ornelas-Quintero, and by Ms. Garcia and Mr. Murguia the second day. In keeping with gathering input from other conferences and meetings, copies of the 1994 revised document were shared with participants for local, regional and national input. Facilitators discussed the history of the document's process, inclusion of over sixty organizations and agencies, original funding from the Ford Foundation and ongoing activities associated with revisions/updates on a national and regional basis since 1994.

Many issues were discussed that included suggestions for all three levels: 1) educate Congress and targeted agencies to the NH/LA document; 2) enlarge the circle of information-sharing from AIDS service organizations currently in Latino/a networks to bring in agencies outside of AIDS for a more comprehensive 1996 sign-off campaign; 3) keep younger Latino/as involved in the policy-setting process to carry on the work; and 4) become politically proactive as Latino/as by exercising their right to vote at all elections.

National issues that need to be added: 1) institute grievance procedures for future Performance Partnership Grants (PPG) processes; 2) assign one national Latino/Latinas organization to spearhead the update and revision process of the 1994 document, with a dissemination role to their constituency as well as the original sponsors; and 3) build in regional meetings to discuss and explore the current CPP and future PPG processes, outcome, and direction for developing plans which will enhance prevention initiatives and service delivery for all persons of color.

Regional issues that need to be added: differences of language, culture, health access, migrant and seasonal worker outreach, civil rights, immigration, data collection, types of service delivery/care.

Local issues that need to be added by each locality: (perhaps as a cover letter to the document when reviewed by local agency representatives): 1) impact of AIDS funding in block grant format on minorities and Latino/as in particular; 2) historical perspective of collaborative efforts and their success/failure; and 3) collaborative efforts currently underway and those that may be beneficial in the future for Latino/as as funding changes.

Specific regional differences to be addressed/added: included for the Midwest are:

1. Target younger children with curriculum in schools, church-based programs and community centers on prevention messages about drugs and protection. An example included a *promotaras de salud* for young girls eight years old and above with their mothers through a church-based program.
2. Acknowledge abandonment issues of the children of infected mothers from other family members – the need for counseling and preparation for the family and children.
3. Acknowledge and respond to the lack of cooperation and coordination of the five major Latino agencies that cohabitate in metro-Kansas City between the states of Kansas and Missouri.
4. State of Indiana's Latino/a population varies between mid-state (Mexican and Mexican-American) and other parts of the state (South American). This has implications for specific health materials literature and data collection activities for those ethnic differences to be acknowledged by providers and funders.
5. Acknowledge the differences in literacy and economic levels in terms of access to information/communication, which are essential for Midwest Latino/as receiving health messages. Not enough Spanish-speaking radio or public TV programs that are non-cable (Univision is only cable-accessed).
6. Acknowledge differences in assimilation and acculturation in the impact of health care/access.
7. Acknowledge the demographics of the Midwest region as populated by a few major cities surrounded by more rural areas, and address the specific difficulties of service delivery, care, research, and funding for Latino/as. Examples included Cincinnati, Columbus, Cleveland Ohio, Indianapolis, Ft. Wayne, Gary, Indiana, St. Louis, Columbia, Springfield, Kansas City, Missouri; Topeka, Garden City, Wichita, Kansas City, Kansas; Des Moines, Ames, Iowa; Omaha, Lincoln, Nebraska; Springfield, Elgin, Chicago, Illinois.
8. Acknowledge the differences and difficulties of the migrant stream in the Midwest for providing health care and prevention messages to the workers and their families.
9. Acknowledge the language/communication needs of Midwest Latino/as in obtaining and maintaining access to health services and care. The AT&T interpreter service currently used in Indiana has proven to be harmful to Spanish-speaking patients. Examples from Indiana indicated that the level of patient pain cannot be determined through this method and a mistake in the interpretation of a prescription by the operator informed the patient to take 2 tablespoons of medication rather than 2 teaspoons, which brought a law suit filed on behalf of the patient.
10. Provider training in cultural and linguistic issues about Latino/as must be addressed with the availability of quality consumer health materials in languages other than English.

coordination with Monica Medina, Tom Valverde, Mizzette Fuenzalida, Martin Ornelas-Quintero, Donald Babb, Frank Beadle de Palomo, Charlene Ortiz and Henry Pacheco M.D.

Copies of the NHLA should be distributed to city, state and regional health directors and to their HIV/AIDS Program Managers. Use the media to discuss NHLA local/regional updates.

2. Performance Partnerships – Concerns for Minority Health.

Presenters: William Mayfield, Regional Minority Health Coordinator for DHHS/USPHS Region VII and Roberto Vazquez-Pacheco, Coordinator of HIV Prevention for National LLEGO.

In this session, a review of the proposed performance partnership grants (PPG) was presented. Dr. Susan Stoiber, from the Office of the Secretary of Health and Human Services, is the main contact person who is coordinating the proposed program within the DHHS. Ta Zitans is the contact for Region V/VII, 202-690-7316. The grant program collapses 35 current funding streams into five major health areas: 1) Mental health/substance abuse, 2) STD/HIV/TB, 3) Chronic Diseases, 4) Immunization, and 5) Prevention of Sexual Assault/Rape. The performance grant blocking has significant implications for the entire country and regional health issues. It will be necessary for each state to have local input into the process of priority setting of health issues.

There will be a meeting for participants from states and territories in Federal Regions IV, V, and VII in Chicago, April 29 and 30. The purpose of the meeting is to develop information that will enhance PHS decision making in establishing performance measures for the next three to five years for selected public health programs, including HIV/STD/TB. These measures will form the basis of DHHS management of public health grants to states. The meeting is by invitation of the Assistant Secretary for Health, Dr. Phillip Lee, and will include approximately 350 persons. It was suggested that persons in Region V and VII contact their state health department, regional minority health coordinator, governor's office, federal PHS funding agencies' project officers, and local media to bring attention to the process and have their name entered as an invitee.

Discussion: How to address the special health needs of minority populations is not evident in the proposed language of the PPG document. The term "at-risk populations" is used; however, there is no discussion specific to the five federally recognized health disadvantaged minority groups; i.e., Hispanics, Asian/Pacific Islanders, Alaskan/Native Americans, African Americans. The health remedies for these five minority groups must be addressed before PPGs move forward. This is especially necessary since there is a significant percentage rise of AIDS morbidity/mortality in the people of color communities over the white populations.

The current PPG document does not indicate means of accountability. Enforcement mechanisms to ensure that all parties of the partnership will be held accountable are lacking. The PPG document must include mechanisms for accountability to ensure equal playing fields for all parties in the proposed partnerships. Measures to ensure performance must be determined and included.

The proposed formula to determine funding allocations of the PPGs by states were: 20% total population, 25% at or below poverty level, 5% geographic size, 50% morbidity data [HIV 15%, AIDS 15%, STDs 10% and TB 10%]. The implications for the Midwest states in Regions V and VII are devastating in all categories. Examples were given for Iowa that does not keep statistics on HIV and whose offices of STDs and TB do not share data. The total population of Iowa would not get as many points as Illinois, nor would the numbers of persons below the poverty level in Iowa get as many points either. It is hoped that 5% for geographic area would be points for Iowa, but in comparison to other states in Regions V and VII, it is doubtful. Other states, such as Missouri and Illinois, expressed extreme reservations as to whether the recent surge in HIV/AIDS cases among minorities would show up in current statistics, given the nature of how minorities are least likely to access prevention and treatment in the early stages due to the limited number agencies targeting minorities in the Midwest.

Barriers: At a meeting in February 1995 in Maryland for regional minority health coordinators, state minority health directors and others, requests were made to have information sent to all participants pertaining to the proposed PPG plan. To the knowledge of those in attendance at the present HIV/AIDS Forum, as of late October 1995, no Midwest participants have received the requested information. **The immediate problem to overcome is how to get input from the Midwest to the Office of the Secretary of HHS in time to have an impact on the PPG process.**

Proposed Midwest strategies: To overcome the lack of communication requested in February of '95, participants suggested the following for contacting agencies/elected officials on a local, state and national level:

1. Roberto Vazquez-Pacheco, LLEGO, to send by phone/fax the address, phone and fax of national organizations that were not at the conference; NALEO, NABCO, NGA, NASADAD, NASTAD, ASTHO, NACCHO.
2. Increase voter registration immediately on the local level and hold voter registration drives in conjunction with other agencies for more visibility.
3. Contact state and federal representatives to explain the implications of PPGs for people of color locally.
4. Contact Dr. Stoiber's office to request filing specific names of people of color as invitees to the upcoming regional meetings.
5. Contact state health departments to request filing specific names of people of color as invitees to the upcoming regional meetings.

Specific areas for clarification: In discussions with the above organizations, agencies, representatives, and interested parties, the following were issues that need clarification and attention:

1. What is the public health rationale in the PPG proposed document?
2. What is the public health rationale for the formula?
3. How will the PPG and its formula improve the public health?
4. Oppose the block grant approach in lumping STD/TB/HIV together due to incompatible public health data collection techniques. Partner notification for STDs or HIV compromise confidentiality whereas TB partner notification has been mandated.
5. Instead of PPG being mandated legislatively, the proposed process of block granting health care/services can be accomplished administratively. SAMHSA funding streams have been block granted successfully.

3. Civil rights of persons with limited English proficiency – equal access to services.

Presenter: Joseph Estrada, federal investigator for the Office for Civil Rights (OCR), Office of the Secretary for DHHS assisted by Dr. John Halverson, Region VII Manager for OCR.

Background: An overview of the federal OCR (800-368-1019) within HHS was presented with its relationship to the Office of the Inspector General and the Office of General Counsel. The ten regional offices of HHS OCRs are housed with their corresponding DHHS Regional Offices: Boston, Region I (617-565-1340); New York, Region II (212-264-3313); Philadelphia, Region III (215-596-5381); Atlanta, Region IV (404-331-2779); Chicago, Region V (312-886-2300); Dallas, Region VI (214-767-4056); Kansas City, Region VII (816-426-7277); Denver, Region VIII (303-844-2024); San Francisco, Region IX (415-556-8367); and Seattle, Region X (206-442-0473).

Definitions were explained regarding applicant, Title VI of the Civil Rights Act of 1964, types of Federal financial assistance and institutions covered by Title VI, Hill-Burton Act, discriminatory acts, employment rights and compliance.

Title VI discussion: "No person in the United States shall, on the ground of race, color, or national origin be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." Since 1964 there have been subsequent additions to race, color and national origin and those are age, religion, sex and handicap (sexual orientation is not included).

Participants questioned if the statement "no person..." would hold true for some states that are currently withholding access to undocumented persons under Ryan

White funding. The presenters indicated that the 1964 federal law overrides any state law and that the reading of "No person in the United States..." does not specify citizenship or legal status, but rather states that anyone in the U.S. cannot be denied benefits or discriminated against by agencies receiving Federal funding.

The issue of health institutions, as providers of health care, legally providing translators and interpreters for limited-English speaking clients was discussed. The institutions, as Title VI regulations call for, must provide translators or interpreters to patients when they arrive for health care services at no expense to either the patient or the patient's family. Neither the patient nor their family need to bring in their own interpreter (unless they wish to). They are not to be told to come back on another day or go to another clinic site because an interpreter cannot be found. That is the legal responsibility of the institution if it receives Federal funds.

Eight specific types of discrimination that are prohibited under Title VI (45 CFR) Part 80 were listed and discussed at length by participants for their relevance to access and health care for HIV/AIDS programs in the Midwest. The eight that are prohibited are to:

1. Deny services, financial aid, or other benefits provided as a part of health or social service programs.
2. Provide different services or services in a different manner from those provided to others under the program [equal access to health care, treatment, prevention, communication in language of origin, deny access to Ryan White services].
3. Segregate or separately treat individuals [quarantine of HIV/AIDS patients].
4. Treat individuals differently in the determination of their eligibility for services [request at any time by any health care provider receiving federal funds for patient's legal status documentation is prohibited].
5. Deny individuals the opportunity to participate in a program by providing them based on race, color, or national origin, an opportunity to participate in a different program [sending Latino/as to a different health clinic or treatment site because of the lack of translators/interpreters].
6. Select a site for delivery of services which has the effect of excluding individuals from services [assigning Latino/as to a health clinic or satellite office cross-town that is inaccessible by public transportation or takes three bus rides to reach].
7. Deny an individual the opportunity to participate as a member of a planning or advisory board [special consideration may apply to current CPP or future PPG boards and commissions].
8. Use criteria or methods of administering the program which have the effect of subjecting individuals to discrimination [non-communication of

agency policies, evaluation tools are not equitable for diverse personnel, treating employees differently with different standards of excellence].

Hill-Burton Act was reviewed in relation to the possible discriminatory acts or non-compliance of health care institutions. The Hill-Burton Act (H-B) has funded, and continues to fund, health care institutions to deliver services to all persons regardless of ability to pay, race, color or national origin. At the admissions office of each institution that receives or has received H-B funds, a notice of compliance should be visible in both English and Spanish which explains the program.

The providers who receive H-B funds are required to pay back 1/20 per year of the total funding by forgiving the debts of their indigent clients. Under the Community Assurance Program, emergency services are available "in perpetuity" at institutions that receive or have received H-B funds. These institutions must accept Medicaid and Medicare and work out a method of payment from their clients that is satisfactory to the clients. Call the regional office of OCR to receive a listing of all current and previously funded H-B institutions.

Employment rights: An overview was provided of the limited protection available under Title VI. It applies to hiring, termination, rates of pay, and other benefits. There appears to be greater difficulty in getting a ruling from this title due to application of other Federal, state and local laws/regulations that may apply. OCR offices frequently refer to other agencies if the applicability would be better served under a different statute. An example would be to use EEOC complaint process rather than OCR.

Compliance sanctions are rare but institutions/agencies receiving or benefiting from HHS Federal financial assistance are required to comply with Title VI regulations. The two types of compliance are: 1) voluntary, and 2) technical assistance. The enforcement of compliance is undertaken through investigation, seeking to resolve complaints and periodically review recipient organizations for compliance.

Suggestions/recommendations:

1. The OCR office of Region VII will be available to enter into joint training sessions concerning civil rights and discrimination with Latino and other limited-English proficient communities, on request of those communities.
2. To acquire a thorough financial background search of any agency receiving Federal funds, request to review the Federal Catalogue of Domestic Assistance from the local library.
3. Anyone (either as a complainant or on behalf of) can file a complaint with OCR for alleged discrimination.
4. OCR office will follow-up on coverage of ambulance service for H-B funds.

5. Institutions receiving Federal funds must provide translators/interpreters for all patients who are of limited-English proficiency at the time health services are needed.
 6. Institutions and health providers who receive Federal financial assistance cannot ask for documentation pertaining to legal status from any patient, at any time.
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4. Preventing the Dually Diagnosed: Substance Abuse and AIDS.

Presenters: Barbara Garcia, Associate Administrator for AIDS for SAMHSA and Adolfo Mata, Acting Branch Chief HIV, Linkage division of Clinical Programs for CSAT/SAMHSA.

Background: An overview was presented of the restructuring of Alcohol, Drug Abuse, and Mental Health Administration. Research is now housed in NIH, and the services component is now in the Substance Abuse Mental Health Services Administration (SAMHSA). The three centers housed in SAMHSA are the Center for Substance Abuse Treatment (CSAT), the Center for Substance Abuse Prevention (CSAP) and the Center for Mental Health Services (CMHS).

The National Clearinghouse for Alcohol and Drug Information (NCADI) provides publications on the various programs and projects funded by SAMHSA. The toll-free number is 800-729-6686 at PO Box 2345 Rockville, MD 20847-2345. Technical Assistance Publications (TAPs), Treatment Improvement Exchange (TIE) and Treatment Improvement Protocols (TIPs) are available by request.

CSAT's demonstration program budget has decreased from \$10.2 million in FY92 to \$6.5 million in FY95 and is currently expected to be totally defunded by Congress during this session. SAMHSA's programs have traditionally been block grants to state substance abuse authorities, including those for prevention and treatment.

The current profile of substance abuse nationwide indicates that IDU (not just heroine) is prevalent in the East, amphetamines are the drug of choice on the West coast. Therefore, different treatment, prevention and follow-up strategies are required for various sections of the country to be successful. It is imperative that CBOs, health care institutions, elected officials, advocates, and others knowledgeable of the trends in their area be engaged in planning strategies and service delivery.

Substance abuse and HIV transmission in the Midwest: participants who work in the substance abuse field indicated that the four favored substances are crack, injection drugs, alcohol, marijuana, and crank. Some cities and localities have needle exchange programs; most, however, are not sanctioned by local laws and

are an underground operation. There is a Federal ban on the purchase of sterile needles without a prescription. This requirement is affecting the decision of providing a needle exchange program in many local areas.

The moral dilemma of needle exchange programs was described as having three separate views: 1) perceived increase in IDU by providing clean needles; 2) perceived increase in HIV by withholding clean needles; and 3) perceived legalization of drugs by providing clean needles. For communities of color the moral choices are interwoven with deep-seeded cultural and ethnic issues of religion, distrust of institutions, and perceived strategies for extinction of people.

Local action: three major components of a local action committee to address HIV/AIDS and its connection to substance abuse would be: 1) perform a needs assessment; 2) create comprehensive plans that are inclusive of the entire Latino community, not just AIDS; and 3) formulate specific localized action plans for the present year and future years. Acknowledge that with AIDS, any projections should be in ten year segments due to the nature of the disease. Prevention strategies must begin earlier in Latino communities due to the relative youth of the population, with an average age of 24. Waiting until the teenage years 14-19 to address prevention is too late.

How to address local government and agencies about HIV/AIDS: It is essential to have new mechanisms to collect data and have data collected on all ethnicities of Latino/as (the Americas: central, south, Caribbean basin and mainland U.S.). Data influences decision making on all levels. If data cannot be gathered from traditional institutions (local, state health departments, morbidity/mortality updates etc.), then anecdotal information that is well documented will need to be used in creating local action plans.

Anecdotal data can be derived from documenting specific interventions and programs for Latino/as. An example was presented of the Latino Equity Program instituted in Watsonville CA, in which the local population was compared/contrasted with the percentage of those at or below poverty. Well documented needs assessments can be a strong defense against unwarranted budget cuts in the Latino community. The local United Way became a partner in providing seed funding for the needs assessment to document anecdotal information in the Watsonville model.

Needs assessment protocol: COSSMHO has a needs assessment protocol that can be revised to fit the specific needs at the local level in the area of health. Contact Barbara Garcia at SAMHSA, or COSSMHO in Washington DC, for additional information on the needs assessment.

A study funded by COSSMHO challenged Latino/a and non-Latino/a leaders and

health providers to identify the five leading causes of death in Latino/as. Of interest is the perception of non-Latino/a leaders that infant mortality was the leading cause of death for Latino/as. In reality, data indicates that heart attack is the #1 leading cause of death. The study points out the discrepancy of the perceptions about health in Latino/as. Needs assessments and data collection are integral to presenting accurate information.

Document the connection between substance abuse and HIV: Examples of anecdotal data to integrate substance abuse and HIV are:

1. Review the number of treatment slots and treatment providers;
2. Number of requests for treatment on demand;
3. Number of persons on the treatment waiting lists;
4. Coordinate with the local needle exchange program in gathering data;
5. DUI records;
6. Emergency room admissions;
7. Number of liquor stores in the county/city;
8. Number of domestic violence 911 calls handled where alcohol or drugs were indicated;
9. Ethnographic information by counting the number of persons seen shooting up or engaging in unsafe sex practices at particular sites;
10. Number of self-reporting alcohol or substance abuse at intake interviews; and
11. Number of drop out rates by ethnicity, age, sex.

Recommendations: Participants indicated changes in policy, partners, funding, and programs. Some strategies are:

1. In order to increase accountability, increase voter registration efforts and citizenship drives to begin immediately in each locality.
2. Local politicians and city officials need to be included in the dialogue identifying the needs of Latino/as in health, HIV/AIDS and substance abuse.
3. State legislators and congresspersons need to be addressed on an individual, group, and regional basis in the dialogue identifying the needs of Latino/as in health, HIV/AIDS, and substance abuse.
4. State substance abuse and state mental health councils need to be addressed on an individual, group, and regional basis in the dialogue identifying the needs of Latino/as in health, HIV/AIDS and substance abuse.
5. Local Community Planning should be attempted in mental health and substance abuse to identify and address gaps in existing services.
6. The use of volunteers and the hiring of Latino/a paraprofessionals must increase.
7. Perhaps the traditional HIV outreach worker could be folded in with other health workers; e.g., STDs.

8. Partnerships must be formed with local university researchers and schools of health to assist Latino CBOs document the connection between HIV/AIDS and substance abuse. The partnerships must be equal and long term, with all data collected, analyzed, and recommendations shared with the community.
9. National organizations must begin to address the specific needs of Latino/as locally, regionally, and nationally by providing funding for culturally appropriate technical assistance. Those organizations are: NASADAD, NASTAD, ASTHO and NACCHO. Latino and Latina health advocates should seek opportunities to work with these organizations and participate in their strategic planning for communities of color.

IV. ADDITIONAL WORKSHOPS

1. Promoting Effective Community Collaboration Work.

Presenters: Martin Ornelas-Quintero, Director of AIDS Programs for National LLEGO and Monica Medina, Acting Executive Director for Midwest Hispanic AIDS Coalition (MHAC).

An effective coalition or collaborative effort has a clearly defined purpose, scope, and procedures for developing policies and agreement by all parties to those core ideals. Community collaboration (project specific, mutual benefit, or to address broader community need) is difficult to maintain within a political context. For success at the "table," Latino/as need to have a sense of historical perspective and find allies to help advocate for those who are not present or considered expendable. Collaboration, resources, and power imbalances are factors that continue to influence the current Community Prevention Planning (CPP) process. All members of CPP must work together to create trust, ensure a level playing field, be knowledgeable of the parameters of local power, and have the ability to equal dialogue with the local/state health department.

Barriers to successful collaboration for Latino/as include: racism; homophobia; sexism; the need to acknowledge that we are a multicultural community with some shared cultural aspects that must be changed or built upon. We need shared strategies on how to work together, and shared terminology in our language to overcome communication barriers that exist.

Recommendations: 1) Put all agreements in writing; 2) acknowledge that the U.S. government will not "save us;" 3) release the demons within that divide us; 4) bring all diverse community persons to the "table," including persons living with AIDS; and 5) continue *cuentas claras* (straight talk) and refuse to engage in *chismes* (gossip).

2. Multilingual/Cultural Health Materials for HIV/AIDS and Related Health Topics.

Presenter: Mizzette Fuenzalida, President of Fuenzalida & Associates, Minority Health Consultants.

Several sources for information gathering were handed out: NAC publications on Hispanic materials, AOL disks, 1995 *Multilingual Health Education Resource Guide* and the 1995-96 *Connecticut Multicultural Health Reference Manual*. Ordering information for the free MHER Guide and CMHR Manual was included along with the referenced materials.

Samples of health materials in Spanish that are currently being used in other areas of the country were shared with participants. Over 35 materials were reviewed in Spanish and/or English on HIV/AIDS, TB, Hepatitis B, Nutrition and AIDS, STDs

and family planning. Material evaluation forms were completed and participants shared their assessments with the group.

Assessments indicated that most samples would NOT be acceptable to the participants' clients due to: 1) too much text; 2) no pictures or pictures didn't reflect Latino/as; 3) color of graphic was inappropriate for Latino/as; 4) terminology was medically incorrect (pre-1990); and 5) demeaning or judgmental terminology. Participants found three to four materials suitable for their agencies: a 1995 nutrition booklet for African Americans that is being considered for Latino/as (Philadelphia PA); an inclusive booklet for Latinas in Spanish on HIV/AIDS, safer sex, testing, family planning, medical care (APLA); an American Red Cross booklet in Spanish; a TB-AIDS brochure in Spanish that could be used with explanation (MA).

Discussion also centered around the process of developing original materials through native-speaking focus groups in Connecticut by Fuenzalida & Associates (10/95). Original materials were developed for the "1995 Opening Pathways AIDS Campaign" sponsored by the Connecticut State Department of Public Health for Cubans, Laotians, Cambodians and Vietnamese on HIV/AIDS, TB, STDs and breast health.

Recommendations: for all health materials that are in languages other than English, pre-test with local community members who speak and read the language for accuracy of terminology, understanding health messages, cultural accuracy, and syntax. Don't expect that all non-English health materials have been tested. Development of original health materials must include date of publication and local agency address/phone or space to be provided. All health materials must be reviewed for accuracy, and changes incorporated before copies are disseminated. Use the health materials evaluation form provided to begin assessment of currently used health materials

3. *Today's Latina Lesbian and Gay Latino Agenda.*

Presenters: Martin Ornelas-Quintero, Director of AIDS Programs for National LLEGO and Mizzette Fuenzalida, President of Fuenzalida & Associates, Minority Health Consultants. Facilitator: Barbara Garcia, Associate Administrator for AIDS for SAMHSA.

All participants agreed to change the name of the workshop to be inclusive of Latina Lesbians.

The National Latino/a Lesbian and Gay Organization (LLEGO) presented a vision for the Gay Latino agenda that included creating a safe space; increased visibility; cultural redefinition; challenging taboos; training, mentoring, and nurturing of gay latino males, and building communities and environments in which HIV prevention

can be redefined to address the needs of gay latino men. Issues discussed surrounded terminology of men-who-have-sex-with-men (MWM or M&M) as to whether they are actually straight latino males or gay latino men with outreach strategies discussed for both definitions.

It was noted that neither a national Latina Lesbian agenda nor a Latina Lesbian health agenda exist, mainly due to the lack of non-anecdotal information. The dearth of statistics for latina lesbians complicates the dialogue on a focused health agenda. Two previous questionnaires in 1992 and 1993 did not have a large enough sample to assist in a national health policy debate.

National agenda issues to be considered by, for, and about latina lesbians under health are domestic violence, substance abuse, health insurance, family issues (child care), HIV/AIDS, and breast/cervical cancers. General issues that must be addressed in a national agenda are employment discrimination, equal housing opportunities, immigration, and all womens' rights. Overarching issues for inclusion are empowerment of all women; i.e., lesbians, latina lesbians and others; core issues of wellness: mental, spiritual, emotional, and physical; and equality: access to and treatment of health care, economic, and political issues.

Until such time as a national needs assessment can be designed, implemented, and analyzed, the anecdotal information on Latino/Latina health would indicate: 1) a distressed and non-use of the medical community in services, prevention, treatment, and research; 2) misperceptions of health care providers; 3) higher percentage of dually diagnosed HIV/AIDS and substance abuse. The anecdotal information of Latin lesbian's health would indicate: 1) misdiagnosis of infectious diseases; 2) economic and employment barriers to spousal health insurance benefits; 3) lack of research and clinical trials specifically designed for Latina lesbians; 4) higher percentage of diagnosed terminal illness when the health system

Anecdotal information pertaining to health issues of Latino gay men and MSM would suggest that 1) bisexual behavior often increases the risk of all sexually transmitted disease infections to their female partners; 2) lack of social support is a contributing factor to the higher incidence of suicide for young, gay Latino males; 3) internalized homophobia is a barrier to the reception of prevention messages by Latino, gay males and MSM; 4) poor self worth and group peer pressure contribute to a higher percentage of Latino men who abuse alcohol and/or drugs; 5) gay males have an increased risk being victims of violent behavior, suffering broken limbs and, in many cases, even death. The beating of gay men has occurred with such frequency that a phrase, "gay bashing", was coined; 6) an implicit part of the Machismo attitude is the denial of personal risk even when engaged in high risk, sexual activities. These and other indicators must have equal consideration by the medical institutions, public health, and policy makers of this country. A long history of ignorance and dismissal of particular segments of the population cannot

continue.

Recommendations

At the minimum, a regional/local needs assessment of health practices, knowledge and behavior of latino gay men, MSM and latina lesbians desperately needs to be funded. Ideally, the assessment would all Hispanic/Latino persons.

- Investigate the use of universities to develop pilot studies to study these Latino groups.
- Use existing data, if it is available, from reports of research organizations, Health Departments, and AIDS planning groups to create research/data networks with the purpose of expanding and sharing the knowledge gathered from research in the Hispanic/Latino community. Use this data to support and justify the work of Community Based Organization's.
- Provide training and technical assistance to Latino Community Based Organization's to enhance their capacity to create, access, and analyze data.
- Convene community focus groups with the purpose of seeking solutions to and identifying improved health/prevention interventions for Latino gay men, MSM, Latina lesbians, and young persons.

4. Building Responsive Networks Among Agencies Serving the Latino Community.

Presenters: Monica Medina, Acting Executive Director for MHAC; Henry Pacheco, MD, Director of the Center for Health Promotion for NCLR; Tom Valverde, President Hispanic AIDS Coalition of Greater Kansas City.

Each of the presenters established specific strategies that are currently used on the national, regional, and local levels to build stronger and more responsive support systems for service providers to the Latino community.

Regional/local strategies and recommendations to assist in forming effective coalitions include ten characteristics that are common to all successful partnerships:

1. The coalition has a clearly defined purpose and scope.
2. The coalition has regular meetings with a substantive agenda.
3. Membership requirements are clear and specify whether members may include any other organization.
4. The coalition is effective in obtaining resources and financial commitments from its members.
5. All members agree to the principles, purpose and scope.
6. On issues that support specific actions, there is a well defined procedure for developing policies.
7. A steering or executive committee meets more often than the general body.
8. The coalition does not take positions which are bound to be divisive by putting the interests of some coalition members against the interest of other members.

9. The coalition is effective in obtaining programmatic commitments and ongoing active participation from its members.
10. The coalition finds ways to obtain staff resources.

Specific issues and recommendations for the local metro-Kansas City area were discussed as part of the work the HACGKC has done since April 1995. It was noted that the Coalition by itself cannot make the changes happen. The changes must take place as a community-driven partnership with the Coalition in cooperation with: 1) the local health department; 2) Hispanic leaders of the metro area, elected officials, business, school, religious, health agencies, and others; and 3) from the state health departments of Kansas and Missouri.

1. Additional/increased Hispanic representation is needed to advocate for local Hispanic concerns. The Coalition has made changes in its bylaws to include a new committee, the Care Committee. The committee develops the organization's policy position on service needs and reports on Ryan White and local health department Positive Care meetings. Participation of the Coalition Care Committee at health department meetings provides representation of Hispanic health concerns.

2. Increased involvement in HIV/AIDS is necessary and expected of CBO directors whose agencies serve the Hispanic community. Round table discussions have been attempted to raise the level of local directors' awareness about Hispanics and HIV/AIDS. These have been done in partnership with the City office of Minority Health, KCMO health department, PHS Region VII Minority Health Coordinator and the Coalition.

3. A broad-based community supported initiative is essential to the Coalition's future successful partnerships. A media campaign describing the work of the Coalition must be developed and implemented to raise the awareness of the local Hispanic community about HIV/AIDS. The Coalition will submit articles to regional print outlets that serve Kansas, Oklahoma, and Texas and will request assistance from NCLR's media director in providing technical assistance to the Coalition on press release, press conferences, press packets, etc.

4. In order to bridge the cultural/linguistic barriers present for the local Hispanic community when attempting to access health care, more bilingual/bicultural HIV/AIDS health care workers must be hired by the local health departments of KCMO and KCKS. The Coalition has taken the lead in the request of hiring language/cultural appropriate case managers for Hispanics who have HIV/AIDS or who are at risk and need specific prevention messages. Cooperation and equitable partnerships are recommended by the Coalition to all agencies who serve Hispanics who are at risk of acquiring HIV, are HIV + or who have AIDS.

5. The Coalition has set HIV/AIDS prevention outreach for youth as a priority to be addressed via a newly formed Youth Committee. In the Kansas City metropolitan area, one third of HIV and AIDS cases are represented by youth 13 to 29 years of age. The charge of the Youth Committee is to recruit and educate school-age youth in a manner that is sensitive and respectful of issues involving individual development, sexual orientation, gender preference, language and culture. Youth who have been trained would provide community outreach to promote abstinence from high risk behavior using peer prevention interventions. The Coalition's goal is to have the youth conduct their outreach activities on a city-wide basis and enlist the collaboration of youth programs from various member agencies of the Hispanic community.

In addition, the Youth Committee will serve to address the special issues of young Latinos and Latinas. Some of the issues include: 1) peer pressure to engage in high-risk behaviors such as alcohol and drug use, sexual intercourse with multiple partners; 2) body piercing; 3) tattooing; and 4) survival sex for money and/or drugs.

Youths with a background of dysfunctional families often encounter and experience homophobia, lack of self-worth, teen pregnancy, poor mental health, low literacy levels, poverty, lack of positive values, homelessness, and difficulty with gender-defined roles. To attempt to reach as many at-risk young persons as possible, the Youth Committee will offer prevention interventions directed toward juvenile offenders, school dropouts, gang members, young immigrants with minimal English language skills, and youth involved in migrant and seasonal work. Some Coalition member agencies which serve youth will seek to collaborate with the Centers for Disease Control (CDC) Prevention Marketing Initiative. Technical assistance would be provided by the CDC in the areas of social marketing and behavioral principles to improve prevention messages and interventions targeting young Hispanic persons.

Since the Spring of 1994, a continual dialogue has taken place between the director of AIDS programs at National LLEGO (Latino/a Lesbian and Gay Organization) and the President of the HACGKC. Discussions have centered on the lack of HIV prevention outreach activities currently experienced in Kansas City that target the Latina/o lesbian and gay communities, as well as strategies to address this need regionally and nationally. The establishment of a local Latina/o lesbian and gay organization has been viewed as a priority for the Midwest region, and Kansas City in particular. Concerns and ideas were brought to the attention of the HIV/AIDS Director for the Kansas City, MO Health Department and the director expressed enthusiasm about the potential of such a group for AIDS prevention. Coalition board members, volunteers and others are aware of the urgent need to reach this segment of the Hispanic community and have increased their support. Harvest America Corporation, a member

agency of the Coalition, submitted a proposal to expand their work in HIV prevention targeted to Hispanic men who have sex with men and in September, 1995, hired two health educators for that specific program.

5. Use of HIV RNA Testing and its Implication for Anti-retroviral Therapy.

Presenter: Patrick Nemecheck, DO, Medical Director of the Center for Special Immunology of Kansas City.

A review of the characteristics of HIV disease were presented including the shifting paradigm of HIV from 1983-1995; the viral burden in HIV disease describing the four stages of pathogenesis and additional genetic discussions on the mutation of the virus.

Discussions: centered around: 1) CD4 lymphocyte kinetics, production vs. destruction and HIV pathogenesis conclusions; 2) treatment implications and predictive value of surrogate markers of CD4 cell count and HIV RNA with implication of clinical outcomes; 3) individualized antiretroviral therapy in disease progression and laboratory monitoring and viral replications that tracked diseases progression through clinical trials; and 4) the effects on antiretrovirals on plasma HIV RNA levels and response to therapy with RNA which included a glimpse in to the future using AZT/STC combinations.

HIV as a manageable, chronic illness: within a medical setting indicated a possibility for immune restoration by IL-2 infusion, stem cell expansion and lymphocyte transplantation along with prophylaxis for opportunistic infections and early antiretroviral therapy to slow the progressive deterioration of the immune system.

HIV as a manageable chronic illness within nutritional areas suggests a routine BIA and dietary intake assessment, treatment of hormonal or digestive disorders, appropriate vitamin supplementation, aggressive use of nutrition supplementation and aggressive treatment of malnutrition and wasting syndrome.

HIV as a manageable chronic illness within psychological aspects indicated honest, open assessment of psychological skills, professional guidance through psychological wellness programs, treatment of depression and anxiety disorders and a goal to improve one's psychological skills prior to a crisis rather than during the crisis.

3. Within collaborative partnerships, no one agency or organization can or should be asked to take on all the work. Instead, all agencies within the partnership should commit to portions of the total work.
4. Each agency or organization is responsible for determining its role within the AIDS prevention and services agenda. They must be responsible for, adapt to, determine what fits in their own agency's agenda, and is the most reasonable for them to take on.
5. Educational efforts must be directed to the leaders of Hispanic/Latino churches, community-based organizations, and other agencies to make them more knowledgeable of the communities' needs surrounding HIV/AIDS.
6. In creating allies, persistence and patience are necessary to get their support and build on it. Always extend an invitation to participate to those persons who might be able to help. Keep them informed and create a nurturing atmosphere so that they can ask questions comfortably. Always keep your own community well informed.
7. If data is available from existing reports of other organizations, health departments, AIDS planning groups, etc., use that data to support your agency's work. Don't waste time and energy trying to recreate surveys and documentation.
8. Gather support from other racial/ethnic minority groups involved with HIV/AIDS and ask them to support the needs of Hispanic/Latino communities.
9. Develop a community plan. Convene representatives of city/county health departments, elected officials, educators, civic organizations, religious leaders, media, employers, health professionals, and Hispanic/Latino community advocates who know the needs and are able to express them.
10. The community planning sessions must have members who are dedicated to a re-education and re-alert of the Hispanic/Latino community about the AIDS epidemic.
11. Develop a position statement that all community planning members can sign to demonstrate support for AIDS prevention and services with the Hispanic/Latino community.
12. Use the position statement, local data, and support from allies to educate the mayor, city council, health administrators, elected officials, and others. Establish a network of supportive allies from the community.

V. Summary of General Session:

Mesa Redonda I – Everyone Has a Role to Play in HIV/AIDS Mobilizing the Community.

Facilitator/presenter: Eunice Diaz, Ph.D. M.P.H., Health Care Consultant

The following considerations and recommendations were discussed relevant to effectively mobilizing the Hispanic/Latino community locally, statewide, and regionally around the complex issues of HIV/AIDS. The overall recommendations are that: 1) all leaders are responsible for creating a heightened awareness of HIV/AIDS; 2) all persons from the community must be reached; 3) make use of existing institutions and activities to create HIV/AIDS awareness; 4) utilize fundraising events to create more awareness; 5) develop a unified statement of commitment to help the Hispanic/Latino community with HIV/AIDS issues; 6) have the unified statement read from pulpits to reach the communities of faith; and 7) the price of advocacy can be as small as the cost of a stamp.

Considerations:

1. United and accountable leadership at all levels must exist in the Hispanic/Latino community.
2. Hispanic/Latino leaders' continuous dialogue with members from the community serves as repetitive reinforcement that, with time, constituents will share and uphold as their own concerns regarding HIV/AIDS.
3. Burnout, turf issues, and the need to form strong collaborative relationships for more secured funding are issues that need to be addressed in setting successful strategies to determine what must be done and who (agencies) will do the work.
4. Each agency or organization is unique and has a segment of the community for which they are responsible, or are connected with.
5. Within the Hispanic/Latino communities we have advocates and allies in churches, community-based organizations, and other agencies. Those groups set the tone for how people are served and how services are accessed.
6. Creating allies and keeping advocates informed of our communities' needs is often difficult due to a lack of successful communication techniques with media, not being able to get access to leaders, time, turf, etc.
7. Data collection and methods to collect data that are specific to the Hispanic/Latino communities' diversity are issues that local/state/regional agencies try to address. Funding justifications depend on data and statistics for HIV/AIDS prevention and services targeted for Hispanic/Latino communities.

Recommendations:

1. Hispanic/Latino leaders must set HIV/AIDS as a health priority.
2. Continued communication with the community by Hispanic/Latino leaders is absolutely necessary on the topic of HIV/AIDS.

ADDENDA

SECOND ANNUAL HIV/AIDS FORUM

CONFERENCE SPEAKERS

Eunice Diaz, Ph.D., M.P.H.
Health Care Consultant
2064 Las Tunas
Santa Barbara, CA 93103
Phone: 805-957-0900
Fax: 805-681-7332

Joseph Estrada, Federal Investigator
Office for Civil Rights
601 East 12th Street
Kansas City, MO 64106
Phone: 816-426-7234
Fax: 816-426-3686

Mizzette Fuenzalida, President
Fuenzalida & Associates
Minority Health Consultants
11017 Cone Lane
Silver Spring, MD 20902
Phone: 301-949-3696
Fax: 301-949-6544

Barbara Garcia, Assoc. Admin. for AIDS
USPHS/SAMHSA
5600 Fishers Lane
Parklawn Bldg., #12-95
Rockville, MD 20857
Phone: 301-443-5305
Fax: 301-443-3817

Dr. John Halverson
Region VII Manager
Office for Civil Rights, HHS
601 East 12th Street
Kansas City, MO 64106
Phone: 816-426-7277
Fax: 816-426-3686

Jacqueline Horton, Chief
Office of Minority Health
Missouri Department of Health
PO Box 570
Jefferson City, MO 65102
Phone: 800-877-3180
Fax: 314-751-6041

Sharon Lee, M.D., Medical Director
Southwest Boulevard Family Health Care
340 Southwest Boulevard
Kansas City, KS 66103
Phone: 913-722-3100
Fax: 913-722-2542

Adolfo Mata, Acting Branch Chief
HIV Linkage
Division of Clinical Programs
SAMHSA/CSAT
Rockwall II, 5600 Fishers Lane
Rockville, MD 20857
Phone: 301-443-8435
Fax: 301-443-3543

William G. Mayfield, Regional Minority Health
Coordinator
USPHS Region VII
601 East 12th Street, Room 210
Kansas City, MO 64106
Phone: 816-426-3291
Fax: 816-426-2178

Monica Medina, Acting Executive Director
Midwest Hispanic AIDS Coalition
1753 North Damien Avenue
Chicago, IL 60647
Phone: 312-772-8195
Fax: 312-772-8484

Matthew Murguia, Deputy Director
Division of Policy and Data
DHHS/Office of Minority Health
Rockwall II,
5515 Security Lane, Ste. 1000
Rockville, MD 20852
Phone: 301-443-9923
Fax: 301-443-8280

Peter Nemecheck, D.O., Medical Director
Center for Special Immunology
7301 Mission Road, Suite 339
Prairie Village, KS 66208
Phone: 913-384-7307
Fax: 913-384-5373

Mark H. O'Dell, HIV/AIDS Public Health
Specialist II
KCMO Health Department
1423 East Linwood
Kansas City, MO 64109
Phone: 816-923-2600
Fax: 816-861-3299

Martin Ornelas-Quintero, Director
AIDS Programs
National LLEGO
1612 K St. NW, Suite 500
Washington, DC 20006
Phone: 202-466-8240
Fax: 202-466-8530

Henry Pacheco, M.D., Director
NCLR Center for Health Promotion
National Council of La Raza
1111 19th Street, NW Suite 1000
Washington, DC 20036
Phone: 202-785-1711
Fax: 202-785-0851

Regena Polk, Visiting Fellow
Division of HIV and AIDS
Centers for Disease Control and Prevention
1600 Clifton Road, MS-D21
Atlanta, GA 30333
Phone: 404-639-0906
Fax: 404-639-0910

Irene Salazar, Minority Health Coordinator
Division of Health Education and Chronic
Disease Control
KCMO Health Department
301 E. Armour Boulevard, Suite 430
Kansas City, MO 64111
Phone: 816-561-1044
Fax: 816-561-6384

Tom Valverde, President
Hispanic AIDS Coalition of
Greater Kansas City
1333 South 27th Street
Kansas City, KS 66106
Phone: 913-677-0100
Fax: 913-362-8250

Roberto Vazquez-Pacheco, Coordinator of
HIV Prevention
National LLEGO
1612 K St. NW, Suite 500
Washington, DC 20006
Phone: 202-466-8240
Fax: 202-466-8530

**HISPANIC AIDS COALITION OF GREATER KANSAS CITY
BOARD OF DIRECTORS**

Tom Valverde, President
Civic Volunteer

Vanessa Finley
Youth Opportunities Unlimited

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Guadalupe Center, Inc.

Mary Lona
Civic Volunteer

Angel Rizo, Secretary
Harvest America Corporation

Mykl Moraes
Harvest America Corporation

Roberto Archuleta
Civic Volunteer

Anne Roberts
Y.M.C.A., KCMO

Ingrid Backus
Y.W.C.A., KCKS

Stella Ruiz
El Centro, Inc.

Maureen Blair
KC Free Health Clinic

Hope Zapien
Cabot Westside Clinic

Forum Exhibitors

Center for Health Policy Development, Inc.
6905 Alamo Downs Parkway
San Antonio, Texas 78238
Phone (210)520-8020 Fax (210)520-9522

Center for Special Immunology
7301 Mission Road, Suite 339
Prairie Village, Kansas 66208
Phone (913)384-7307 Fax (913)384-5373

Department of Health and Human Services
Center for Substance Abuse Treatment
Rockwall II
5600 Fishers Lane
Rockville, MD 20857
Phone (301)443-8435 Fax (301)443-3543

Department of Health and Human Services
Office of Minority Health
Rockwall II
5515 Security Lane
Rockville, MD 20852
Phone (301)443-9923 Fax (301) 443-8280

Department of Health and Human Services
Substance Abuse Mental Health Services Administration
5600 Parklawn Bldg.
Rockville, MD 20857
Phone (301)443-5305 Fax (301)443-3817

Good Samaritan Project
3030 Walnut
Kansas City, MO 64108
Phone (816)561-8784 Fax(816)531-7199

Guadalupe Center, Inc.
2641 Bellevue
Kansas City, MO 64108
Phone (816)561-6885 Fax(816)561-7009

Hispanic AIDS Coalition of Greater Kansas City
1333 South 27th Street
Kansas City, KS 66106
Phone (913)677-0100 Fax (913)362-8250

Midwest Hispanic AIDS Coalition
P.O.Box 470859
Chicago, IL 60647
Phone (312)772-8195 Fax (312) 772-8484
National Council of La Raza
Center for Health Promotion
1111 19th Street, N.W., Suite 1000
Washington, D.C. 20036
Phone (202)785-1670 Fax (202) 785-0851

National LLEGO
1612 K Street, N.W., Suite 500
Washington, D.C.
Phone (202)466-8240 Fax (202)466-8530

U.S. Public Health Service
Center for Disease Control and Prevention
1600 Clifton Road
Atlanta, GA 30333
Phone (404) 639-0906 Fax (404) 639-0910

U.S.Public Health Service
Region VII Minority Health Program
601 E. 12th Street
Kansas City, MO 64106
Phone (816) 426-3291 Fax (816) 426-2178

Visiting Nurse Association of Greater Kansas City
527 West 39th St.
Kansas City, MO 64111
Phone (816) 531-1200 Fax (816)531-8231

Minority Health Perspective

Prevention Starts with Us

*By Clay E. Simpson, Jr., PhD, Acting Deputy Assistant
Secretary for Minority Health*

In our companion editorial, Patricia Fleming reviews the data for minorities and the tragic story these statistics tell about HIV in our communities.

Our people—African Americans, Hispanics, Native Americans, Asian Americans, Pacific Islanders—know this story in their hearts. We know that AIDS is spreading among children and adults, men and women, straight and gay. We know that AIDS does not “see” race, gender or sexual orientation. But still, too many people think the disease can’t affect them.

This attitude of denial must change. Our communities must address AIDS in an informed and collective manner. For those already involved in this effort, we applaud you. For others, we ask that you join us.

I know that minority communities receive limited health funding, and that AIDS is not always on the top of the list among people who worry about jobs or housing. Yet, we do have proof that AIDS prevention programs can succeed if they are based on sound scientific and cultural perspectives.

We must recognize that the federal government’s role in prevention and service provision is changing. There is a shift to the state level. In the coming months, you will hear more about block grants, or “performance partnerships.” This means that states would be able to choose from health objectives suggested by the federal government, or determine their own. States would be relatively free to determine action plans. The federal government would be more concerned about outcomes than strategies.

But you cannot wait for federal or state governments to come to you and ask, “What do you think?” You must go to them and say, “This is what we think!” By participating in planning committees and attending public hearings, you can become a part of developing your state’s performance partnership plans.

If you don’t know how to contact your state health policymakers, your state minority health office, or your local AIDS service organization, call our OMH Resource Center (1-800-444-6472), and we’ll put you in touch with the right people.

HIV disease is devastating our communities and will continue to do so. Today, there is no cure, only prevention. Prevention works, but only if our brothers and sisters hear the message. And the only way they will hear the message is if we all commit to telling and retelling the prevention story. The future is now.

No Time to Retreat

*by Patricia S. Fleming
National AIDS Policy Director, The White House*

In June, our nation passed a milestone as we entered the fifteenth year of the AIDS epidemic. We have lost more than 300,000 men, women, and children to a disease that was not even in the medical books in 1980. Among those are more than 100,000 African Americans and more than 60,000 Hispanics/Latinos.

The AIDS epidemic continues to sweep through communities of color. In 1994 alone, African Americans diagnosed with AIDS represented nearly 40 percent of all cases in the United States. Hispanics/Latinos diagnosed with AIDS represented nearly 19 percent of all cases. Nearly three-quarters of women reported as having AIDS were African American or Hispanic/Latino. And seventy-nine percent of the children diagnosed with AIDS were African American or Hispanic/Latino.

Statistics like these demand action. In the last few years, the federal government has been aggressively fighting AIDS in minority communities. In the three budgets he has submitted to Congress, President Clinton has increased AIDS funding by 40 percent, despite the pressures of a zero-growth budget. Included in that increase is a 33 percent boost in AIDS research and a 108 percent gain for the Ryan White CARE Act, which delivers primary care services to people living with HIV/AIDS.

But along with funding, we need leadership and vision. That’s why we have been working closely with the National Minority AIDS Council to develop new strategies for AIDS prevention. One such program that I am excited about encourages minorities infected with HIV to get early treatment with antibiotics that can prevent *Pneumocystis carinii* pneumonia, the leading cause of death for people with AIDS.

We must pay close attention to our young people. Recent studies show that half of new HIV infections in this country hit people under the age of 25, and a quarter affect those under 20. We also must do more for gay and bisexual males. A recent report shows that between 1989 and 1994, the number of cases affecting gay and bisexual African American men rose nearly 21 percent.

We must continue to search for better and less expensive treatments. Providing high-quality, affordable health care must remain a top priority. And as a nation, we cannot afford to slow our efforts to find a vaccine and a cure.

Celebrating “El Dia de los Muertos” BACKGROUND INFORMATION ON ALTARES

Since the sixteenth century, the custom of preparing “altares”(altars) has been an on going tradition among the Spanish speaking countries of the Americas. Altares welcome ancestral spirits to visit and to once again be among the living. This custom allows families and friends to remember and honor their deceased loved ones.

Altares represent the blending of the indigenous religious culture with that of the Spanish church in the indigenous world where death is not feared but viewed and celebrated as an integral part of life. Death is life on another stage. Corpses and skeletons were new images of death brought to this hemisphere by the early European settlers. The dichotomy of life and death, is celebrated in a communion between the living and “los difuntos”(the departed) loved ones.

This communion is realized via the altares prepared in homes and served with offerings for the spirits of the deceased. Foods such as “pan de muerto” (bread of the dead), fruit, tamales, tea wine and liquor is offered. Religious symbols — “santos” (saints) and crosses, saint cards, colorful flowers and mementoes recalling the deceased are customary. Votive candles “light the way” for the deceased. Waterfilled glass bowls are placed on the altares as water is symbolic of the transition of life from one state to another. Water also suggests purity and purification. Water filled glasses are also made available for the spirits to enjoy after their long journey back to earth.

“El Dia de los Santos” (All Saint’s Day) is traditionally observed on November 1. “El Dia de los Muertos” (the Day of the Dead) is celebrated on November 2..

Suggested items for the altar include but are not limited to the following:

Photos, greeting cards or note cards with messages, keys, small stuffed animals, crystals, stones, ristras, shells, potpourri, silk and paper flowers, slogan pins. Marigolds are the traditional fresh flower used. Red ribbons would be appropriate because this is an AIDS altar.

Information compiled by Tom Valverde

ATTACHMENTS

Second Annual HIV/AIDS Forum Participant Comments

"Next year could State/Local Health Departments provide scholarships? Maybe even Federal agencies participating at forum."

"Please have Dr. Avendaño from NAPWA return next year. He did a fantastic job last year."

"The Altar for celebrating El Dia de los Muertos was a very nice addition; good to share culture with persons from other backgrounds."

"Very good atmosphere for meeting. Good idea to meet in small groups."

"Brochures, flyers very informative and useful. Great job by all exhibitors."

"Need to work with and involve media as a more integral part of the forum for next year."

"Evaluation Form needs to allow for additional comments; indicate what was most/least useful part of forum."

"Forum format well planned; diverse workshop topics with very good presenters."

"Very interesting overall; excellent speakers - very knowledgeable and personable."

"Was a very good conference for networking with others; will be here next year and will tell others to attend."

"Enjoyed the small group presentations; more conducive to active participation by all."

"Impressed with non-Hispanic persons in attendance. They demonstrate a great concern for Hispanic people."

"Persons from CDR, OMH and SAMHSA very helpful and knowledgeable. Didn't expect them to be so approachable. Really enjoyed them all."

"Both the participants and the presenters very prepared and knowledgeable about cutting edge issues in HIV/AIDS and Latino issues."

"Was here last year; this year even better! Enjoyed the Latino Caucus - great idea. Please keep for next year."

"The information presented regarding coalition building was fantastic! It was so clearly presented. I'm very impressed with Ms. Medina."

"The Mexican pastries were wonderful. The opening reception was very nice and a good way to meet new people."

"Our issues and concerns were very evident in the planning of the workshops with the most appropriate presenters."

"This was a wonderful meeting. I've gained a lot of new information and I've made a lot of new contacts."

"Impressed with diversity of groups presented from LLEGO to NCLR, OMH to SAMHSA CDC to MHAC, CHPD to CSAT. My first opportunity to meet these persons. They were all so informative and really wanting to help me in my AIDS work."

"Would like to see new tracks next year on youth, their issues and prevention

needs, and on doing advocacy to our Senators."

"Invite representatives of United Migrant Organizations (UMO's) from Milwaukee to present next year."

Community Based Organizations serving the Hispanic community need to all be represented by their Board Chairs, Officers and Executive Directors to demonstrate their real concern for this issue. Leaders need to lead!"

"Next year's Forum should involve the participation of other gay Latino groups - not only National LLEGO"

"Is it possible to earn CEU's for participating at the Forum?"

"Members of State Community Planning groups and Ryan White Consortia should attend this forum. Especially those persons who are on minority issues committees to present their work for Hispanics and to hear and then report back to their groups, the HIV/AIDS concerns of the Hispanic community."

"The Forum should include persons openly living with AIDS as presenters to give us their unique perspective on how to improve services for them."

"Would like to have more information about the Hispanic AIDS Coalition - how to join; also the Midwest Hispanic AIDS Coalition."

"Forum very well organized. Appreciate the time allowed to network and the Latino Caucus."

"Television on Altar good attention grabber. The sign, "The many faces of AIDS" which was on it is very thought provoking - good for illustrating how you never can tell who may be infected."

"Thank you for offering materials in both English and Spanish. Keep it up!"

"Need to address Community Based Organizations and ASO need for involvement in advocacy and public policy. Have TA workshop spelling out advocacy for HIV/AIDS 101."

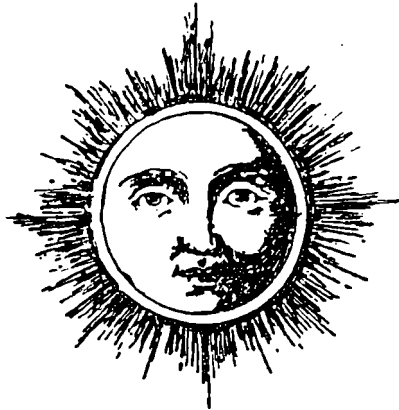
"Both Latino Caucuses very good. I liked the "talking fish" and the moderator who clearly set rules for group discussion. Very good moderator."

Twenty evaluation forms were received. The following are the total scores for each of the eight questions. A score of 200 would indicate a perfect 10 points for all 20 questions.

Out of a possible total of 1600 points, the Forum scored 1258.

"Strengthening Community-Partners Against AIDS"
"Fortaleciendo a la Comunidad-Aliados en Contra del SIDA"

The Second Annual HIV/AIDS Forum



Friday and Saturday, October 27 and 28, 1995

Kansas City Marriott Downtown

Overall Forum Evaluation

The Hispanic AIDS Coalition of Greater Kansas City sought to achieve a number of objectives via the annual HIV/AIDS Forum. Please indicate how well each of these objectives were met.

1. Identify Hispanic HIV/AIDS needs and concerns

0 5 10
Not at all Well Very well

2. Develop new, stronger and more effective partnerships

0 5 10
Not at all Well Very well

3. Facillitate networking among people of color groups and organizations

0 5 10
Not at all Well Very well

4. Recommend inclusion of substance abuse and mental health interventions into agendas of other Hispanic organizations

0 5 10
Not at all Well Very well

5. Provide a better understanding of performance partnerships

0 5 10
Not at all Well Very well

6. Advocate increased access to clinical studies and treatment

0 — — — — 5 — — — — 10
Not at all Well Very well

7. Promote effective interventions to reach Hispanics from various at risk groups

0 — — — — 5 — — — — 10
Not at all Well Very well

8. Observed "El Dia de los Muertos"

0 — — — — 5 — — — — 10
Not at all Well Very well