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BRIDGING THE GAP:
A WORKSHOP ON HIV TREATMENT INFORMATION DISSEMINATION
FEBRUARY 25-26, 1993

Omni Georgetown Hotel
Washington, DC

This workshop report, like the meeting itself, is the result of a collaborative effort among community-based constituency groups, the Public Education Technology Transfer Working Group (PETT), the Office of AIDS Research and the National Institute of Allergy and Infectious Diseases of the National Institutes of Health, and the Health Resources and Services Administration. As such, it reflects a diversity of perspectives on both problems and alternative solutions to dissemination of information about HIV treatment. The recommendations from the meeting are a call to action for all individuals, community groups, and agencies responding to the AIDS epidemic.

The points of view expressed in this document do not necessarily represent those of the Department of Health and Human Services or any of its component agencies. This report was developed for information purposes only; information presented is as presented at the meeting. Statistics and figures cited by the participants have not been verified. Mention of trade names, commercial products, or organizations does not constitute endorsement by the U.S. Government.

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Prepared by Johnson, Bassin and & Shaw, Inc. and Prospect Associates

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Introduction	1
Summary of Recommendations	4
Improve the Quality of HIV Treatment Information Materials	4
Improve Access to HIV Treatment Information	6
Improve Coordination of Information Dissemination	7
Day One Plenary Report	9
Plenary Session: Perspectives on Information Issues	10
Roles and Resources:	
NIAID	10
HRSA	10
PETT	11
Personal Perspectives	11
Community Perspective	12
Key Issues	13
Plenary Session: How Can We Better Communicate HIV/AIDS Treatment Information?	
Gary MacDonald	15
Michael Carbine	15
Nelvis Castro	16
Jerome Boyce and Lisa Padro	16
Corey Dubin	16
Day One Breakout Group Summaries	17
Group #1: People in Contact With the Health Care System	19
Group #2: Populations Facing Oral and Print Communication Barriers	25
Group #3: Culturally Specific Populations	31
Group #4: Women	37
Group #5: Age-Specific Audiences	43
Group #6: Substance Users	48
Group #7: Sexually Defined Communities	54
Group #8: Health Care Workers and HIV Educators	58
Day Two Plenary Report	62
Plenary Session: Federal Government Perspectives and Resources	62
NIAID	63
HRSA	63
CDC	64
NAPO	64
NLM	65

Summary of Day Two Breakout Sessions 67

Conclusion. 77

Appendices: Planning Committee
Full Agenda
Participants List
Acronyms

INTRODUCTION

This workshop is the result of a cooperative effort among the National Institute of Allergy and Infectious Diseases (NIAID) Office of Communications, the Office of AIDS Research of the National Institutes of Health, the Health Resources and Services Administration (HRSA), and the Public Education Technology Transfer (PETT) Working Group.

The charge of the workshop was to tackle the challenge of providing HIV/AIDS treatment information to the people who need it in an innovative, effective, efficient, and expedient manner. To address this issue, more than 125 representatives of organizations and agencies and interested individuals who want to improve HIV/AIDS treatment information exchange met for two days to discuss a myriad of issues related to treatment information development and dissemination. The participants represented community-based organizations; academia; local, state, and Federal government; industry; and individuals living with HIV/AIDS. "The meeting allowed for a diverse group to come together and provided an extraordinary opportunity for everyone to take advantage of the collective experience."

The primary objectives of this workshop were:

- To develop recommendations for mechanisms that would foster the dissemination of information about HIV-related standards of care, new treatment options, and information about clinical trials to primary care providers, community-based HIV/AIDS service organizations, and persons with HIV/AIDS.
- To develop recommendations regarding the varying communications styles that may be most appropriate for particular ethnic and cultural groups and for traditionally underserved or hard-to-reach persons.
- To identify communication networks with which Federal organizations may link to disseminate information and to determine how non-Federal organizations may best make use of local and regional networks for communication.

The mood of the workshop reflected a new spirit of collaboration. Participants were highly motivated to confront barriers to information dissemination and to discover new paths and directions for disseminating information to HIV-affected communities. "The hope of the conference was that, together, participants could find some common ground, find a way to begin to address the problems concerning information dissemination, and begin to solve them."

The workshop was structured to encourage participation from all attendees. Plenary sessions were followed by breakout sessions led by experienced facilitators knowledgeable about HIV/AIDS. The sessions were: People in Contact With the Health Care System (originally titled "People With Access to HIV/AIDS Information"); Populations With Barriers to Oral and Print Communications; Culturally Specific Populations; Women; Age-Specific Audiences; Substance Users; Sexually Identified Groups; and Health Care Workers and HIV Educators. The breakout sessions on day-one were designed to identify barriers, information objectives, and possible solutions for a particular population. The breakout sessions on day-two addressed implementation issues. Each group identified a particular communications strategy and discussed how it could be implemented.

This report follows the general format of the two-day workshop. The plenary sessions are summarized, followed by summaries from the breakout sessions. The day-one breakout sessions are reported individually. Day-two breakout sessions are reported in a single section to provide continuity and clarity. Because several general themes were common to all groups, this section is organized by communications strategies, followed by a summary of the ideas discussed by the groups.

A summary of recommendations follows this introduction. It contains a description of the general recommendations and approaches suggested by the participants. These recommendations will help guide NIAID, HRSA, other Federal agencies, community-based organizations, and other groups and individuals in their efforts to disseminate HIV/AIDS treatment and clinical trials information to the individuals and organizations that serve people with HIV/AIDS.

"We worked together (the community groups and representatives of the Federal Government) and really talked about the issues and how they arose. It wasn't just the community people telling the Feds what they wanted. It was a give and take."

A Brief History of This Workshop

NIAID is responsible for developing and testing new therapies for people with HIV/AIDS. The PETT Working Group, which grew out of NIAID's AIDS Clinical Trial Group, has as its major goals improving access to HIV/AIDS trials-related information and making persons with HIV/AIDS or those at risk aware of new treatment options. The AIDS Research Advisory Committee (ARAC) advises NIAID on issues relating to AIDS research and information dissemination. HRSA ensures the support and delivery of primary health care services, particularly for the disadvantaged and underserved.

The PETT Working Group and ARAC recommended that NIAID undertake more HIV/AIDS communication initiatives, noting that special emphasis needed to be put on reaching populations traditionally lacking access to treatment and research

information, such as people of color, women, substance users, and those with barriers to reading materials written in English. At the same time, HRSA's AIDS Program Office, with support from its AIDS Advisory Committee, wanted to expand existing information dissemination activities. The organizations recognized their complementary ability to address the important issue of improving public knowledge of and access to HTV/AIDS treatments and clinical trials, and in August of 1992, NIAID and HRSA began looking for more effective ways to exchange information and disseminate it to their respective grantees. They also recognized the vital role of community-based organizations in reaching traditionally underserved populations, a particular concern of the PETT Working Group. The result was a meeting to explore all of these issues -- Bridging the Gap: A Workshop on HIV Treatment Information Dissemination.

SUMMARY OF RECOMMENDATIONS

"When you think about it, we are creating history . . . it really makes you think that all the people we have loved and lost didn't die in vain, because we are all here trying to work it out." -- Dr. Jifunza Wright

"Bridging the Gap" brought together representatives of organizations and agencies that included advocates for women with HIV/AIDS, people of color, diverse sexually defined communities, health care professionals, substance users, youth, people with hemophilia, and those with and without access to HIV/AIDS information. The willingness and ability of highly diverse groups to work together at this meeting was itself an important step forward.

In two days of plenary presentations and breakout group sessions, participants discussed important needs and barriers that affect information dissemination as well as possible solutions and recommendations. This summary presents the crosscutting themes that emerged from many hours of detailed, dynamic, and heartfelt discussion. It includes recommendations to improve the quality of HIV/AIDS information, access to HIV/AIDS information, and information coordination.

The themes and recommendations that follow are axioms to be considered by all groups engaged in HIV/AIDS treatment information dissemination, including individuals and organizations at the community level and Federal Government agencies.

Recommendations To Improve the Quality of HIV Treatment Information

An important priority in improving HIV/AIDS information exchange is improving the quality and appropriateness of the information provided. The recommendations that follow suggest creative approaches for meeting the information needs of diverse audiences.

1. Tailor information to the needs, preferences, and characteristics of the audience.

Participants underscored the need to involve people from the target audience when developing new materials because they can most appropriately determine whether materials suit their needs. This was considered part of a "social marketing approach." Specific suggestions included using audiences' language and terminology, targeting at an appropriate level of complexity, paying attention to audience attitudes and sensitivities, and using familiar images and points of reference.

This issue encompasses more than the need for culturally appropriate products. It also includes the need for health care professionals to provide more sensitive one-to-one counseling and education. Participants uniformly expressed concern that people of

color and other groups do not trust the medical establishment. Similarly, many health care providers are not comfortable dealing with people from other cultures and communities they may not understand. As a result, many people with HIV/AIDS do not receive information in a sensitive, compassionate way. Several groups recommended that providers receive training in how to communicate effectively with individuals from diverse populations. Some participants suggested using a "harm-reduction model," which is a treatment model in which providers respond to priority issues as defined by the patient and in which providers avoid castigating or stigmatizing people with HIV/AIDS for their behaviors or choices.

2. Provide information in formats people can use.

While many written materials are available on HIV/AIDS topics, many people who need treatment information cannot read, have low literacy skills, or do not respond well to written materials. Variations in language, literacy, and learning styles suggest that a greater variety of information products and approaches should be developed. Some ideas include videotapes, television programs, photographs, advertisements, comic books, street theater, music, comedy, computerized materials, user-friendly factsheets, and cassette tapes. It was also suggested that "chaptered videotapes" (organized in sections, or chapters) be created to allow people to access chapters individually so that they can deal with various issues as they arise.

3. Provide information on all topics people need to understand.

Participants suggested that current materials do not address a wide enough range of topics. Some felt that information about clinical trials is more available than basic information about where to get care, what may occur over time, and what people living with HIV/AIDS should discuss with their health care providers. People with HIV/AIDS also need information on technical medical issues such as CD4 counts and different types of treatment. People also want to know about psychological and coping issues such as living with HIV/AIDS and hopelessness, as well as about nontraditional and alternative therapies. In addition, materials should do more than simply educate people; they should motivate people to change their lives.

4. Ensure the accuracy of information provided.

Two primary concerns were expressed by participants. HIV/AIDS products need to convey the most up-to-date facts about HIV/AIDS and treatment, and they need to be monitored for accuracy. It was noted that, due to the fast-breaking nature of HIV/AIDS advances, it may be difficult to keep materials up-to-date in a timely manner. However, quality control must still be a priority. Second, more diverse and accurate images of people living with HIV/AIDS have to be portrayed. The mass media was particularly criticized for the negative picture it paints. Media images do

not recognize that many people with HIV/AIDS look good, feel well, live independent and productive lives, and manage their condition as a chronic disease.

Recommendations To Improve Access to HIV Treatment Information

Another key to improving information exchange is improving the availability of appropriate information. Yet, many noted underlying barriers that are beyond the scope of what the represented groups have the ability to change: poor access to health care and the economic and social problems experienced by many people with HIV/AIDS. For educational efforts to be effective, the basic needs of people with HIV/AIDS must be taken into consideration. Recommendations to address these barriers and make critical information more accessible included the following:

- 1. Involve peers in the development and dissemination of materials and, whenever possible, hire a person from the target community.**

No theme received greater emphasis than the need for peers to help develop materials and disseminate the information. For example, women with HIV/AIDS want to be counseled by other women with HIV/AIDS who understand their family situations, their problems with self-esteem, and the ways in which HIV/AIDS affects women differently. Hiring the "right" person is important at all levels, but it is especially so in outreach efforts.

- 2. Reach people where they are.**

Given that individuals in many communities have little access to traditional health care settings, information dissemination efforts must move beyond the hospital/clinic setting. Participants suggested an enormous range of channels for reaching out with information, including religious organizations, community meetings, culturally specific support organizations, in-home focus groups, supermarkets, WIC and AFDC offices, homeless shelters, shooting galleries, prisons, mental health offices, public bathrooms, the workplace, schools, and adult education programs.

The specific strategy most often suggested was one-to-one communication, which many at the workshop believed is the most effective way to provide information. The outreach activity most often suggested was the creation of population-specific hotlines and "warmlines" staffed by trained peer educators to provide sensitive, one-to-one information.

- 3. Engage the media.**

Many participants felt that the mass media currently are not playing the most appropriate role in communicating HIV/AIDS treatment information. Participants encouraged agencies such as NIAID, HRSA, and the Centers for Disease Control and

Prevention (CDC) to sponsor working groups to talk about the role of the media in HIV/AIDS education, help the media communicate culturally sensitive messages about HIV/AIDS, and promote media coverage of HIV/AIDS treatment information. In addition, these agencies could stimulate community action by providing technical assistance in media relations to community-based organizations (CBOs) and by issuing a call to action.

4. Recognize the potential of HIV-infected individuals to educate those around them.

Regardless of whether individuals choose an advocate role, as many meeting participants have, each person living with HIV/AIDS can play a critical role in educating those around them about both prevention and treatment. They can help deliver prevention and treatment messages in their communities and serve as role models. The key to widespread involvement, however, is creating a safe environment for open dialogue that avoids stigmatization.

5. Provide funding for community-based organizations to develop and distribute information products.

Many expressed the belief that grassroots organizations could make more effective use of limited resources than national agencies. Local groups know their audiences and share cultural identities; they also have existing relationships and communication channels within their communities. This approach overcomes barriers of credibility and trust that sometimes interfere with acceptance of information provided by national organizations.

Recommendations To Improve Coordination of Information Dissemination

In addition to addressing the products and the dissemination channels, efforts to improve information exchange must also address the "system" in which communication occurs. Currently, the participants believe that this system is fragmented and that not enough collaboration occurs. They developed four recommendations to address these issues. In addition, participants stressed the need for more complete representation of the spectrum of people with HIV/AIDS in the research, planning, and education processes.

1. Sustain the collaborative approach this meeting represents.

Participants recognized the importance of creating and maintaining long-term linkages among community-based organizations, research organizations, other service provider groups, industry, and national agencies and organizations. Only by continuing to work together can recommendations become reality.

2. Coordination of Federal efforts should be a top priority.

Everyone agreed that more resources were needed at all levels but that limited resources were the reality. One strategy suggested was to make more effective use of Federal dollars, in part by increasing coordination among Federal agencies. The National AIDS Program Office of the Office of the Secretary of Health is currently addressing this problem by developing an inventory of all activities throughout the Public Health Service. Federal representatives also noted that collaboration fosters better use of resources because it allows each agency to take a relevant chunk of the problem and address it fully, rather than responding partially to the many unmet needs they see.

3. Duplicative efforts and materials should be minimized; wider distribution and use of what already exists should be maximized.

Many useful HIV/AIDS information materials currently exist. Yet, not only are many duplicative but they are also available only to limited audiences. Thus, the ultimate impact of all these similar materials is disproportionately small. Improved collaboration can help ensure that new products are created to fill unmet information needs. It can also promote wider availability of all products.

"We don't need another newsletter."

4. Communication networks should include community-based organizations, rather than relying so much on national organizations.

One example was the need to include grassroots hemophilia groups, which reach a different constituency than that served by the National Hemophilia Foundation. The CDC already has a network that includes more than 30 local and regional groups that represent a variety of minority populations. The NIAID has also established ongoing linkages with many community organizations for research, information development, and information dissemination. As efforts like these are augmented, two-way communication can foster greater awareness and cooperation.

"Together we stand. United we walk. Let's build a bridge. Tear down the walls. Let us respond to our people's call," were the words sung by workshop participants in a closing ritual.

DAY ONE PLENARY REPORT

February 25, 1993

"Bridging the Gap" included representatives from the many communities affected by HIV/AIDS. The planning committee and workshop participants were driven by a sense that the many diverse communities affected by and active in dealing with HIV/AIDS all have information that could benefit each other, but currently it is not being shared effectively. "Bridging the Gap" also gave community representatives a forum for voicing their concerns and needs as well as an opportunity for them to share with others at the workshop the knowledge they have acquired in their communities. It was the planners' intent that the meeting would result in creative proposals for improving communication between and among communities. Finally, they hoped that the workshop would improve the communication of valid, timely treatment information to individuals, their families, and those who treat and serve them.

The workshop began with greetings from Dr. Daniel Hoth, Director of the Division of AIDS at the National Institute of Allergy and Infectious Diseases (NIAID). Dr. Hoth welcomed all participants and briefly remarked on the "extraordinary opportunity" the meeting provided to take "advantage of the collective experience" that was represented by such a diverse group. Dr. Hoth expressed his hope that the meeting would result in the development of a strategy that "will result in effective, targeted dissemination of information about HIV disease." He then introduced the co-chairs of the workshop, Martin Delaney and Dr. Jifunza Wright, both members of the NIAID AIDS Research Advisory Committee, an advisory board that is charged with providing recommendations to NIAID on HIV/AIDS research and the dissemination of research-related information.

Mr. Delaney greeted participants and briefly reviewed the evolution of the workshop. He explained how the Community Constituency Group (CCG) of the NIAID AIDS Clinical Trials Group for some time had been keenly aware that a great deal, perhaps "an avalanche," of treatment and research information was available to the well-educated, middle-class patient, "but that information has not successfully reached many of the other populations that are so deeply affected by AIDS." A subgroup of the CCG, the Public Education Technology Transfer (PETT) Working Group, was then formed to address the situation. This group worked to bring together representatives of the organizations, agencies, and populations most affected by this lack of information concerning treatment of people living with HIV/AIDS.

Dr. Jifunza Wright began by requesting that participants relax and take advantage of the opportunity to work with members of different communities. She reminded participants that "no particular way [of communicating] is right, wrong, good or bad, or better or worse than the other," that the task facing everyone in attendance was to "come together and share," and that "this [is] a beginning, and we can continue

to be [part of the] process." Dr. Wright introduced the Public Health Service Regional AIDS Coordinators and encouraged participants to exchange ideas and suggestions with them throughout the workshop. The coordinators represent 10 different geographical regions and act as liaisons between community agencies and the Federal government. Participants were asked to consider the coordinators personal resources and links to the Federal government.

Plenary Session: Perspectives on Information Issues

Presenters in this session discussed the roles and resources of national organizations currently involved in HIV/AIDS treatment information dissemination and gave their perspectives on key issues that needed to be addressed. In addition, a panel of researchers and representatives from HIV/AIDS communities shared their personal experiences and perspectives and gave voice to the day-to-day realities of people living with HIV/AIDS.

Roles and Resources

National Institute for Allergy and Infectious Diseases

Dr. Hoth explained that NIAID's primary role is to sponsor and conduct HIV/AIDS research, with the ultimate goal of discovering new ways to prevent, treat, and cure HIV infection and AIDS. *"But ultimately, if we are to be effective, we recognize that is only half the job. If our research is to be effective, it has to reach the people who need it."* For this reason, NIAID also takes an active part in disseminating research information to the health care community and to people living with HIV/AIDS through mechanisms such as the AIDS Clinical Trials Information Service (ACTIS), a telephone hotline for health professionals and the public, and a variety of information products for patients, providers, and researchers. Dr. Hoth called these activities the "passing of the baton" to the wider world that makes use of the information. NIAID also seeks information from a range of groups representing communities affected by HIV/AIDS, such as the AIDS Research Advisory Committee (ARAC) and the PETT Working Group. Dr. Hoth concluded that NIAID is aware of the importance of disseminating information to the HIV/AIDS communities and hoped to learn from its participation in the workshop better, more effective ways of accomplishing this part of its mission. *"We want to listen to you."*

Health Resources and Services Administration

Dr. Stephen Bowen, Associate Administrator for AIDS at the Health Resources and Services Administration (HRSA), then addressed the session. He told participants that HRSA is involved in HIV/AIDS issues through its mandate to train health care providers in HIV/AIDS care and to fund HIV/AIDS treatment services. HRSA sponsors two telephone information outreach activities. The first is a warmline that provides HIV/AIDS medical management advice to health care professionals. This service encourages and supports professionals in providing treatment themselves, rather than referring their patients with HIV/AIDS to a specialist. The warmline has recently been expanded nationally, and health professionals can call the 800 number weekdays between the hours of 7:30 a.m. and 5:00 p.m. to speak with a medical specialist. The second is a quarterly clinical conference call that updates health professionals on specific aspects of HIV/AIDS treatment. Through the Ryan White CARE Act, Titles I, II, and III(b), its Maternal and Child Health Programs, and its AIDS Education and Training Centers, HRSA funds several thousand individuals who provide primary health care services around the country. HRSA is eager to create an effective network for the speedy transfer of HIV/AIDS advances.

The Public Education Technology Transfer Working Group

The next speaker was Bob Hultz, editor of the publication *Positively Aware* and a member of the PETT Working Group. Mr. Hultz began his presentation by calling the meeting *"an historic, first-time collaboration among NIAID, HRSA, and community groups"* and by predicting that *"if we do our jobs, we are going to see . . . lives changed."* Mr. Hultz explained that *"PETT has no budget, no organization, no funding, no office, but we do have a mission."* The PETT Working Group's mission is to improve access to information about clinical trials and HIV/AIDS among people who have, are at risk for, or are involved in the lives of people with HIV/AIDS. The group's special focus is to increase collaboration and funding to reach people and communities who have had poor or inequitable access to information. The PETT Working Group also wants to give people information that will enable them to take charge of their lives and to help the lives of their care givers, their care partners, the people for whom they are caring, the people in their agencies, and the people in their local governments. The PETT Working Group believes that if people are given this information, they will have more treatment options, and if their feedback is solicited, they may become more interested in enrolling in clinical trials. Through this workshop, Mr. Hultz explained, the PETT Working Group hopes that the government and the communities would find ways to exchange information effectively about HIV/AIDS treatment. Mr. Hultz showed a visual

presentation of people living with and dying from AIDS. This very powerful slide presentation underscored the value of visual and nonprint media.

Personal Perspectives

The plenary session was addressed by two HIV-positive individuals who gave poignant presentations from their personal perspectives about their experiences obtaining HIV/AIDS treatment information. Travis Hall, a Native American, shared his feelings of anger, fear, and sadness after learning that he was HIV positive. Upon learning his HIV status, Mr. Hall returned to his home on the Navajo Reservation in Arizona, where he became frustrated with not being able to find treatment or information about treatment. He shared his feeling of offense at the lack of respect he has received from staff of treatment facilities. He said that the Native American community has almost no HIV/AIDS treatment services and very little information about treatment. Because of his experiences, Mr. Hall realized the need *"to step forward . . . and help others in [his] situation."* By addressing the plenary session and participating in the workshop, Mr. Hall hoped to help bring treatment information to the Native American community. By participating in clinical trials, he hoped to contribute in a small way to finding a cure for the disease. *"For many people, being positive means death. For some . . . it means life. For me it was the beginning, a new beginning, a starting over . . . There is a lot more work to get done."*

The second speaker, Lisa Hernandez, founder of For AIDS Children Everywhere (F.A.C.E.), is a mother who is HIV positive and who lost a child to AIDS. She reminded participants of the growing numbers of women infected with the HIV/AIDS virus. Drawing on her own experience, she spoke of women's needs for child care, for respect as individuals, for access to information through familiar channels such as supermarket brochure displays, and for interaction with treatment staff who have sensitivity to their needs and concerns. Ms. Hernandez hoped her participation in the workshop would bring attention to the needs of this quickly growing component of the HIV/AIDS community: *"We don't have the time to wait for thousands of us to die so people can realize, hey, we have got to do something about women. No, we have got to start now."*

Community Perspective

Plenary participants also heard from Debra Fraser-Howze, executive director of the Black Leadership Commission on AIDS, member of the Community Constituency Group, co-founder and chairperson of the PETT Working Group, and one of the planners of the workshop. Ms. Fraser-Howze spoke to the group about the efforts that had brought the dream of the workshop into reality, about the efforts of so many individuals to plan and organize the gathering, and about the desire of the organizers to bring to the workshop participants who have shown continuing innovation and determination in facing the HIV/AIDS epidemic. *"This workshop is a testament to*

what is right in America and in the AIDS communities." She asked the participants to "give [the workshop] the gifts of their knowledge base and creative energies--sources that have not, in the past, been tapped."

Key Issues

During their session, the presenters identified a number of factors that will affect efforts to increase the availability of useful information. These include:

- Patient information needs. People with HIV/AIDS need to know where to go to get care, what may occur over the course of their illness, and what they should talk about with their health care professionals. Family members also need to know what to expect. Information about HIV/infection, when it becomes AIDS, the validity of combination and alternative therapies, technical medical issues such as the meaning of CD4 counts and p24, and specific information about clinical trials need to be more accessible.
- The need for empowerment. The panel members pointed out that HIV/AIDS treatment information can do more than educate people; it should give them the power to change their lives, including increasing their willingness to enter clinical trials.
- The need for creative media. The panel members agreed that it is imperative for approaches to go beyond print materials and effectively convey messages to diverse audiences.
- Barriers. These include the following: lack of communication and coordination among Federal Government agencies; lack of funds at the community level; lack of information sources that provide accurate facts about HIV/AIDS; difficulty in knowing about and getting access to existing information, such as newsletters; and stigmatization.

Suggested Information Channels

Panel members stated repeatedly that information needs to be communicated in multiple, varied, and creative ways, and must be communicated by people with a thorough understanding of the target audience. Some channels the panel members suggested include:

- Spanish radio.
- Person-to-person mechanisms.

- Community meetings, such as those sponsored in different cities by Project Inform (a San Francisco organization).
- Religious organizations.
- Culturally specific support organizations.
- In-home focus groups, such as those conducted by the Stop AIDS Project.
- Computer bulletin boards and better systems of electronic information collection and sharing, such as computer faxing and "fax-back" systems. (This is where a caller can choose a topic of interest from a computer-automated system and receive information back almost immediately via fax.)
- Publications customized for different cities or groups.
- Telephone hotlines.
- Ads in gay pornographic magazines.
- T-shirts and buttons, such as those used by Project Inform and Act Up.
- Peer education and support systems.
- Supermarkets.

Plenary Session: How Can We Better Communicate HIV/AIDS Treatment Information?

In this session, a panel of communications experts shared their expertise to help determine more efficient and successful ways to communicate HIV/AIDS treatment information. The speakers included Gary MacDonald of the Academy for Educational Development; Michael Carbine of the National Leadership Coalition on AIDS; Nelvis Castro, Hispanic Program Coordinator for the Office of Cancer Communication of the National Cancer Institute; Jerome Boyce of Project Survival; Corey Dubin of the Committee of Ten Thousand; and Lisa Padro of the Foundation for Outreach. To focus on the theme of finding better ways to communicate treatment information and to provide a starting point for discussion, panel members offered five suggestions, drawn from their varying experiences and expertise.

Use Social Marketing Techniques

Mr. MacDonald uses the tools and techniques of social marketing to get messages across. In this approach, communication begins by researching and understanding the needs, preferences, and situations of the target audience at the outset of any program. Once communications are tailored to the audience, products and messages must also be tested with the audience to doublecheck for appropriateness and relevance. According to Mr. MacDonald, the success of this very powerful technique is dependent on understanding the target audience. The better that part of the research is conducted, the more successful the project will be.

Tap Into the Workplace

Mr. Carbine suggested that the workplace is *"a golden opportunity for getting the word out about HIV disease and treatment."* According to Mr. Carbine, workers, by virtue of their age, constitute the largest sexually active segment of our society; and, these employees trust information they receive at work. The workplace also reaches the community because employees spread the information they receive to their friends and families. To enable the workplace to serve an informational function, he stated, we need to teach company managers that HIV/AIDS can be a chronic disease, not just an acute illness. Employers need to understand the personal ramifications of treatment for their HIV-positive employees and learn about the community resources their employees may need. If the workplace is to become a feasible information channel, Mr. Carbine pointed out, companies will also need to develop the policies and attitudes that promote employee trust and openness. This can be accomplished through measures taken to combat discrimination and company policies that demonstrate that employees who are living with HIV/AIDS are valued.

Target Hispanic and Other Cultural Audiences Wisely

Ms. Castro recommended that communicators adapt successful National Cancer Institute approaches for reaching Hispanic audiences. These include using the INFORUM database to gather demographic and psychographic information; following a very extensive translation adaptation process; using Hispanic celebrities; using vocabulary understandable by all Hispanic audiences (broadcast Spanish); reflecting the diversity of the Hispanic community, which includes Mexican-Americans, Puerto Ricans, Cubans, and others; and working in partnership with the media and Hispanic organizations. Ms. Castro also shared three important lessons from the Hispanic Cancer Education Program: (1) never make special population considerations an afterthought; (2) involve the community; and (3) invest in good translations, but do not assume all Hispanics speak or prefer Spanish.

Address Community Realities and Cultural Barriers

Mr. Boyce and Ms. Padro stressed the importance of paying attention to community realities in designing information strategies. In the real world, they said, many cultural barriers to patient-professional communication exist, including lack of professional familiarity with the learning styles preferred by African-Americans and a lack of provider sensitivity. Another important barrier pointed out by Mr. Boyce is that there is little time for physicians to counsel patients. He said that information needs to be presented in small pieces so that individuals can digest it as they are dealing with the emotional and physical manifestations of HIV/AIDS. In addition, according to Ms. Padro, people who are living in the streets need reliable personal outreach to receive HIV/AIDS and clinical trials or treatment information. To be relevant, efforts must address their immediate needs for food and shelter. "We need to see some sort of deeper sensitivity concerning the plight of so many millions of us across the country."

Engage the Media

Mr. Dubin spoke of the need to engage the media. Currently, he said, many of the messages and images in the media about HIV/AIDS are overly negative and inaccurate. By making demands on television and radio stations, community organizations can help redefine the "realities" the media create and turn a problem into a positive communication channel. The media must move beyond the current monolithic portrayal of HIV-positive people as "passive victims condemned to die a horrible death" and begin to reflect the reality of active individuals living with a chronic disease and participating in their treatment and illness management.

The presentations helped form a framework for the breakout groups that followed. Dr. Wright adjourned the plenary session by asking participants to participate in the breakout groups *"in a spirit of open, honest willingness to share in*

creating solutions" for the current gap in HIV/AIDS treatment information dissemination.

INTRODUCTION TO DAY ONE BREAKOUT SUMMARIES

The Day One Breakout Sessions were designed to identify communication objectives, barriers to treatment information dissemination, and possible solutions or recommendations for defined HIV-affected audiences. These workshops were led by experienced facilitators knowledgeable about HIV/AIDS.

Before the workshop, participants preselected the session in which they would participate. In preparation for the workshop, participants considered the difficulties they and their constituencies have experienced in obtaining and disseminating useful HIV/AIDS treatment information. They brought with them knowledge and experience about what strategies and methods have or have not been successful and about the priority needs among their constituents. Resource people, including representatives from the private sector, non-government organizations and the Federal government, participated in each session to provide background information and answers to questions as they arose. This approach furthered the ability of participants from various communities to work together to develop innovative solutions.

The breakout groups focused on how to communicate with people and organizations who are involved with the following populations:

- People in contact with the health care system (original name: People with access to HIV information)--"It's a problem of appropriate information and information channels; not one of too little information."
- Populations with barriers to oral and print communications--"Barriers to oral and written communications affect all of us."
- Culturally specific populations--Noting that lack of trust is a key barrier, participants approached their solutions with the understanding that "trust comes from developing relationships."
- Women--"The barriers to information sometimes seem secondary to the fundamental problem of access to care, but there are solutions."
- Age-specific audiences--"If I'm afraid of getting shot on my way to school, I don't give a damn about a virus that may kill me 15 years from now."
- Substance users--"They need to understand that there's a real difference between the drugs they're on and drugs that can help them."
- Sexually identified groups--"Taking care of myself means to love myself."

- Health care workers and HIV educators--"There are three fundamental issues: the lack of continuing clinical education; a sense that service delivery organizations are not meeting the needs of people; and the current lack of defined standards of care that exacerbates these two problems."

The spirit of collaboration was obvious in these sessions, even though many people were from very different communities and were working together for the first time.

The following section of this report describes the outcomes of these individual breakout sessions. Each section is organized to reflect the main areas the groups were asked to discuss, including a detailed definition of the target audience, barriers to information for this audience, communication objectives, and recommended approaches to improve treatment information dissemination.

Group #1: People in Contact With the Health Care System (original title: People With Access to HIV Information)

Introduction

"It's a problem of appropriate information and information channels, not one of too little information."

This group was directed to consider the needs of individuals who are already in contact with the health care system but, for whatever reasons, are not using HIV/AIDS treatment information as it is currently available. The sense of this group was that this audience is overwhelmed by information, but it is not in a usable or understandable format. The group suggested that perhaps new mechanisms to organize and disseminate information may need to be created.

Summary Recommendations

This group recommended several ways to improve treatment information dissemination:

- Develop "user-friendly" factsheets.
- Encourage the Federal government to develop standards of care. [Editor's Note: The Agency for Health Care Policy and Research is preparing to release HIV Treatment Guidelines.]
- Encourage the Federal government to create a coordinating body of agencies working on HIV/AIDS issues to reduce the duplication of effort.
- Develop a community-based peer review system for new materials and an advisory committee to work with the Federal coordinating body.
- Use nonprint media and advanced communications-transfer technology.
- Develop a peer-operated 1-800 hotline service to meet the needs of varying populations.
- Establish a non-government HIV/AIDS information clearinghouse.
- Provide training and technical assistance to information providers.
- Develop a peer-run review process to collect information on nonstandard therapies.

Target Audience Definition

The group defined the target audience as individuals who are currently receiving treatment or care; individuals who have an awareness or knowledge of treatment; participants in clinical trials; care partners of people with HIV/AIDS; those who access hemophilia services; transfusion recipients; parents or guardians of children with HIV/AIDS; and the people who are in the public health care delivery system in ever-increasing numbers.

Barriers to Information

To develop recommendations for increasing dissemination of treatment information to those who are not receiving enough or appropriate information, the group first discussed the reasons why these individuals are not receiving the information they need. These barriers ranged from the lack of use of existing information because people cannot access it to lack of use because they cannot understand the information in the currently available format. Specific barriers identified by the participants included:

- Patients, health care providers, and care givers are not using the information sources available.
- Patients, providers, and care givers are not necessarily aware of how to get the available information.
- People who need the information are overwhelmed by the complexity of it. Some of the basic information (e.g., the meaning of test results, scientific terms, etc.) can be confusing, even to those who have been exposed to it.
- Often, medical care personnel either do not have the time to explain information or do not have up-to-date information.
- There is confusion about what materials a person really needs.
- Materials are not well tailored to the needs of specific groups.
- It is difficult to obtain information about issues other than clinical trials.
- Community-based organizations (CBOs) often do not have the equipment or expertise necessary to receive information as it is packaged nor do they have the resources to disseminate it.
- Due to the lack of coordination between Federal and community agencies, not all information is made available to those who need it.

Objectives

- Develop standards of care. "Standards" were recognized as falling into two categories: (1) those generally accepted by the government on an FDA-approved basis and (2) the cutting-edge treatments, off-label usages, alternative therapies, etc. [Editor's Note: The Agency for Health Care Policy and Research is preparing to release HIV Treatment Guidelines.]
- Develop language to communicate treatment standards to a variety of audiences, that is, take into account literacy levels, languages, and cultural tones as required by the audience.
- Assist people to become educated consumers by improving the advocacy and educational methods used in peer programs.
- Develop new approaches for reaching larger, more diverse audiences to increase the use of resources.
- Empower the community to design programs to reach various audiences with relevant information by providing the resources to CBOs for this purpose.
- Communicate information that is relevant and appropriate for particular individuals and communities.
- Use local resources to disseminate information.
- Provide readily accessible information on treatment and clinical trials.
- Develop a Federal mechanism to help non-Federal agencies distribute treatment information (e.g., newsletters, treatment directories, etc.).
- Use nonprint media and other types of communication (e.g., videotapes, cassette tapes, computer diskettes, faxlines, etc.) and alternative locations (e.g., hospital waiting rooms, etc.) to reach different populations.
- Provide more training in communication strategies for health care providers, including nurses, case managers, and social workers.
- Establish and strengthen two-way communication among Federal agencies and grant recipients on all programmatic issues (problems, solutions, successes, and failures).

Possible Solutions and Recommendations

Materials Development

- Develop a series of "user-friendly," informational "factsheets" to address key points, issues, and interventions. These could be one-page, single-topic factsheets or factcards that would provide a variety of information, such as the meaning of an HIV-positive test result, a CD4 cell, or a clinical trial, or the purpose of multiple therapies. The factsheets could be used by clinicians as well as patients, and training in their use for both could be provided through Federal and community channels. They could be developed by a Federal agency but should be researched and developed in collaboration with various Federal agencies (e.g., NIAID, HRSA, CDC, PHS/NAPO, NLM, etc.) and community organizations, using a peer review process to ensure relevant input. The process used by AHCPR to develop the Guidelines for Evaluation and Management of Early HIV Infection may serve as a model for fact sheet development. Distribution of the factsheets could be handled via an information packet that could be updated regularly. The materials should be available in various languages to reach a broad audience.
- Create a new community-based peer review committee. Because some information, especially for controversial or experimental treatments, is unlikely to be disseminated by the government, the group proposed the creation of this committee to generate materials dealing with these sensitive issues. The Federal government would fund periodic meetings of activists from many HIV/AIDS communities to review and discuss such therapies.
- Urge the Federal Government to develop, with input from the community, standards of care that could be updated periodically.

Communications Technology

- Provide treatment information at the community level by using proven successful mechanisms, including electronic bulletin boards, CD ROM, modems, faxlines, etc. The AmFAR Treatment Directory, for example, could be placed on computer disk CD ROM and thus accessed easily by the community. [Editor's Note: The AmFAR Directory currently is available on disk. For more information, contact AmFAR.]
- Develop and establish a peer-operated national 1-800 telephone hotline/warmline to meet the needs of varying populations to provide treatment information and counseling for populations affected by HIV/AIDS. The telephone service could provide referrals for community-

level networks, resource identification, service and counseling support, and information on current clinical trials. Materials such as factsheets and newsletters could be provided. This type of service could be developed to meet as many needs as possible of the majority of information seekers, including health care providers and consumers.

- Develop and provide 1-800 number phonelines, as well as multimedia resources (e.g., videotapes and monitors), in health care provider locations so that people with HIV/AIDS can have convenient and timely access to HIV/AIDS clinical trials and treatment information.
- Urge the Federal Government to develop and provide more information to organizations that provide information by means other than printed materials.

Information Flow

- Encourage the Department of Health and Human Services to create a body to coordinate activities of all agencies and offices involved in HIV/AIDS treatment information dissemination to coordinate and consolidate current efforts, avoid duplication, and work to fill identified gaps in services. [Editor's Note: This is the role of the NAPO Task Force on HIV Information Dissemination.]
- Form a parallel community-level advisory committee (along the lines of CCG) to advise and work in collaboration with the Federal agency coordinating body. This body would network with community-level organizations to enhance information sharing. The advisory committee would evaluate research, treatment ideas, and scientific theories that appear in various newsletters and media. The committee would also develop a second "standards of care," reflecting treatment strategies that do not yet have government sanction, to complement the Federal standards. Finally, the committee would help identify resources to effectively reach affected populations in rural and hard-to-reach areas.
- Develop a mechanism through which the Federal government can facilitate the ability of community groups to develop materials.
- Establish a nongovernmental AIDS/HIV treatment information clearinghouse to increase the exchange of information between community-level organizations. Of particular interest is information related to alternative, unproven, or non-FDA approved treatments, which is unlikely to be distributed by Federal agencies.

- Establish a mechanism to increase information sharing among community-based organizations and to increase their access to research and drug companies. Use newsletters to share information across CBOs and the pharmaceutical industry.
- Provide training and technical assistance through regional and national conferences to those supplying treatment information. Employ social marketing techniques to disseminate information, using the National Minority AIDS Council Skills Building Conferences as a model.

Other

- Recommend broader information guidelines and an increase in funding under the Ryan White CARE Act so treatment and clinical trials information can be distributed with the use of these funds. [Editor's Note: The Ryan White CARE Act, as presently written, supports the provision of ambulatory, outpatient health and support services to low-income, uninsured people living with HIV/AIDS. The provision of care is the primary purpose of the law. However, Title I (grants to eligible cities) and Title II (grants to states) will support outreach programs to inform low-income individuals with HIV/AIDS about care services provided under the Act.]
- Use Title I Planning Councils to support and fund existing hotlines, newsletters, and drop-in services.

Group #2: Populations Facing Oral and Print Communication Barriers

Introduction

"Barriers to oral and written communications affect all of us."

This group was asked to discuss how populations that face barriers to oral and written communications can be reached more effectively with HIV/AIDS information. During the discussion, the participants perceived isolation as a common barrier for all groups, stemming from emotional and psychological barriers as well as geographic conditions. The consensus of the participants was that issues of barriers and access interact with issues of identity and group membership and that individual needs should be at the center of information dissemination processes. Responsibility and accountability for designing programs should be shared among people with HIV/AIDS, grassroots organizations, community-based organizations, the Federal government, and other funding sources.

Summary Recommendations

This group developed many recommendations to address the barriers faced by these populations, including:

- Increase communications skills training for these special populations.
- Develop special materials for the sight or hearing impaired.
- Develop culturally sensitive and properly translated materials.

Target Audience Definition

Noting that many people may face barriers to oral and written communications, the participants identified specific audiences on which to focus their discussion, including the hearing impaired, the visually impaired, non-English speaking populations, those low literate and/or illiterate in any language, "nontechnicalese"-speaking people, the mentally impaired, substance users, those who require anonymity (who may not want information mailed to them), the homeless, the incarcerated or people isolated for geographic or institutional reasons, adolescents, those who do not identify with the information or with high-risk groups, and health care providers dealing with these groups.

Barriers to Information

The group identified many reasons why these populations are not receiving appropriate information about HIV/AIDS. As noted above, isolation is a major barrier. Language comprehension, the inability of providers to communicate with these groups, and the lack of materials developed specifically for groups that have difficulty understanding written and spoken English were stated as other main barriers. A more complete list follows.

Isolation

- Cultural barriers, inhibiting use of the mainstream medical model of treatment.
- Geographic or emotional isolation, which can prevent treatment and information dissemination.
- Lack of resources other than financial, such as transportation.
- Absence of a support system.

Language/Comprehension

- Not enough health providers who know sign language; the fact that sign language is different across cultural and national origins.
- The lack of familiarity with the language or jargon of HIV/AIDS.
- The technical nature of HIV/AIDS information.

Psychological Issues

- Heightened emotional issues in this population, that is, hopelessness, denial, or lack of personal power.
- Absence of a cure, which deters information seeking.
- Inability to relate to or identify with the information.
- Fear of stigmatization.
- Lack of confidence in making decisions about care.

Providers

- Lack of an appropriate messenger/provider (properly trained peers, etc.).
- Cultural and organizational barriers within mainstream medicine that prevent providers from working effectively with this population.
- Lack of willingness of doctors to provide treatment or lack of access to information. Many providers have little information about HIV/AIDS treatment, especially in rural communities.
- Low expectations of the doctor-patient relationship and little interaction.
- Lack of skills among providers on how to present and use materials appropriate for these audiences.

Other Barriers Identified by the Group

- Lack of set priorities about the messages to be communicated.
- Lack of trust from the audiences due, in part, to little investment on the part of the messenger.
- Possible financial priorities may be focused on issues related to physical or emotional disabilities or other issues.
- Fear of deportation.
- Lack of understanding of preventive health care measures.
- Lack of availability of information at the right time and place, that is, when information can be accessed is not necessarily when or where it is available.
- Inappropriate information sources being given to information seekers.

Objectives

The group identified the following kinds of information this population should receive via targeted communication:

- Basic HIV/AIDS information, such as general clinical trials information, explanations of CD4 counts, drug treatments, the disease process, etc.

- Where and how to gain access to the entire spectrum of care, treatment, and support--both medical and nonmedical--that is available.
- How to spot fraudulent claims of treatments or cures.
- Low-cost options and self-care strategies.
- Information about the research process, treatment risks and potential benefits, the right to informed consent, confidentiality rights, limitations of research, costs of care and treatment, processes for entering or leaving a clinical trial, and rights to study findings.
- Access to alternative or nontraditional treatments and how traditional and nontraditional treatments may complement each other.
- The fact that one can live with HIV/AIDS.
- The standards of care.

Possible Solutions and Recommendations

The underlying theme of the solutions discussed was that "collaboration" is essential--collaboration among many individuals and agencies at every possible level. The group agreed that personal survival issues (priority needs) must be addressed before the individual can attend to HIV/AIDS treatment concerns. For instance, a homeless person would need information about resources for shelter, food, and clothing. Therefore, strategies should be developed that acknowledge individuals' priorities to provide incentive to get them into treatment. In addition, it was noted that people may not require the level of sophistication and detail that the messenger often possesses.

The following are tactical recommendations provided by the group for reaching this audience.

Communication Skills Training

- Train health providers who serve this population with effective and appropriate communication skills, including one-to-one communication and counseling skills, because treatment information should be discussed individually.
- Identify peers and others from the community to communicate with these audiences and provide them with the appropriate training.

- Provide cross-training among providers of various services to broaden their knowledge of available resources and information.

Material Development

- Develop audio versions of newsletters to target the visually impaired.
- Develop materials using pictorial and conceptual images for the hearing impaired in collaboration with the resources of the hearing-impaired community.
- Develop taped treatment information to be distributed through audiocassette subscription services for the visually impaired. Collaboration and cross-training would be vital to this tactic.
- Modify audio/visual presentations that have been effective for prevention education so that they are appropriate for communicating treatment information. Preferably, they should be produced by peers.
- Use prevention education tactics that have proven to be successful with certain populations, such as street theater, music, or comedy, particularly if they remedy cultural or language barriers.
- Develop a video such as the AmFAR-funded "OnStreet Video" to show in shelters and clinics.
- Translate and distribute materials in a culturally sensitive manner. Be mindful of the dialect variations.
- Translate information and research results into the language level appropriate for the target groups and in collaboration with the populations who will receive and use the information.
- Develop materials that answer the key questions people are asking.

Effective Use of Experts, Nationally and Locally

- Establish scientific advisory committees to monitor data and standards of care before disseminating the information.
- Place trained people who focus on treatment information dissemination at HIV/AIDS test sites where they can provide a critical link to clinical trial centers and health care providers.

- Involve people in the planning and development of strategies who have various levels of sophistication, both locally and nationally, including people with HIV/AIDS.

"If people with HIV/AIDS are not involved in the design of the programs, those programs are likely to be less effective."

Use of High-Tech Resources and Media

- Expand the use of computers and high-tech resources to capitalize on technology that is commonly used by hearing-impaired people. Put systems in place to ensure that information provided through those channels is accurate. Provide training to providers for using technology.
- Expand the use of broadcast media (television) in rural areas to provide referrals to national, regional, and local 24-hour hotlines.
- Enable mobile clinics to provide CD4 testing within a matter of days, instead of months, to facilitate more time-appropriate information dissemination.

Peer Support

- Develop peer-support systems to enhance patient-provider relationships and to provide one-to-one support. Ancillary services, such as child care and transportation, would facilitate women's ability to access services and clinical trials.
- Implement anonymous, peer-operated, 24-hour hotlines locally and regionally.
- Use currently operating ACT UP Network and other networks to provide word-of-mouth outreach at peer levels.

Group #3: Culturally Specific Populations

Introduction

"Trust comes from developing relationships."

This group identified trust as a key barrier. The participants recognized that providers and patients need both support and training to get beyond the trust barriers. The group also noted that *"trust requires cultural sensitivity and competency."* These are the underpinnings of the group's discussion.

Two linguistic clarifications apply to this summary: the term "treatment information" is meant to incorporate a full range of healing opportunities, including indigenous practices, basic HIV-related health care information (e.g., "What does a T-cell mean?"), and experimental drugs and other trials; the term "provider" is meant to incorporate a wide range of primary care practitioners including, but not limited to, doctors.

Summary Recommendations

This group reported several recommendations to improve information development and dissemination, including:

- Support communities to conduct research to better understand the health and healing beliefs of culturally specific communities.
- Train health providers so that they better understand the health and healing beliefs of these communities.
- Fund community groups to develop and distribute culturally specific materials to fill information voids. Use alternative mechanisms, including comic books and audio and video devices.
- Provide health care settings with appropriate materials and staff.
- Provide the information and resources necessary for people with HIV/AIDS to educate their peers.
- Include representatives of culturally specific populations in all stages of drug treatment and trial protocol development.

Target Audience Definition

Culturally specific populations are those whose cultures define how they perceive HIV/AIDS, how they understand health care issues and practices, and how they transmit and receive information. In this discussion, they were defined to include indigenous people, Hispanics, and people who recently came to the United States from other countries. In addition, a broader interpretation of "culture" was given to include any group of people, such as gay men of color, whose lifestyle reflects its own culture.

Barriers to Information

The following is a compilation of barriers to effective information dissemination identified by the participants. It is not intended to be comprehensive.

Lack of Cultural Understanding by Health Care Providers

- Health care providers do not understand or appreciate indigenous communities' health beliefs or healing practices.
- The spirit is an important part of healing and survival in many cultures but is not addressed in most HIV/AIDS treatment paradigms.
- Research activities and information are constructed from "left brain (analytical) functions," which is in contrast to how some cultures approach health and information.
- The cultural concerns of gay men of color, especially black men, are not recognized by health care providers or incorporated into treatment and trial modalities.
- Many cultures rely on oral traditions and communication, which, therefore, must be used for effective treatment information dissemination.
- Treatment information does not constitute all elements of healing relevant to a culture. Treatment information provided should include basic HIV/AIDS health care and protocol descriptions, as well as trial-related information.

Lack of Trust by Affected Cultures/Communities

- Representatives of different cultures do not have a voice in the HIV/AIDS care system. Many communities/cultures do not have access to the "treatment table" where new products and treatment/trial protocols are being developed, including within the pharmaceutical industry. Many groups currently lack the necessary support and training to sit at those tables as effective participants.
- The individuals disseminating treatment information are not from the affected communities. *"African-Americans need to hear this stuff from other African-Americans."*
- Many underserved communities have a history of abuse in both treatment and experimental trial circumstances (e.g., Tuskegee, in which African-American men were exploited in syphilis trials, and mandated sterilization of poor women in the 50's and 60's) and therefore are wary of getting involved in clinical trials.
- *"The healthcare system does not work for us."* The above-mentioned lack of appreciation for the health beliefs and practices on the part of providers feeds the lack of trust on the part of the care seekers, leading them to believe that they cannot be treated by the system. However, systems also do not work for many groups because they are conducted in the wrong language, or because they are intimidating, incomprehensible, complicated, not responsive, and insensitive to the care-seeking behaviors of groups for whom acquisition of medical care may not be the highest need or priority. *"Trust is lacking." "Spirit is wrong." "People are alienated." "People are intimidated." "Workers are arrogant."*
- Homophobia, heterophobia.
- Racism, classism, sexism.

Lack of Access to Information

- Religious organizations are a focal point of many cultures, but some religious institutions exhibit AIDS phobia. In addition, some religious organizations have no access to treatment information and/or no resources with which to disseminate it.
- Treatment information is not available where people are or where they spend their time. Treatment information is not available to those hardest to reach: the homeless, substance users, and the mentally ill.

- Some sites that are available for distribution purposes, such as culturally appropriate community-based organizations, are inadequately used.

Other Barriers Identified by the Group

- Literacy bias--many affected communities have low literacy skills. There may be a lack of understanding among health care providers and educators that literacy skills do not define intellectual capability.
- Financing, and the systems related to acquiring it, can be a barrier to accessing or disseminating treatment and treatment information.
- The lack of transportation, child care, and other practical support are barriers to getting treatment and treatment information.
- The health care system and most treatment paradigms are not oriented to preventive care.
- The commonly expected physician-client relationship (i.e., that the client be "compliant" or obedient) is a deterrent to care seeking and, therefore, to access to treatment information. Moreover, it increases the distrust of the treatment information received.

Objectives/Recommendations

This group recommended an overall principle that should guide the development of appropriate HIV/AIDS treatment information dissemination activities for culturally specific populations: *"HIV treatment information must respect, incorporate, and be consistent with the health beliefs and practices of the targeted community and must reflect the knowledge of special approaches or practices that will facilitate trust, understanding, and empowerment."*

- Expand the understanding among providers about the healing and health beliefs of culturally specific communities, the confidentiality concerns of culturally diverse groups, and the relationship of those beliefs and concerns to HIV/AIDS treatment and trials.
- Support communities in developing focus groups or other mechanisms to help characterize what those beliefs are.
- Change provider/institution attitudes, understanding, and respect about those beliefs.

- Make treatment/trial information responsive to people's health beliefs and modes of understanding.
- Provide training/social marketing support to underserved communities to design and disseminate culturally specific treatment information.
- Fund affected community groups to develop and disseminate treatment information. Such funds should support the creation of culturally specific materials directly from the communities affected and translation capability where necessary. Alternative modes of communication should be supported as appropriate: audio programs, videos, comic books, etc.
- Fund peer treatment communicators and outreach workers.
- Develop focus groups and other mechanisms to identify and to understand what effective cultural information dissemination models already exist. From this research, develop an easy-to-use directory of existing models, including a description of how they were developed, how they are supported, how they work, and any measurements of their effectiveness.
- Make treatment/trial information conveniently available, that is, where people are.
- Fund community-based organization (CBO) staff and outreach workers to effectively disseminate treatment information so that they serve as the primary conduit for that information.
- Provide health care settings (e.g., public hospitals, community health centers, etc.) with appropriate treatment outreach personnel from CBOs.
- Use applicable models and infrastructure from HIV/AIDS prevention activities for treatment information dissemination.
- Use adult education programs for information dissemination.
- Ensure collaboration among the Public Health Service agencies responsible for the development and dissemination of HIV/AIDS treatment information.
- Create an outreach program in conjunction with the National Federation of Community Broadcasters to develop targeted treatment information for use in their media areas around the country.
- Use places and means by which people currently get information, such as support groups, newsletters, culturally specific community forums.

hotlines/warmlines, community leaders and gatekeepers, religious groups, welfare departments, indigenous and alternative healers, and the Department of Veterans Affairs.

- Build and improve trust between culturally specific populations and treatment/research providers.
- *"You can't keep sending the blue suits in."* Train individuals from culturally specific populations and communities who are living with HIV/AIDS to communicate with their peers.
- Include culturally specific populations at the earliest stages of drug treatment and trial protocol development. Provide the training necessary for their meaningful participation and for the appropriate inclusion of their health beliefs and practices.
- Clarify the intent/mission of drug development and treatment protocols for culturally specific groups.
- Provide mechanisms for clinical trials and information dissemination about alternative healing.
- Develop accessible basic HIV/AIDS treatment/health care information.
- Require ETCs (Educational Training Centers) to provide the full range of HIV/AIDS treatment information education for all levels of primary care providers.
- Require consumer quality-assurance mechanisms as a part of Federal contractual obligations.
- Develop a comprehensive resource directory of consumer treatment issue representatives for Federal agencies and groups in the field.

Group #4: Women

Introduction

"The barriers to information sometimes seem secondary to the fundamental problem of access to care, but there are solutions."

An overriding theme and a frustration of this group is highlighted in the quote above. The group, however, identified many issues facing women with HIV/AIDS. Because this group was large, they broke into four teams and approached possible solutions from four different perspectives: (1) peer education, (2) provider-based education, (3) media-based education, and (4) public institutions.

Summary Recommendations

Each group developed several recommendations, including:

- Develop a peer-operated, toll-free hotline.
- Develop and support printed materials by and for women with HIV/AIDS.
- Develop professional peer advocacy programs.
- Ensure that women are part of clinical trials, that ancillary services are provided, and that providers are well trained to treat women.
- Develop comprehensive, one-stop, family-based health care and treatment centers.
- Educate the media to focus on women and HIV/AIDS issues in a responsible manner, encourage and teach women how to communicate through the media, and develop materials that can be used by the media, such as b-roll (video clips for broadcast media).
- Work with product manufacturers to develop more responsible advertising.
- Provide treatment information in public areas that women frequent.
- Provide counseling and support to women with HIV/AIDS and their families.

Target Audience Definition

The following audiences were identified by the group; however, the descriptions should not be considered exhaustive.

- An HIV-infected woman who sometimes gets lost in the health care system may be any of the following:
 - Older; adolescent; homeless; transient; sex worker; lesbian; bisexual; pregnant; mother; substance user; woman in recovery; abused; battered; dual-diagnosed; blind; hearing impaired; mute; incarcerated; institutionalized; dependent; partner of a hemophiliac or transfusion recipient; health care worker; in nonmonogamous relationships with straight, gay, or bisexual partners; in denial; transgender/transsexual; non-English speaking; low-literate; isolated geographically; immigrant; or from the Caribbean or U.S. territories.
- HIV-affected women whose partners, children, families, or other loved ones are infected.

Barriers to Information

The barriers to effective information dissemination were identified as part of the process of developing strategic recommendations to ensure reductions in the lack of information for women. Barriers for this audience include gender-related issues such as that much of the available HIV information is targeted to men. Other issues include low self-esteem and poor physician-women relationships.

Women

- Most HIV/AIDS information is targeted to the gay male community.
- Information that is not targeted to gay men does not address the special needs of women.
- Peer support and professional peer advocates are not typically available to HIV-infected women.

Self-Esteem

- Low self-esteem prevents many women from seeking information and treatment. They believe they do not deserve it. An informal survey at a recent workshop revealed that 80 percent of the HIV-positive women

present had suffered some type of abuse in the past, which has added to low self-esteem.

Care Giver Roles and Responsibilities

- Child care and other family needs are priorities that may cause women to delay or ignore treatment.

Physician Interactions

- Women are often intimidated by their physicians and assume a submissive role, which reduces active information-seeking behavior.
- Women who are HIV positive typically seek care in public clinics, where physicians have less time to explain information and treatments.
- Public clinics may limit the number of visits a patient may have with the same physician. This leads to poor patient/doctor relationships, a general lack of trust, and occasionally less respectful treatment of the woman.
- Women believe male physicians spend more time with male patients.
- The advertising for self-help feminine products (such as over-the-counter yeast infection medications) encourages women to self-treat problems, possibly leading to fewer physician visits. This is problematic because it reduces the likelihood that underlying problems, such as HIV/AIDS, would be discovered in a timely manner.

Clinical Trials

- A majority of trials are conducted using gay male subjects. Women are not recognized as an infected population and are therefore often excluded from participation in the trials. [Editor's Note: In March 1993, the FDA announced proposed changes will that remove many barriers to women's participation in clinical trials, in general.]

Legal Issues

- Information distributed to HIV-infected women does not address legal issues relevant to them, such as child custody, access to care, and informed consent.

Objectives/Recommendations

As explained, the group targeted four areas for information dissemination. The objectives and recommendations for those four areas follow.

1. **Peer-Based Education: Develop mechanisms by which women can seek information and care from other women.**
 - Establish a toll-free, national hotline staffed by women who are living with HIV/AIDS and who are trained to give peer support and information about treatment and trials.
 - Develop and support printed materials by and for women with HIV/AIDS. This might include the provision of financial support for the production of materials that are currently being developed but do not receive adequate funding, such as newsletters. This type of support should be developed through mechanisms that are not highly bureaucratic.
 - Develop a Survival Guide, by and for women with HIV/AIDS. The guide would be distributed at clinics when a woman tests positive. It would include pictures of women living with HIV/AIDS and address the real issues for women living with HIV/AIDS.
 - Develop professional Peer Advocate Programs that provide training, support, and compensation to (a) conduct home visits; (b) keep a list of the patient's questions and symptoms; (c) go with women to medical appointments to take notes and ensure that all questions are answered and understood; (d) go to clinical trials with women to ensure that proper informed consent is obtained before women enroll in trials; and (e) encourage social events and networking for the affected women and their families by organizing forums or events with other peers and their families.
2. **Provider-Based Education: Ensure that women have access to well-trained, sensitive providers and services similar to those available to gay men.**
 - Provide incentives, including financial incentives, through Federal programs to clinicians and health care workers who provide health care services to women with HIV/AIDS.
 - Provide for child care and transportation in all women's research protocols.
 - Recruit culturally aware research personnel and outreach workers for AIDS Clinical Trials Units and Community Programs for Clinical Research on AIDS (CPCRA) and/or mandate diversity training.

- Mandate and monitor inclusion of women in Phase I-III clinical trials.
[Editor's Note: In March 1993, the FDA announced proposed changes will that remove many barriers to women's participation in clinical trials, in general. In addition, NIH requires the inclusion of women in clinical trials.]
 - Develop support groups for mothers whose children are receiving treatment.
 - Develop comprehensive models to act as "one-stop," family-based health care and treatment centers. This model already exists within some HRSA-funded projects, but it must evolve to be able to meet the increasing demands of HIV-positive women and their families.
 - Expand CPCRA sites for trials and information dissemination to include county health departments, where most women receive health care services.
- 3. Media-Based Education: Deliver sensitive, accurate information about women with HIV/AIDS to the media.**
- Educate the media to focus on women on both local and national levels:
 - Arrange to speak at media forums and meetings to discuss the issues of women with HIV/AIDS.
 - Fund collaboration between the media and private sector. For example, work with a large retail drugstore to distribute materials and arrange for local and/or national publicity to recognize their contributions.
 - Teach women to use the media to communicate key messages.
 - Work with product manufacturers to develop alternative ads for such products as yeast infection medications, douches, and other feminine hygiene products to include messages about the importance of regular physician visits.
 - Develop a b-roll video consisting of a variety of 10- to 60-second soundbites or clips that could be used nationally to address key issues.
- 4. Public Institutions: Ensure that the appropriate services and information are available to women via the public institutions to which they have access.**
- Expand the role of HRSA to provide clinical trials information to public health nurses, social workers, HIV/AIDS educators, mental health case

managers, prison staff, and other service providers to better educate the women they serve.

- Provide treatment information in public locations women frequent on a regular basis, such as Women, Infants, and Children (WIC) and AFDC offices.
- Require health care workers to provide basic health information to their patients, for example, about female anatomy.
- Improve physicians' access to clinical trials information for women.
- Provide counseling to women with HIV/AIDS and their families to help them make informed treatment and trial decisions.

Group #5: Age-Specific Audiences

Introduction

"If I'm afraid of getting shot on my way to school, I don't give a damn about a virus that may kill me 15 years from now."

"Age-specific" can define a wide group of people. The group noted that 60 percent of children in the fifth through twelfth grades are sexually active, and therefore decided to define the scope of their discussion to youths/adolescents ages 13 through 19. This group determined that information about HIV/AIDS prevention and about treatment and clinical trials should not be separated for this audience. A key theme was diversity in dissemination: the group agreed that information must be given repeatedly, in diverse ways, through diverse people, and in diverse places. Finally, the group pointed out that youths cannot be expected to sit across a desk and receive information. The participants recommended that information dissemination be restructured to fit adolescents' needs, desires, and priorities to reach them effectively. The group expressed disappointment that only one member of their group, at age 20, was near the 13 to 19 age range.

Summary Recommendations

The recommendations developed by this group are summarized below.

- Prevention should be the key focus of information targeted to youths.
- Involve youth in planning, decision-making, training, and education.
- Create a friendlier atmosphere for youth within the clinic setting.
- Bring the programs to the kids!
- Use role models, heroes, and the popular media to reach out to youth.
- Involve parents, teachers, and school administrators.

Target Audience Definition

Once the group decided to focus on youth, the categories identified for discussion included those who are gay, male, female, foreign born, incarcerated, or homeless, and living in rural, suburban, and urban settings. It was difficult for the group to settle on a specific "type" of youth on which to focus because the participants recognized that each particular age group faces its own particular problems. For example, the discussion about homeless youth included both the rural and suburban

homeless and defined no less than 20 barriers to reaching them (e.g., difficult to find, difficult to follow up with, lack of support systems, etc.). Although the group wanted to consider the difficulties of reaching all youth, the participants recognized that all of the needs of all youth could not be discussed within the day's framework.

Barriers to Information

Most of the barriers identified were the same or similar for different geographical areas. The group recognized that the characteristics of youths took precedence over their geographic location: *"Human disease knows no geographic boundaries."* Other broad prevailing issues, such as legalities, affect them as well. The barriers can be categorized along the following lines:

Difficulty in Engaging Youth

- It is often difficult to engage youth. It can be even more difficult with some populations, such as homeless youth.
- Because of the nature of youth and their particular circumstances, it can be difficult to locate them, follow up with them, or assign outreach workers to them.
- Priorities in youth are different than in adulthood. There is a more "live for the moment" attitude, which makes reaching them and engaging them in prevention activities difficult.
- Programs and materials are not developed with the priorities of youth in mind.
- There is a great deal of fear and ignorance on the part of youth about HIV/AIDS.
- Discussing sexual issues with others may be embarrassing for youth.
- Youth often have a general lack of trust for adults.

Systemic and Resource Issues

- Youth are not always covered by any health insurance, including their parents' policies. This is particularly true for homeless youth.
- They have a general lack of other personal resources, including transportation and money (reducing their capability to pay for services, particularly if they do not have insurance).

- Due to their age, youth have little experience with the health care system, increasing their difficulty in communicating within it.
- Health care personnel will sometimes refuse to deal with youth because of perceived behavior issues or inability to pay.
- Because of their inexperience, discomfort, or lack of personal resources, there is often a general lack of access to community or other outside resources, reducing their ability to take advantage of what is available to them.

Legal Issues

- Legal issues, such as parental consent, limit the ability to reach youth directly.

Involvement of Youth in Decision-making Processes

- In general, youth are not involved in the development of most aspects of programs for them, including planning, implementing, evaluating, or funding reviews.

Informational Issues

- Information generally is not available where youth are likely to obtain it, such as schools.
- Because the numbers of infected youth are still low, they are not seen as a critical audience, resulting in a lack of information targeted to them.
- There is a lack of programs that address youths' needs, such as skill-building programs that address HIV-related issues, such as negotiating safe sex or saying "no."
- There is a lack of peer-to-peer programs, which, if available, might be an effective way to reach youth.
- Adults have not been trained to communicate health-related information to youth.

Objectives and Recommendations

The message of the day was prevent the problem. Due to the nature of youth, the group agreed that it was more important for educators to focus on teaching youth about HIV/AIDS so that HIV/AIDS can be *prevented, rather than getting them into clinical trials*. They noted that prevention is still an appropriate priority because the numbers of infected youth are still relatively low. (Furthermore, some participants suggested that it may not be appropriate for youth to get into clinical trials because of their immaturity and irresponsibility.) A number of solutions were put forth with this goal in mind.

- Involve youth in planning, decision-making, training, and education.
 - All programs designed for particular audiences should have the involvement of those audiences; yet, youth are rarely researched or brought into the planning or implementation of programs for them.
 - Include (feature) youth with HIV/AIDS in educational/informational videos.
- Create a friendlier atmosphere for youth within the clinic setting.
 - Train staff in relevant areas, including adolescent medicine.
 - Conduct a needs assessment to determine what is necessary to provide services to youth.
- Bring the programs to the kids!
 - Use alternate clinic environments, such as "one-stop health shops," mobile health units, outreach workers, or school-based clinics to reach out.
 - Develop a hotline for youths. A hotline would allow them to control the situation, reduce embarrassment because the encounter would not be in person, and enable the contact to be anonymous.
 - Use block parties, dances, and summer job programs to give messages.
 - Reduce barriers to seeking treatment. Provide travel vouchers and/or financial incentives to come into the clinics for care.
 - Develop a summer camp or program for adolescents where they can share their experiences with HIV/AIDS, learn from each other, and get support to deal with their personal or family issues.

--Develop a program by which youth can obtain transportation to HIV/AIDS testing centers without notifying their parents. This may be possible by working with local health departments.

- Use role models, heroes, and the popular media to reach out to youth.

--Develop a television program about HIV/AIDS, featuring real children from diverse communities. The program would be targeted to a wide audience of parents and a variety of children's age groups.

--Use a variety of adults with HIV/AIDS to act as educators, including drug users, gays, heterosexuals, lesbians, hemophiliacs, transfusion recipients, etc., to demonstrate the diversity of the HIV/AIDS community.

--Select and engage appropriate role models with whom youth can identify.

- Involve parents, teachers, and school administrators.

--Provide mandatory training for parents, students, teachers, and administrators through the school systems.

--Support the creation of a comprehensive school-based health curricula that includes information about clinical trials.

Other Suggestions

- Set aside a percentage of Title I and II funds for youth programs. [Editor's Note: The Ryan White CARE Act, as presently written, supports the provision of ambulatory, outpatient health and support services to low-income, uninsured people living with HIV/AIDS. The provision of care is the primary purpose of the law. However, Title I (grants to eligible cities) and Title II (grants to states) will support outreach programs to inform low-income individuals with HIV/AIDS about care services provided under the Act.]
- Develop more trials for HIV-positive, asymptomatic individuals.

Group #6: Substance Users

Introduction

"They need to understand the difference between the drugs they are on and the drugs that can help them."

Initial discussion focused on what were thought to be the primary issues for substance users: they need to be reached with information, and they need to know that continued drug use will produce an adverse outcome. They need to understand the difference between the drugs they are on and treatment drugs, and they need to understand that they must get off the drugs they are on so that they can be responsible for their treatment. The group recognized that volumes of materials about substance-using populations are available, and these materials could be used effectively to bring communications to a higher level. For example, information could be provided to clinicians or other providers about what drug-using populations call themselves ("addicts," "drug users," etc.), and whether the terms providers currently use are offensive. The group agreed to use the term "user" to describe the population, believing that this was the most inclusive term. The group also agreed to refer to the substances that were being used as "mood-altering substances."

Summary Recommendations

- Recommend ways to make the best use of money available to influential groups to affect policy.
- Provide training for health care workers and others working with users on the language of users.
- Encourage the use of the "harm-reduction model" so providers do not scare potential patients.
- Provide training in case management.
- Develop programs that recognize the priorities of the user.
- Reach physicians with information and treatment updates by conducting office visits to capture their attention.
- Develop a collaborative effort to provide a full range of services.
- Find the messenger appropriate for the audience.

- Develop and provide information for users so that they can take charge of their lives.
- Evaluate and update programs and strategies on an ongoing basis.
- Monitor providers to ensure accountability.

Target Audience Definition

The group agreed that it is important to recognize the shift in the spectrum of people involved with drugs over the past decade. Targeting only those who are injecting has become inadequate due to the association of sex and other behaviors with the use of many drugs, including alcohol. The group identified a number of categories of substance users, including persons in and out of treatment, persons in recovery, persons who are not being treated, and others. However, the group also recognized the audiences most useful to target to disseminate information to users include treatment providers, researchers, family members, other support system members, clergy, law enforcement people, and probation officers. Within each of these groups, one must consider age, gender, and culture.

Barriers to Information

The group identified many barriers to reaching this population effectively and spent the majority of their time on this topic.

Issues Involving the Health Establishment

- There is sometimes prejudice on the part of health care providers.
- Attempts within clinical environments to address problems are not always motivated by the right reasons, that is, sometimes there is a desire to *look as if* the clinic were responding in an appropriate manner, which diverts energy and reduces the chance of success.
- The health system is overwhelmed, and partly for that reason, users are not as high a priority for care as others.
- Health care providers are not receiving relevant information in a timely manner.
- There are not enough substance use specialists in the health care community.

- Some providers are confused about their role. For instance, some do not know if they are clinical trial recruiters or information disseminators, or both.

Population-Related Issues

- It is difficult to work with people who are loaded or high.
- Typically, users are not highly motivated; often they have problems with followup and difficulty heeding recommendations.
- Peer-to-peer outreach is important, but sometimes recovered users have an elitist attitude and therefore are ineffective in reaching the drug user population.
- Myths and misinformation are common within the drug user population.
- There is a distrust of Government-funded research.
- Users are often in denial about aspects of their lives.

Research-Related Issues

- Sometimes research data are published too early, without enough research having been conducted.
- Clinical trials call for mandated treatment or participation; users may not be able to respond to the needs of this type of environment.

Treatment Issues

- Appropriate incentives for users to participate in programs are lacking. There are ethical issues involved with offering financial incentives for participation, but this is probably the most appealing incentive to users.
- The types of recovery programs available, primarily of the 12-step variety, are not acceptable to everyone.
- Enhance the effectiveness and capacity of outreach workers and community-based organizations.

Resource Issues Other Than In the Health Establishment

- Systems outside of the health care establishment are overwhelmed. Staff is limited. Funding priorities are top heavy. There are not nearly enough outreach workers to deal with the numbers.
- The funding and resources that are made available, for both health and other issues, are not always used effectively.
- The priority needs of the population, such as food, housing, child care, and money, compete with treatment.

Communication Issues

- Cultural issues are a problem; health care workers cannot relate to the population.
- There are language and literacy barriers.
- The media puts an inaccurate slant on information.
- Communication problems exist between the substance-using population and those trying to reach them (i.e., How should the first contact be made? How does a person speak when trying to engage the user?).

Information Availability

- Little information is available about existing services.

Community-Related Issues

- Too few links are formed between the various community agencies who could help this population.

Other

- Some users turn to religious zealots and God and believe that God will cure them.

Possible Solutions and Recommendations

"Get the information out to people so that they can make their own decisions."

This statement became the "rule of thumb" for developing possible solutions. With this in mind, the group suggested the following recommendations:

- Recommend policy changes to influential groups about how to make the best use of available money while recognizing that funding is limited. The group believed this to be a priority that needs to be stated.
- Train health care workers and others working with substance users about the language of users and how to translate technical information so that a user can understand it in written materials (i.e., use "street Spanish" or "street English").
- Encourage the use of the "harm-reduction model" so that providers do not scare potential patients. Users need to know that providers will not judge or harm them. [Editor's Note: The harm-reduction model is a model of treatment based on handling those issues that a patient views as most important rather than what the provider deems important. In other words, if a patient entering treatment sees child care as the biggest issue, the provider would deal with that before discussing treatment issues.]
- Provide training in case management, with a concentration on how to follow patients who are elusive, who disappear, or who come and go as they relapse.
- Reach physicians with information and treatment updates by conducting office visits to capture their attention.
- Develop a collaborative effort to deliver a comprehensive services approach to care. Provide information on access to trials and staying clean or sober by involving social service agencies and the local and Federal Government to provide a smooth transition from "street life."
- Find the messenger who can communicate most effectively with the user.
- Develop and provide information for users so that they can take charge of their lives.
- Evaluate and update programs and strategies on an ongoing basis.
- Monitor providers to ensure accountability.
- Cross-train substance abuse service providers and health care providers. [Editor's Note: The NIDA/HRSA module is currently being updated and revised. For more information, contact the Center for Substance Abuse Prevention at NIDA.]

Group #7: Sexually Identified Groups

Introduction

"Taking care of myself means to love myself."

This group recognized that although their discussion focused on gay men and gay men of color, the barriers for sexually identified groups seeking HIV/AIDS medical treatments--eastern, western, herb-based, or drug-based--are common to many sexually identified groups: difficulties inherent in getting the message to where people are and using culturally appropriate language and messengers. In addition, unique barriers were also identified: (1) the low self-esteem experienced by some sexually identified people is compounded by the stigma of HIV/AIDS; (2) the lack of adequate encouragement by people, agencies, and other sources they trust; and (3) the readiness to hear information about their status, HIV disease, and AIDS may evolve in stages. However, participants also indicated that a key message in reaching this population is, indeed, **"Taking care of myself means to love myself."**

Summary Recommendations

- Create and increase access to culturally appropriate messages.
- Improve the image in visual advertising of people living with HIV/AIDS so that others have a more positive outlook about seeking treatment.
- Increase the type of and access to information coming through the gay community.
- Increase and enhance the information reaching the clinical establishment to better their ability to reach HIV-positive individuals in differing circumstances.
- Provide information on the emotional issues surrounding HIV/AIDS in the right way and at the right time.

Target Audience(s) Definition

After a lengthy debate about how to define this category, the participants recognized that although there were perhaps a few groups into which all others would fit (i.e., gay men, bisexuals, heterosexuals), a vast array of sexually identified communities could be described. They included gay men, men who sleep with other men but do not identify as gay, lesbians, gay and straight men and women of color, male and female sex workers, heterosexual men and women, bisexual men and women, and transvestites.

Issues that cut across all of the sexually identified groups include race, class, and urban and rural issues. With this understanding, the group addressed why information about clinical trials and treatment was not being received by the various sexually identified groups.

Barriers to Information

A number of barriers to providing information to various sexually identified groups were identified, but the discussion primarily centered around access- and stigma-related issues. The barriers included the following:

Lack of Appropriate Information and Messengers

- Little information about alternative medicine is available.
- Generally, "gatekeepers" of information for specific groups have not been properly identified or used.
- Questions surround the issue of "entitlement" (i.e., Why are some people referred to clinical trials and others not? Is this a question of class?).
- Information is not available where people congregate or live.

Stigma

- HIV-positive people are stigmatized by family, society, MDs, and others.
- Proprietors are reluctant to place HIV/AIDS information where people congregate for sexual activity (e.g., bathhouses).
- Because people at risk for HIV/AIDS are categorized (gay, drug user), some people do not want to step forward for treatment for fear of bearing the stigma of the category.

Lack of Awareness or Concern

- Little information appears in targeted newsletters, especially information geared toward minority audiences, for example, African-American or Asian.
- There is a lack of interest on the part of the community and the government, within clinical settings, and even within the gay community (e.g., some papers for gay populations will not give free advertising space for trials).

Psychological Issues

- Lack of self-identification. If people do not self-identify with the label or image in the message, they will not listen to the message.
- The images presented of different populations are inappropriate and/or insensitive.
- HIV-positive people are depicted poorly in print and pictures (as looking ill).
- Homophobia and heterosexism are long-standing issues.
- There is a lack of phased information approaches for people in different emotional stages.
- Low self-esteem leads to a lack of problem-solving behavior.
- Messages about treatment are not safe or familiar; they are not, but should be, tied to things of value and comfort, such as food, family, and religion.

Possible Solutions and Recommendations

- Create and increase access to culturally appropriate messages.
 - Tie treatment messages to important, traditional, or familiar affairs in peoples' lives (e.g., messages on rice bags for the Asian community, on pornographic videotapes, or in churches, as appropriate).
 - Use the proper "gatekeepers."
- Improve the image in visual advertising of people living with HIV/AIDS so that others have a more positive outlook about seeking treatment.
 - Create videos, PSAs, advertisements, and other visual media that promote a positive image of living with HIV/AIDS. These images should show people who have sought and received treatment living good, full lives.
- Increase the type of and access to information coming through the gay community.
 - Find out what information is needed to convince the gay industry and entertainment fields to promote treatment messages as eagerly as they

promoted the safe sex and prevention message and then approach them with the information.

- Increase and enhance the information reaching the clinical establishment to better their ability to reach HIV-positive individuals in differing circumstances.
 - Promote HIV/AIDS standards of care.
 - Enhance the clinical establishment's counseling capabilities.
- Provide information on the emotional issues surrounding HIV/AIDS in the right way and at the right time.
 - Create a "chaptered" video that introduces the issues of self-esteem, self-care, and treatment in a gradually intensified fashion. People would be free to watch chapter after chapter as they are emotionally and psychologically prepared to listen and watch. (This idea is discussed more fully in the Day Two Breakout Summary).

Group #8: Health Care Workers and HIV Educators

Introduction

"Anything that moves people ahead is OK."

This group chose to design a model approach to improve the dissemination of clinical research information to health care workers and reported on their product, the Clinical Options Communications System (CLOCS), as well as identified barriers and information objectives.

Summary Recommendations

- Use electronic media to expedite dissemination of information.
- Define the information needs of each category of health professionals in different areas of treatment education.
- Educate clinicians about the type of service(s) they should provide for patients.

Target Audience(s) Definition

The target audience was defined as urban and rural primary care providers who are interested in and/or are already caring for people with HIV/AIDS.

Barriers to Information

The structure of the system that provides support for clinicians was examined for barriers to information dissemination. Three issues were seen as particularly important in ensuring that the information goes where it needs to: the lack of continuing clinical education specific to HIV/AIDS; the sense that service delivery organizations are not meeting the needs of the people; and, how the current lack of standards of care exacerbate these two problems. It was with these three issues in mind that the following barriers were discussed.

Educational Needs

- Lack of adequate education and training of health professionals in the area of transmitting and sharing information with other health care professionals and with their patients.

Research and/or Informational Needs

- More information and materials should be developed for specific populations about HIV/AIDS, such as children.
- More clinical trials should be conducted in certain areas to generate enough information.
- More information is needed about how to "package" information for providers.

Logistical or Programmatic Issues

- Information needs to flow two ways between the provider and receiver. The provider needs to listen and learn from the person receiving care as much as the other way around.
- It is difficult to reach physicians with skill-building information and activities.
- There is a void between the availability of information and training and education.
- The mechanisms for providing unpublished data to the community are inefficient.
- There is a lack of timeliness in getting the information to clinicians, particularly on the primary health care level and in rural areas.

Service Issues

- Post-test counseling and referral are inadequate.
- Little information is presented in an other-than-print format.
- An established and confirmed evaluation process for the materials being generated is needed; physicians are comfortable with the peer review process of examining materials, but materials also need to be evaluated by the audiences who generate and use them.
- The immediate needs of the individual in the clinic situation are not being met. If an individual is not reached during the crucial time of the visit to the health professional, he or she may be lost to followup.

Objectives

It was agreed that people learn in different ways and that multiple mechanisms are needed to address the various styles and situations of clinicians in the acquisition and dissemination of information. The focus of the group was to meet the needs of the clinicians that are not currently being met. Objectives discussed included:

- Develop a mechanism to ensure advance notification of available information.
- Develop or reinforce a mechanism that will provide clinicians with an expedient way to obtain information, such as through drug company distribution systems.
- Develop a standardized process that looks at new developments and that can sanction their use in a timely fashion. The best place for this type of process to be developed would be within a respected academic center or a national health institute.
- Enhance the skills of physicians by training them on how to use the currently available information channels for better treatment education.
- Develop a mechanism to communicate clinical trial results in a timely fashion.
- Develop better clinician-targeted education marketing mechanisms.

Possible Solutions and Recommendations

- Use electronic mail, faxing, and computer bulletin boards to expedite the dissemination of information.
- Define the information needs of each category of health professionals in different areas of treatment education.
- Educate clinicians about the type of service(s) they should provide for patients.

Clinical Options Communications System (CLOCS)

The group recommended that when information about new HIV/AIDS research and clinical care options becomes available from the Centers for Disease Control and Prevention, the Food and Drug Administration, and NIH, it should be HRSA's responsibility to communicate it through an active communication system to existing clinical information dissemination networks, which would be known as the Clinical Options Communications System (CLOCS). These include "warmlines" operated by AIDS ETCs (Education and Training Centers) and community organizations such as Project Inform, the systems operated by the National Library of Medicine, the American Medical Association's Physicians Alert System, and others.

Although the group recognized and discussed the differences between HIV/AIDS clinical research information dissemination and continuing medical education (CME), the consensus was to encourage the active participation of the HIV/AIDS clinical CME system in the dissemination of clinical research information. Building on this theme, the group further recommended that HRSA expand the AIDS ETC "warmlines" capability in all areas of the country and that the CLOCS be actively marketed to target audiences by private, professional, and government agencies.

INSERT CLOCS DIAGRAM

DAY TWO PLENARY REPORT

February 26, 1993

Plenary Sessions: Federal Government Perspectives and Resources

The workshop co-chairs opened the second day's plenary session by expressing their sense of excitement about the results of the first day's work and the progress made toward forging collaboration among communities. They felt it important to summarize a few of the major themes that had developed in many of the working groups the previous day. Dr. Wright summarized themes that had been reinforced by many groups, from many perspectives, during the previous day and evening.

1. There is a great need to begin by sharing resources that currently exist and to avoid duplication of efforts. For example, excellent newsletters currently exist. They need to be shared with other organizations; we do not need to use limited resources to create more newsletters.
2. Messages need to be communicated through multiple media, using videotapes, television, and radio. Presently, there is heavy reliance on communicating through pamphlets. The participants felt that no additional efforts are needed to generate more pamphlets.
3. It is important to establish trust within the provider-patient relationship. There is an enormous need for more compassionate and understanding providers.
4. It is important to recognize that there are appropriate divisions between information dissemination functions of the research community, the health care delivery community, and the activist/advocacy community.
5. There is a need to adopt a harm-reduction model that motivates people to seek treatment without condemning them for their condition or threatening them into management.
6. Peer educators, peer support, and the presence of HIV-positive people should be in the treatment system to serve as living testimony that people can live positively with HIV/AIDS and to enhance communication efforts.

Existing/Emerging Federal Communication Resources

Following a discussion of these and other points, five Federal agency representatives (National Institute of Allergy and Infectious Diseases (NIAID), Health Resources and Services Administration (HRSA), Centers for Disease Control and Prevention (CDC), National AIDS Program Office (NAPO) of the Office of the Assistant Secretary of Health, and the National Library of Medicine (NLM)) elaborated on the Federal role in collaborative treatment information dissemination. These panel speakers also offered their thoughts on the workshop proceedings and their ideas for improving HIV/AIDS communications.

National Institute of Allergy and Infectious Diseases

Dr. Jack Killen, Deputy Director of the NIAID Division of AIDS, shared his reaction to the workshop with informal remarks. He mentioned that "the atmosphere yesterday around this meeting was really incredible . . . in my mind, unprecedented." He spoke of his recognition that "these problems that we are talking about are immense in their magnitude" but there are "a lot of people from a lot of different perspectives willing to work together" and "that is real different from what I have felt before." He also expressed his hope that the remainder of the meeting and efforts in the future "will help define even more specifically what it is that we need to do."

Health Resources and Services Administration

Dr. Eric Goosby, Director of HRSA's Division of HIV Services in the Bureau of Health Resources Development, explained that HRSA's very specific focus is to increase access to care for people with HIV/AIDS who do not have insurance and to provide care to people with HIV/AIDS generally. HRSA also provides educational and financial support to care providers in a variety of settings throughout the United States. He said experience taught him that "access to care is an extremely difficult concept to realize. It gets difficult to talk about in one spot, let alone many spots throughout the country."

With an appreciation of this difficulty, Dr. Goosby said that HRSA tries to target support to groups of providers, including those primarily involved in research, those who provide care to persons with HIV/AIDS, primary care providers who see a smaller number of people with HIV at early stages of disease, and those who do not regularly care for people with HIV/AIDS.

Dr. Goosby said that a subcommittee to the HRSA AIDS Advisory Committee is now dealing specifically with information dissemination issues. Its goal is a plan for rapidly packaging HIV/AIDS news in appropriate formats for all health care professionals and patients in the HRSA systems.

Dr. Goosby also told participants that HRSA is working with San Francisco General Hospital and the University of California, San Francisco, to support an established warmline for providers. This is an 800 telephone number that physicians can call and engage in dialogue with an expert about any treatment question they may have. HRSA is supporting the effort and it became available nationally as of March 1, 1993.

Dr. Goosby expressed his sincere hope that HRSA will be able to participate in and contribute to the coordinated efforts of the workshop participants and the meeting recommendations.

Centers for Disease Control and Prevention

Dorothy Triplett, acting Assistant Director for Minority and Other Special Populations for CDC's Office of HIV/AIDS, shared information about CDC efforts to contribute to the dissemination of HIV/AIDS treatment information. She said that CDC provides funding to community-based organizations and national and/or regional minority organizations for activities in HIV/AIDS prevention and information programs. Ms. Triplett said that the hallmarks of these efforts are culturally specific materials for African-American, Hispanic, Native American, Alaska Native, and Asian-American populations. She also said that the CDC sponsors the National AIDS Information Clearinghouse and Hotline, cosponsors the AIDS Clinical Trials Information Service with NIAID, NLM and the FDA, and supports an online bulletin board that provides the AIDS Daily Summary for those with modem capability. The Business Response to AIDS Resource Service is, according to Ms. Triplett, a new collaborative effort involving many national business and service organizations in helping employers deal with HIV/AIDS issues. Ms. Triplett ended her remarks by saying that she was "truly, truly encouraged, excited, and committed to assist in collaborative efforts . . . [and] concerned with making improved health an asset to all."

National AIDS Program Office

Vesta Jones of NAPO told participants that to coordinate Public Health Service (PHS) dissemination of HIV/AIDS information, the Assistant Secretary for Health created a committee with representatives of all PHS agencies. This workgroup has conducted a PHS-wide inventory of available HIV/AIDS information, is planning a community needs assessment, and is developing a model to increase understanding of PHS information dissemination activities and of where to go for information. Ms. Jones said she wanted participants to know about these efforts so that they can be assured that the PHS is aware of the need for this information to get into the communities.

National Library of Medicine

Dr. Elliott Siegel discussed efforts currently under way by the NLM related to HIV/AIDS treatment information dissemination. He announced that the NLM is sponsoring a conference on HIV/AIDS information dissemination with participants from the clinical research community, the health professions, and the media that is scheduled for June. Dr. Siegel said that NLM databases can be useful resources for community groups that sponsor hotlines. He also stated that the NLM encourages collaboration. He encouraged participants who might be interested in gaining better access to the NLM's resources to contact him and he would be happy to work with them to establish innovative, experimental arrangements.

Suggested Strategies

The plenary session also heard from Dr. Roy Widdus, Executive Director of the National Commission on AIDS. Dr. Widdus offered some "next step" suggestions of actions. They included:

- Continue to emphasize collaboration. This approach allows each Federal agency to take a chunk of the problem and contribute at a meaningful, yet realistic, level. It also fosters local involvement, which is a clear requisite of successful communication.
- Set effective priorities for the use of Federal funds. With more coordination and local input, Federal information dissemination dollars can be better spent.
- Recognize the interrelationship between poor access to health care and poor clinical trial accrual rates among people of color and other groups. In general, people do not enter trials unless they have a regular source of primary care. It is also unreasonable to expect research studies to provide primary care because they do not have the resources. HRSA has defined a continuum of care in an effort to increase points of access to HIV/AIDS care throughout the course of the disease for the populations the agency serves.
- Explore new information dissemination channels. Suggestions included the Minority Health Professionals Foundation to target information to medical schools, Federal grant project officers, and providers of gynecologic care.
- Make communication networks inclusive of community-based organizations, rather than relying on national organizations. One example was the need to

include grassroots hemophilia groups, which reach a different constituency than that served by the National Hemophilia Foundation.

- Increase the number of minority researchers who help set the research agenda in HIV/AIDS. One important aspect of this task is to expand communication to minority scientists to ensure their awareness of grant opportunities.

The plenary session ended with a question and answer period and was followed by the four breakout sessions.

SUMMARY OF DAY TWO BREAKOUT SESSIONS

Introduction

The breakout sessions on the second day were used to define more completely the implementation activities discussed during the first day of the workshop. The workshop facilitators modified the structure of the Day Two Breakout Groups from the initial plan. Rather than focusing on collaboration, resources, media, and written and oral communication separately, the groups attempted to apply each area to one or two specific suggestions from day one. The issues described below reflect the common themes and the many points of view developed by the working groups.

This summary highlights those common themes. The first part of this section summarizes thoughts about the use of hotlines, an idea repeatedly identified as important, and offers specific suggestions about how to implement a hotline. One-to-one communication was the mechanism considered most effective and trust-inducing, which was also reflected in many of the participants' suggestions about how to improve treatment information dissemination. Other groups discussed ideas such as clinical conference calls, materials development, electronic networks, communication between the community and the national levels, and the media. The following account of Day Two Breakout Groups is organized by idea and summarizes group discussions.

24-Hour, Peer-Operated Hotlines, Warmlines, and Outreach Services

A number of groups suggested operating 24-hour local, regional, and/or national hotlines to provide treatment and clinical trials information and emotional support to a variety of populations (e.g., gay men, women, and substance users). Several groups suggested developing individual hotlines for specific subpopulations (e.g., black gay men, low income women, homeless substance users) because their needs are very specific. However, overall recommendations about how hotlines can be managed were similar. Most people agreed, for example, that peers should handle the hotlines, training, and outreach to build trust and maximize effectiveness. One group suggested that peer treatment educators be HIV positive and from the communities being targeted. There was general agreement that peer counselors should receive adequate training and financial support. Another group suggested that local and national telephone companies should be solicited to donate telephone time free or offer reduced rates. Yet another group recommended that a "how to" guide be developed so that people would have direction to help start a hotline if they were provided with the resources. In fact, one group used the time to develop start-up suggestions, thus providing guidance to others.

The following summarizes this group's specific suggestions for how to collaborate with others and with whom to collaborate, what resources might be needed, and how to use media-based and oral communication methods.

How To Start a Telephone Hotline

The group organized their approach by discussing the central questions originally planned for the day two workshops, looking at general principles involved, and finally providing suggestions from which to work.

Questions To Ask

The following questions were used as the starting point:

- What kinds of collaborations would need to take place to implement the hotline?
- What kinds of resources would be needed to implement the hotline?
- What sorts of media-based communication should be used to inform organizations and individuals?
- What oral communication methods would be needed or employed to achieve the objectives?
- What could they do to implement the strategy?
- What could their agency do and how would it support implementation?
- What should happen at the Federal level to assist the community-level organizations to accomplish the strategy?

Principles To Take Into Consideration

This group noted that several principles are important when discussing communication styles and processes and should be recognized when developing a hotline:

- People have different learning styles, and they receive information from multiple sources, all of which should be taken into consideration. Multiple sources of information should be used to design, implement, and evaluate strategies. Various tactics can serve to reinforce the messages an individual receives.
- To create solid programs, all recommendations should recognize and include the various components that are a part of communication programs: resources needed, content development, message delivery, and evaluation.

- The need for accurate information is paramount to a good program.
- Effective and ongoing training for all staff, volunteers, and counselors is needed.
- Collaborating with and creating linkages between community-based organizations is needed to create good programs. Collaboration can include local community research organizations and constituency groups and service provider groups who operate hotlines, such as state health departments that are mandated to operate hotlines for maternal/child health services. National hotlines can be used best to augment local efforts to provide information and technical assistance. All the networks created can serve as strong referral sources.

Suggestions, Strategies, and Methods

A number of specific suggestions about the use of hotlines were put forward. The group gave general suggestions categorized to address specific issues, including collaboration, resources, and oral and media communication.

General Suggestions

It was noted that the following types of suggestions should be considered when developing a hotline service.

Use the "hotline" in a "warmline" capacity, that is, connect the caller with a peer and use other expert staff persons to check information and make appropriate followup. Have "Point People" currently in treatment or in clinical trials available through a telephone network or hotline channel to provide intervention.

Collaboration Strategies

Collaboration was emphasized as an essential element in managing a hotline. "The problem isn't getting the information, it's managing it. There's a huge waterfall of information, and your job is to narrow it down to a manageable stream." Following are the organizations suggested for collaborative efforts.

- AIDS task forces/HIV/AIDS consortia.
- HIV antibody test sites.
- Mental health clinics.

- Current AIDS service providers with hotlines/TTY.
- State and local health departments.
- Local media outlets.
- Local communication organizations.
- Religious organizations.
- Community research organizations.
- Social service agencies (benefits, etc.).
- Multiethnic/cultural organizations.
- Libraries.

Resource Strategy Components

The group identified the following items/resources that would be necessary to create an effective hotline service. In some cases, specific organizations have been identified to provide resources.

- Hire the right staff and volunteers: those who are empowered, motivated, multicultural/ethnic, skilled at communicating with hard-to-reach populations, and living with HIV/AIDS.
- Technical assistance.
- Centers for Disease Control and Prevention resources for financial support of the hotline.
- Other Federal sources.
- Referral lists for each community.
- Private financial support sources.
- Supervisory/management resources.
- Equipment donations, including TTY/TTD equipment for the hearing impaired.

- Training resources for staff, volunteers, peer-educators, etc.
- Information resources; databases and online services.
- Liability insurance.
- Title V (prenatal) funding resources.
- Title X (family planning) funding resources.
- Title I and Title II funding resources.

Media-Based Communications Methods

Media-based communications were recognized as crucial to the information process. A number of channels were identified.

- Radio and television public service announcements (PSA).
- Bus posters.
- Flyers.
- Brochures.
- Posters.
- Videotapes.
- Motion picture trailers.
- Community-based newsletters/newspapers.
- Educational institution-based newspapers and bulletin boards.
- Collaborative links to other HIV/AIDS efforts.
- Refrigerator magnets.

Location-Based Outlets for Media-Based Communications

- Supermarket bulletin boards.
- Local clinics.

- Social service agencies (public and private).
- Student unions.
- Local businesses.
- Truck stops.
- Public bathrooms.

Oral Communications Methods

The group also recognized that one-on-one and group conversations are important to ensuring communication about HIV/AIDS.

- Street outreach by peers.
- Outreach at fairs and festivals.
- Speaker bureaus.
- Local clinics.
- Social service agencies.
- Schools and student unions (for one-to-one and group counseling).
- Local businesses.
- Community gatherings.
- Religion-based sermons, conferences, and counseling.

Although the group did not come to a final conclusion about the best way to create a hotline, they felt that the session provided them with a useful tool for developing a communication needs assessment that they could use at a future time.

International State-of-the-Art HIV Clinical Conference Call Series

The clinical conference call series has been successfully implemented by HRSA in collaboration with NIAID/NIH to deliver state-of-the-art HIV-related information to primary care providers. During these live, interactive, toll-free teleconferences, multidisciplinary primary care providers from ACTU and CPCRA sites, community health center workers, health professionals, health clinic personnel, medical center

personnel, private practitioners, and people working in correctional and other facilities have the opportunity to address timely clinical issues with internationally renowned clinical experts. Preprogram needs assessments determine which topics and specific questions will be discussed at each teleconference. A final collated list of questions is distributed to the providers and experts before each session.

Topics have included tuberculosis and multidrug-resistant disease (September 1992), the use of ddI and ddC (November 1992), and therapeutic HIV vaccines (February 1993). It was announced that the next session was planned for April 8, 1993, during which time two topics would be discussed: the idiopathic CD4 lymphocytopenia syndrome, and convergent combination therapy with nonnucleoside reverse transcriptase inhibitors. It was suggested that women's issues be scheduled for a future program.

Materials Development

Written Materials

It was agreed that survival guides, materials about standards of care, treatment factsheets, and other user-friendly materials should be developed and used in local forums and educational outreach programs. Outreach should include crack houses, shooting galleries, gay bars, places where foreign-born nationals gather, and schools. Materials should be developed with input from the targeted populations and funded by the Department of Health and Human Services.

Photographs

Photographs showing healthy, normal images of people with HIV/AIDS across the full range of races, cultures, classes, and lifestyles should be made available to organizations for use in newsletters and other printed materials. These images can be used to promote the concept that people are coping with HIV/AIDS. The group felt strongly that all copyright considerations be waived.

PSAs

PSAs targeted to HIV-positive women should be developed for print and broadcast media. They should feature empowering messages and images.

Chaptered Videotape

One group examined the possibility of producing a chaptered videotape to examine potential types of collaboration between various types of media. The initial segments of the videotape would gradually introduce issues surrounding being HIV positive and would develop ideas in each successive chapter, taking into account what

has been documented about people's ability to deal with different types of information at different stages of knowledge and acceptance. Issues would include drug use, nutrition, avoiding reinfection, telling a date that you are positive, finding a primary care physician, insurance, the importance of regular monitoring, early medical intervention, and clinical trials participation.

The videotape would attempt to overcome several barriers to seeking treatment:

- Lack of Trust--The videotapes could be customized for certain audiences, using languages, ethnic groups, and symbols that are familiar to the audience.
- Stigma--Using videotapes would allow audiences to view the materials in the privacy of their own home, avoiding some of the stigma and embarrassment attached to seeking information.
- Confusion and Overload--The presentation would use a "chaptered" approach to avoid overwhelming viewers with more than they are able to handle at one time.
- Limited Community Resources--The videotape would ease some of the burden on community-based organizations, which often do not have enough resources to develop and implement this type of educational approach.
- Dated material--The modular format of the videotape would allow for easy editing to keep the information up to date.

A number of organizations could handle production efforts, separately or in collaboration. Government agencies have prepared cassette tapes on clinical trials. In San Francisco, an interactive CD-ROM is being piloted in some African-American bars. The organizations that have developed these projects could come together to marshal resources for the videotape. Universities and schools of education as well as psychologists, community experts, linguistic experts, and broadcast networks are other resources currently available throughout the country. Some might be willing to volunteer time and resources. Community-based organizations with this expertise could also be involved.

Grants could be solicited from the pharmaceutical industry and professional associations, such as the AMA, to provide seed money for a pilot videotape that could be targeted and tested for one or more groups.

An interactive telephone system could also help people get information from the segments they want to hear. It was noted that some people do not have telephones or

VCRs. The videotapes could be made available to health care centers, clinics, doctors' offices, and other locales that have the needed equipment to access the videotapes.

Electronic Networks

Conference participants recommended the use of electronic networks, such as electronic bulletin boards, fax networks, information clearinghouses, telephone hotlines, and newsletter networks. These could be developed to help ensure rapid dissemination of consistent and accurate information. Developing electronic links between local networks would also enable communities to be responsive to local cultural, social, and geographical needs of persons with HIV/AIDS and their care providers.

Collaboration

An underlying theme of many discussions was that collaboration was essential. Participants identified agencies and groups that could collaborate, for example, on women's issues included: the Office of Research on Women's Health (NIH); local women's health organizations; CDC; national hotlines; local AIDS hotlines; local sexual assault hotlines; local suicide prevention hotlines; local networks of HIV-positive women and other related groups; telephone companies; ACTG; ASO/CBOs; HRSA; NIAID; treatment localities; clinical researchers; and groups that develop and distribute printed materials. All groups noted that it is important to strengthen the networks among researchers, primary care providers, and specialized agencies (e.g., substance abuse agencies) and to provide cross-training for groups.

Communication From the Community to the National Level

There is a pool of knowledge at the community level and a feedback loop should be developed to channel that information up to the national level. It was recommended that the system should be designed in such a way to ensure open communication so that trust develops. The group felt that the community knows what to do to make the system work, but that they are currently not given the opportunity to show it. *The bottom is always being told what to do.* The feedback system should include community-based organizations, county and public health systems, and people who are HIV positive. In addition, the network of experts involved in the feedback loop should be expanded. The AIDS ETCs (education and training center programs) also can be involved in this process. This system should be developed at the Federal level, with input from the community level. It should be designed to accommodate the flow of information about complementary therapies, such as nutrition and stress and pain management.

Media Suggestions

"Failing to involve the media in the big picture has repeatedly crippled national and local efforts at change for many years. Reducing media to getting the releases out fails to confront the important relationship between creating and delivering messages that serve the long-term goals of community empowerment for all of us."

Media-oriented recommendations included:

- Develop NIAID/HRSA-sponsored media working groups to discuss the role of media in AIDS education and encourage the media to provide culturally sensitive messages about HIV/AIDS.
- Encourage NIAID/HRSA to provide support for increased involvement of the national media with the purpose of changing the type of HIV/AIDS coverage available. While NIAID and HRSA are working for change at the national level, local organizations should be doing the same on their level to build momentum.
- Develop a series of workshops across the Nation on how to manage media relations programs with NIAID and HRSA funding.
- Develop a NIAID- and HRSA-supported "how-to" media planning guidebook to help "media novices" develop media relations skills.
- Develop a nationally televised treatment information campaign, using the media to provide technical assistance geared to the individual needs of communities.

CONCLUSION

By all accounts, the charge of the workshop "Bridging the Gap," to provide recommendations to improve HIV/AIDS treatment information dissemination, was met. The enthusiasm and collaborative spirit of the participants was obvious and resulted in lively discussion and the development of a number of important recommendations that address the needs of primary care providers, community-based HIV/AIDS service organizations, and persons with HIV for specific information directed to various populations.

Ryland Roane from Richmond, Virginia, who has been HIV positive for 7 years, provided the closing address and challenge. He sorted out some issues of consequence brought out by the workshop: that the key to the solution is how effectively the HIV communities communicate with each other; that knowledge and understanding for many is empowerment; and that what was most significant about this workshop was that many of the relevant players were brought to the table.

His closing challenges included the following:

1. Prioritize.
2. Remember the needs of people in rural areas and the small cities in America.
3. Train community-based organizations and make sure that they are well instructed and understand the administrative tasks necessary for effective treatment information dissemination.

It is the desire of everyone attending the workshop that the various communities make use of the workshop's many recommendations, thus ensuring the availability of information to those who need it.

"Together we stand. United we walk. Let's build a bridge. Tear down the walls. Let us respond to our people's call."

-- Words sung by participants during the closing, multicultural ritual.

BRIDGING THE GAP:

A WORKSHOP ON HIV TREATMENT INFORMATION DISSEMINATION

Planning Committee

National Institute of Allergy and Infectious Diseases (NIAID)

Debbie Katz
Kate Perkins
Patricia Randall

Office of AIDS Research

Linda Reck

Health Resources and Services Administration (HRSA)

G. Stephen Bowen, MD, MPH	Pearl Katz, PhD
Buck Buckingham	Abe Macher, MD

Community Representatives

Roxanne Cox-Iyamu, MD	Charles Nelson
Debra Fraser-Howze	Ryland Roane
Greg Haas	Rochelle Rollins
Bob Hultz	Jim Welch
Kiyoshi Kuromiya	Neil Schram, MD

Contract Staff

Wendy Child
Helene Quick

ACRONYMS

ACTIS	AIDS Clinical Trials Information Service
ACTG	AIDS Clinical Trials Group
ACTUs	AIDS Clinical Trials Units
AHCPR	Agency for Health Care Policy and Research
AIDS ETC	AIDS Regional Education and Training Centers Program
BHRD	Bureau of Health Resources Development, HRSA
CAB	Community Advisory Board
CCG	Community Constituency Group
CDC	Centers for Disease Control and Prevention
CMHS	Center for Mental Health Services, SAMHSA
CPCRA's	Community Programs for Clinical Research on AIDS, NIAID
CSAP	Center for Substance Abuse Prevention, SAMHSA
CSAT	Center for Substance Abuse Treatment, SAMHSA
DAIDS	Division of AIDS, NIAID
DHHS	Department of Health and Human Services
FDA	Food and Drug Administration
HRSA	Health Resources Services Administration
NAPO	National AIDS Program Office
NCI	National Cancer Institute
NIAAA	National Institute on Alcohol Abuse and Alcoholism, NIH
NIAID	National Institute of Allergy and Infectious Diseases, NIH
NIDA	National Institute on Drug Abuse, NIH
NIH	National Institutes of Health
NICHD	National Institute of Child Health and Human Development, NIH
NLM	National Library of Medicine, NIH
NIMH	National Institute of Mental Health, NIH
OAR	Office of AIDS Research, NIH
OASH	Office of the Assistant Secretary for Health
PHS	Public Health Service
RAC	Regional AIDS Coordinators
SAMHSA	Substance Abuse and Mental Health Services Administration

Bridging the Gap:
A Workshop on HIV Treatment Information Dissemination
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Participant List

Fozia Abrar, MD
Health Care Coordinator
Commission of Public Health
1660 L Street, NW, Suite 907
Washington, DC 20036
202-673-4551
202-727-9021 Fax

Moises Agosto
ACTG, CCG
PWA Coalition
31 West 26th Street, 5th Floor
New York, NY 10010
212-582-0290
212-447-1508 Fax

Marietta Anthony
Agency for Health Care Policy
and Research
2101 East Jefferson Street, Suite 502
Rockville, MD 20852
301-227-6671
301-227-8155 Fax

Brad Austin
Bureau of Primary Health Care
Health Resources and Services
Administration
5600 Fishers Lane, Room 9-12
Rockville, MD 20857
301-443-8113
301-443-4786 Fax

Dorothy Bailey
Office of Communication
Bureau of Health Resources Development
Health Resources and Services
Administration
5600 Fishers Lane, Room 9-33
Rockville, MD 20857
301-443-6846
301-443-3608 Fax

Tim Baker
Centers for Disease Control
and Prevention
Mail Stop E24
1600 Clifton Road, NE
Atlanta, GA 30333
404-639-0911
404-639-0943 Fax

Marion Banzhaf
Coordinator
New Jersey Women and AIDS Network
5 Elm Row, Suite 112
New Brunswick, NJ 08901
908-846-4462
908-846-2674 Fax

George Bellinger, Jr.
Program Coordinator
Early Advocacy and Care for HIV
944 Market Street, Suite 210
San Francisco, CA 94102
415-403-3800
415-403-3809 Fax

Yvette Benjamin
Social and Scientific Systems
6101 Executive Boulevard, Suite 200
Rockville, MD 20852
301-230-3150

Alicia Blessington
Regional AIDS Coordinator
U.S. Public Health Service
Gateway Building, Suite 1
P.O. Box 13716
Philadelphia, PA 19101
215-596-0123
215-596-0488 Fax

Russ Bloem
Director
HIV Products
Bristol-Myers Squibb
P.O. Box 4500
Princeton, NJ 08543
609-897-2610
609-897-6088 Fax

G. Stephen Bowen, MD, MPH
Associate Administrator for AIDS
Health Resources and Services
Administration
5600 Fishers Lane, Room 11-03
Rockville, MD 20857
301-443-1993
301-443-9645 Fax

Jerome Boyce
Project Survival
3336 Glynn Court
Detroit, MI 48206
313-869-6952

Holly Boyd, RN
Research Director
Southwest Combat Group
1800 North Highland, Suite 610
Los Angeles, CA 90028
213-469-5888
213-464-4404 Fax

Russ Brady
Whitman Walker Clinic
1407 S Street, NW
Washington, DC 20009
202-797-3548
202-797-3504 Fax

Mary Brasler
1700 Research Boulevard
Rockville, MD 20850-3142
301-294-5438

Jerry Breitman
Director of Professional Relations
Burroughs Wellcome
3030 Cornwallis Road
Research Triangle Park, NC 27709
919-248-3896
919-248-0421 Fax

Evelyn Brewster
Prospect Associates
1801 Rockville Pike, Suite 500
Rockville, MD 20852
301-468-6555
301-770-5164 Fax

Joyce Brown-Hassen, RN, BSN
Site Supervisor
McAuley Clinic
550 Cherry Street, SE
Grand Rapids, MI 49503
616-774-2255
616-235-0739 Fax

Mary Caffery
UCSD-ACTG
2760 Fifth Avenue, #300
San Diego, CA 92103
619-543-8080

Jon Campbell
422 Graham Avenue
Brooklyn, NY 11211
718-383-4120

Michael Carbine
National Leadership Council on AIDS
1730 M Street, NW, Suite 905
Washington, DC 20036
202-429-0930
202-872-1977 Fax

Joseph Cardozo
Director of Education
Multicultural AIDS Coalition
801 Tremont Street
Boston, MA 02118
617-536-8610
617-536-9638 Fax

Hector Carrillo, MCP, MPH
Editor
Positive News
San Francisco AIDS Foundation
P.O. Box 426182
San Francisco, CA 94142
415-864-5855 Ext. 2083
415-552-1583 Fax

Nelvis Castro
Coordinator
Hispanic Education Program
National Cancer Institute
National Institutes of Health
Building 31, Room 4B-43
9000 Rockville Pike
Bethesda, MD 20892
301-496-6792
301-402-0894 Fax

Kelly Chambers
Community Advisory Board, F.A.C.E.
P.O. Box 46794
Cincinnati, OH 45246
513-558-3571

Tonisa Clardy
Executive Director
The Resources for Experimental
AIDS Therapies (TREAT)
1915 Rosina Street
Santa Fe, NM 87501
505-983-3633
505-986-3938 Fax

Lance C. Clem
Director
Governor's AIDS Council
Office of the Governor
136 State Capitol Building
Denver, CO 80203
303-837-4869
303-837-4886 Fax

Lois Ann Colaianni
National Library of Medicine
National Institutes of Health
8600 Rockville Pike, Room 2W04A
Bethesda, MD 20894
301-496-6921
301-496-4450 Fax

Don Conner, PA-C
ACTG, CCG
Metropolitan St. Louis AIDS Program
634 North Grand Boulevard, Suite 444
St. Louis, MO 63104
314-658-1159
314-658-1017 Fax

Sally Cooper
Executive Director
PWA Health Group
150 West 26th Street, Suite 201
New York, NY 10001
212-255-0520
212-255-2080 Fax

Stefanie Cooper
Visual Arts Consultant
Multicultural AIDS Coalition
801 Tremont Street
Boston, MA 02118
617-442-1622
617-442-6622 Fax

Jorge Correa
817 South Shenandoah Street
Los Angeles, CA 90035
310-657-6176

Eugenia Cowan, PhD
Executive Director
California Association of AIDS Agencies
926 J Street, Suite 803
Sacramento, CA 95814
916-447-7199
916-447-5302 Fax

Margo Cowan
ACTG, CCG
502 West 29th Street
Tucson, AZ 85713
602-770-7418

Mallory J. Cross
Community Advisory Board
Washington University
St. Louis, MO
314-361-6042

Robert Darga, MD
Director of Programs
National Association of PWAs
1413 K Street, NW, 7th Floor
Washington, DC 20005
202-898-0414
202-898-0435 Fax

Martin Delaney
Founding Director
Project Inform
1965 Market Street, Suite 220
San Francisco, CA 94103
415-558-8669
415-558-0684 Fax

Rebecca Denison
Founding Director
WORLD
P.O. Box 11535
Oakland, CA 94611
510-658-6930
510-601-9746 Fax

Dianne Donovan
Positively Pediatrics &
Adolescents
17 Prospect Drive
Queensbury, NY 12804
518-798-8940
518-798-8940 Fax

Moher Downing, MA
PHREDA Project Director
3130 20th Street, Suite 352
San Francisco, CA 94143
415-476-6117
415-647-7611 Fax

Corey S. Dubin
Chair
Santa Barbara County
HIV CARE Consortium
c/o Coyote Radio
622 Andamar Way
Goleta, CA 93117
805-967-0274
805-967-0274 Fax

Novella Dudley
Program Director
Women Resourcing Women
1346 North Oakley
Chicago, IL 60622
312-292-1140
312-292-1045 Fax

Raymond E. Dumas
Community Based Educator
People of Color Against AIDS Network
1200 South Jackson, Suite 25
Seattle, WA 98144
206-322-7061
206-322-7204 Fax

Michael W. Dunne, MD
Pfizer Central Research
Eastern Point Road
Groton, CT 06340
203-441-3739
203-441-5702 Fax

Dave Durham
Burroughs Wellcome
3030 Cornwallis Road
Research Triangle Park, NC 27709
919-248-3443

Gail Dutcher
National Library of Medicine
National Institutes of Health
Building 38A, Room 3S316
8600 Rockville Pike
Bethesda, MD 20894
301-496-3147
301-480-3537 Fax

Sandra Elkin
President
Media Group
161 West 15th Street, Apt. 7E
New York, NY 10011
212-206-0020
212-989-7324 Fax

Cindy Milam Faries
Program Director
Library & Information Services
Texas Department of Health
1100 West 49th Street
Austin, TX 78756
512-458-7559
512-458-7683 Fax

Lou Fintor
National Cancer Institute
National Institutes of Health
Executive Plaza North, Room 313
9000 Rockville Pike
Bethesda, MD 20892
301-496-5500

John C. Fitzpatrick, PhD
Director of Alcoholism & Substance Abuse
Services
Sunset Park Family Health Center
514-49th Street, 2nd Floor
Brooklyn, NY 11220
718-435-8470
718-633-4256 Fax

Debbie Fletcher
Burroughs Wellcome
3030 Cornwallis Road
Research Triangle Park, NC 27709
919-248-3444

J. Craig Fong, JD
Director
Western Region
Lambda Legal Defense and Education
Fund
606 South Olive Street, Suite 580
Los Angeles, CA 90014
213-629-2728
213-629-9022 Fax

Kevin Fong
Program Director
Asian Health Services
310 Eighth Street, Suite 200
Oakland, CA 94607
510-444-2437
510-451-2786 Fax

Ken Fornataro
Executive Director
AIDS Treatment Data Network
259 West 30th Street, 9th Floor
New York, NY 10001
212-268-4196
212-268-4199 Fax

Linda Frank, PhD, MSN
Project Director
Pennsylvania AIDS ETC
University of Pittsburgh
130 DeSoto Street, Room A-451
Pittsburgh, PA 15261
412-624-1895
412-624-4767 Fax

Debra Fraser-Howze
ACTG, CCG
Executive Director
Black Leadership Commission on AIDS
105 East 22nd Street, 6th Floor
New York, NY 10010
212-614-0023
212-614-0057 Fax

Luis A. Fuentes, MPH
Project Manager
Harlem AIDS Treatment Group
Harlem Hospital Center
Columbia University
506 Lenox Avenue, Room 3107
New York, NY 10037
212-939-4170
212-939-2968 Fax

Robert E. Fullilove, EdD
Associate Dean
School of Public Health
Columbia University
722 West 168th Street, Box 29
New York, NY 10032
212-740-7292
212-795-4222 Fax

Paul Gaist, MPH
(primary liaison for NIMH, NIAAA,
NIDA)
Office of AIDS Research
National Institutes of Health
Building 31, Room 5C06
6100 Rockville Pike
Bethesda, MD 20892
301-496-0358
301-402-7769 Fax

Barbara Garcia
Peer Advocate
Planned Parenthood
815 Eddy Street, Suite 100
San Francisco, CA 94109
415-202-7430
415-776-1449 Fax

David Gold
Editor
Treatment Issues
Gay Men's Health Crisis
129 West 20th Street
New York, NY 10011
212-337-3503
212-337-3656 Fax

Ronald Goldschmidt, MD
Director
Family Practice Inpatient Service
San Francisco General Hospital
1001 Potrero Avenue
San Francisco, CA 94110
415-206-8651
415-206-6135 Fax

Eric Goosby, MD
Director, Division of HIV Services
Bureau of Health Resources Development
Health Resources and Services

Administration
5600 Fishers Lane, Room 9A-05
Rockville, MD 20857
301-443-6745
301-443-5271 Fax

Barry Gordon, RPH
Regional AIDS Coordinator
U.S. Public Health Service
Federal Building, Room 3337
26 Federal Plaza
New York, NY 10278
212-264-2535
212-264-1324 Fax

Joseph Guimento
Projects Coordinator
Treatment Information Services
AmFAR
733 Third Avenue, 12th Floor
New York, NY 10017
212-682-7440 ext. 135
212-682-9812 Fax

Daniel Guzman
CARE Coordinator
AIDS Arms Network
2727 Oaklawn, Suite 222
Dallas, TX 75219
214-521-5191
214-528-5879 Fax

Greg Haas
Committee of Ten Thousand
ACTG, CCG
2459 Harriet Avenue South, Apt. 1
Minneapolis, MN 55405
612-874-7178
612-624-2196 Fax

Travis Hall
1900 West Speedway
Tucson, AZ 85745
602-623-4494

Sue Hammett
Regional AIDS Coordinator
U.S. Public Health Service
1200 Main Tower Building
Room 1800
Dallas, TX 75202
214-767-3879
214-767-0404 Fax

Alan Harris
Regional AIDS Coordinator
U.S. Public Health Service
50 United Nations Plaza
San Francisco, CA 94102
415-556-1138
415-556-2356 Fax

Roy Hayes
President
We the People
425 South Broad Street
Philadelphia, PA 19147
215-545-6868
215-545-8437 Fax

Lisa Hernandez
For AIDS Children Everywhere
467 Grandin Avenue
Cincinnati, OH 45246
513-558-3571
513-558-6386 Fax

Jean Hofacker
Director
Information Services
AIDS Information Network
32 North 3rd Street
Philadelphia, PA 19106
215-922-5120
215-922-6762 Fax

Joan Holloway
Bureau of Primary Health Care
Health Resources and Services
Administration
5600 Fishers Lane, Room 9-12
Rockville, MD 20857
301-443-8134
301-443-4786 Fax

Daniel Hoth, MD
Director
Division of AIDS
National Institute of Allergy
and Infectious Diseases
National Institutes of Health
Solar Building, Room 2A18
6003 Executive Boulevard
Bethesda, MD 20892
301-496-8000
301-402-1505 Fax

Bob Hultz
ACTG, CCG
Editor
Positively Aware
1340 North Astor, Suite 505
Chicago, IL 60610
312-472-6397
312-472-7505 Fax

John S. James
AIDS Treatment News
P.O. Box 411256
San Francisco, CA 94141
415-861-2432

Georgette Jeanty, MD
Haitian American Public Health Initiatives
10 Fairway Street
P.O. Box 88
Mattapan, MA 02126
617-298-8076
617-298-1224 Fax

Rev. Carol A. Johnson
Harvard University Divinity School
Harvard AIDS Ministries
Cambridge, MA 02138
617-493-4729

Saundra Johnson
ACTG, CCG
5249 North Kenmore
Chicago, IL 60640
312-271-2070

Vesta M. Jones
Office of the Assistant
Secretary for Health
U.S. Department of Health and Human
Services
Room 738-G, HHH Building
200 Independence Avenue, SW
Washington, DC 20201
202-690-6248
202-472-7054 Fax

Ted Karpf
AIDS Clinical Trials Information
Service
1600 Research Boulevard, MS 1B
Rockville, MD 20850
301-251-5181
301-738-6616 Fax

Debbie Katz
Division of AIDS
National Institute of Allergy
and Infectious Diseases
National Institutes of Health
Solar Building, Room 2A-20
6003 Executive Boulevard
Rockville, MD 20892
301-496-0545
301-480-5703 Fax

Pearl Katz, Ph.D
AIDS Program Office
Health Resources and Services
Administration
5600 Fishers Lane, Room 14A-21
Rockville, MD 20857
301-443-4588
301-443-1551 Fax

Jack Killen, MD
Deputy Director
Division of AIDS
National Institute of Allergy
and Infectious Diseases
National Institutes of Health
Building 31, Room 7A03
9000 Rockville Pike
Bethesda, MD 20892
301-496-9088
301-496-4409 Fax

Henry Kissman
NLM-ASPEN
1010 Cresthaven Drive
Silver Spring, MD 20903
301-230-3150

Joy Koenig, MD
Regional AIDS Coordinator
Associate Regional Health Administrator
for Clinical Affairs
U.S. Public Health Service
John F. Kennedy Building, Room 1826
Boston, MA 02203
617-565-1420
617-565-3044 Fax

John N. Krzemien, PhD
Regional AIDS Coordinator
U.S. Public Health Service
105 West Adams Street, 17th Floor
Chicago, IL 60603
312-353-1385
312-353-0718 Fax

Kiyoshi Kuromiya
Critical Path AIDS Project
2062 Lombard Street
Philadelphia, PA 19146
215-545-2212
215-735-2762 Fax

Amy J. Kutzbach
Children's Hospital of Buffalo
22 Mariner Street
Buffalo, NY 14201
716-883-4189

Juan C. Ledesma
Clinic Director
AIDS Healthcare Foundation
1300 North Vermont Avenue, Suite 407
Los Angeles, CA 90027
213-662-0492
213-662-0196 Fax

Gail Levinson
Manager
Public Policy
Hoffmann La Roche
340 Kingsland
Building 1, 3rd Floor
Nutley, NJ 07110
201-235-6328
201-235-6031 Fax

Tom Lidot
HIV Coordinator
Indian Health Council, Inc.
P.O. Box 406
Pauma Valley, CA 92061
619-749-1410
619-749-1564 Fax

Gary B. MacDonald
Academy for Educational Development
1255 23rd Street, NW
Washington, DC 20037
202-862-1900
202-862-1947 Fax

Abe M. Macher, MD
Medical Consultant
AIDS Education and Training
Centers Program
Health Resources and Services
Administration
5600 Fishers Lane, Room 4C-03
Rockville, MD 20857
301-443-6364
301-443-1719 Fax

Martin Majchrowicz
AIDS Project of LA
6721 Romaine Street
Los Angeles, CA 90038
213-962-1600
213-962-3475 Fax

Jacqueline Maloney
Kendall Institute
140 Clarendon Street
Boston, MA 02190
617-375-9099

Norma Manuel
Senior Public Health Educator
Fulton County Health Department
HIV Prevention Program
99 Butler Street, SE, Penthouse
Atlanta, GA 30274
404-730-1586
404-730-1499 Fax

Sharon Marsh
AIDS Clinical Trials Information
Service
1600 Research Boulevard
Rockville, MD 20850
301-251-5750

Bill Martin
Interscience Communications
1615 L Street, NW, Suite 1150
Washington, DC 20036
202-973-0374

William Mayfield, MSW
Regional AIDS Coordinator
U.S. Public Health Service
601 East 12th Street, Room 501
Kansas City, MO 64106
816-426-3291
816-436-2178 Fax

Jean McGuire
177 River Street
Cambridge, MA 02139
617-868-0585

Jo Messoro
External Liaison Officer
Office of the Assistant Secretary
for Health
U.S. Department of Health and Human
Services
Room 738-G, HHH Building
200 Independence Avenue, SW
Washington, DC 20201
202-690-5560
202-690-7560 Fax

Eleanor Mitchell
AIDS Treatment Data Network
259 West 30th Street, 9th Floor
New York, NY 10001
718-441-3294

Bea Morris, PA
Director
Clinical Trials Program
Highland General Hospital
1411 East 31st Street
Oakland, CA 94602
510-437-5093
510-437-5170 Fax

Stephen Moskey
Director
Consumer Issues
Aetna Life and Casualty
151 Farmington Avenue
RE6A
Hartford, CT 06516
203-273-2086
203-273-9806 Fax

Charles Nelson
ACTG, CCG
Morehouse College of Medicine
720 Westview Drive, Room 137
Atlanta, GA 30310
404-752-1506
404-752-8443 Fax

Steve Nestler
Regional AIDS Coordinator
U.S. Public Health Service
101 Marietta Tower, Suite 1104
Atlanta, GA 30323
404-331-5879
404-841-2056 or 5490 Fax

Frederick Nunley
1309 Rhode Island Avenue, NW
Washington, DC 20005
202-797-2190

Joseph F. O'Neill, MD, MPH
Director of Research
Chase-Brexton Clinic
101 West Read Street, Suite 211
Baltimore, MD 21201
410-837-2050
410-837-2071 Fax

John Ortega
Bexar County HIV/AIDS Consortium
P.O. Box 12082
San Antonio, TX 78212
210-432-1964
210-520-9522 Fax

Lisa Padro
Director
Women's Service
Foundation for Outreach
406 East 120th Street, 4th Floor
New York, NY 10035
212-289-6629

Rafael H. Pagan, MD
ACTG, CCG
Executive Director
Puerto Rico CoNCRA
112 University Avenue
San Juan, PR 00925
809-753-9443
809-753-2894 Fax

Mara Paternmaster
Manager
HIV Grants Program
U.S. Conference of Mayors
1620 I Street, NW
Washington, DC 20006
202-293-7330
202-293-2352 Fax

Kate Perkins, MPA
Office of Communications
National Institute of Allergy
and Infectious Diseases
National Institutes of Health
Building 31, Room 7A-50
9000 Rockville Pike
Bethesda, MD 20892
301-496-5717
301-402-0120 Fax

Elba Persler
UCLA CAB
ACT UP/LA, Treatment and Data
Committee
11104 Aqua Vista, # 26
N. Hollywood, CA 91602

Nancy McCormick-Pickett
Technical Vice President
Prospect Associates
1801 Rockville Pike, Suite 500
Rockville, MD 20852
301-468-6555
301-770-5164 Fax

Matt Pieper
AIDS Research Consortium of Atlanta
Atlanta, GA
404-876-2317

Ronald Porter
Site Coordinator
La Frontera Center
502 West 29th Street
Tucson, AZ 85713
602-770-7418
602-770-7419 Fax

Patricia Randall
Director
Office of Communications
National Institute of Allergy
and Infectious Diseases
National Institutes of Health
Building 31, Room 7A-50
9000 Rockville Pike
Bethesda, MD 20892
301-496-5717
301-402-0120 Fax

Linda Reck
Office of AIDS Research
National Institutes of Health
Building 31, Room 5C-06
9000 Rockville Pike
Bethesda, MD 20892
301-496-0358
301-402-7769 Fax

Robert Rinaldi, PhD
Director
Division of Health Sciences
American Medical Association
515 North State Street
Chicago, IL 60610
312-464-5000
312-464-5842 Fax

Ryland R. Roane, Jr
HIV/STD Health Educator
Richmond City Health Department
600 East Broad Street, Room 618
Richmond, VA 23219
804-780-4240
804-783-8257 Fax

Audrey Rogers
National Institute of Child
Health and Human Development
National Institutes of Health
6100 Executive Boulevard, Room 4B11K
Rockville, MD 20852
301-496-7339
301-496-8678 Fax

Rochelle L. Rollins, MPH
ACTG, CCG
Research Director
Multicultural AIDS Coalition
801 Tremont Street
Boston, MA 02118
617-442-1622
617-442-6622 Fax

Denise Rouse, MPH
Office of the Assistant
Secretary for Health
U.S. Department of Health and Human
Services
Room 711G, HHH Building
200 Independence Avenue, SW
Washington, DC 20201
202-690-6600
202-690-7122 Fax

Sonia Ruiz
5249 North Kenmore
Chicago, IL 60640
312-271-2242

Karen Ryland
CPCRA/ROW Services
5515 Security Lane
Rockville, MD
301-294-5600

Vikki St. Clair
P.O. Box 3276
Cincinnati, OH 45201-3276
513-558-0500

Donald Schneider, DDS, MPH
Agency AIDS Coordinator
Agency for Health Care Policy
and Research
2101 East Jefferson Street, Suite 502
Rockville, MD 20852
301-227-8354
301-227-8155 Fax

John Seigfried, MD
Pharmaceutical Manufacturers
Association
1100 15th Street, Suite 900
Washington, DC 20005
202-835-3542
202-835-3597 Fax

Walt Senterfitt
Being Alive
817 South Shenandoah Street
Los Angeles, CA 90035
310-657-6176
213-667-2735 Fax

Richard Serwell
219 Rutherford
Redwood City, CA 94061
415-366-8021

Margie Shannon
Southern Christian Leadership
Conference/Women's National AIDS
Program
330 Auburn Avenue, Suite 216
Atlanta, GA 30303
404-681-2437
404-215-9450 Fax

Elliot Siegel, PhD
National Library of Medicine
National Institutes of Health
Building 38, Room 2S20
8600 Rockville Pike
Bethesda, MD 20894
301-496-8834
301-496-4450 Fax

Mitchell Speer
Director
Treatment Information
AmFAR
733 Third Avenue, 12th Floor
New York, NY 10017
212-682-7440
212-682-9812 Fax

Nancy Stanisc
Health Programs Coordinator
Office of AIDS Coordination
FDA Mail Stop HF-12 5
5600 Fishers Lane, 12A040
Rockville, MD 20857
301-443-0104
301-443-4555 Fax

Joel B. Tan
Senior Programs Coordinator
A/PI AIDS Intervention Team
1313 West 8th Street, Suite 224
Los Angeles, CA 90017
213-484-0380
213-413-1539 Fax

Anita Taylor
Director of Public Policy Education
National Minority AIDS Council
300 I Street, NE, Suite 400
Washington, DC 20002
202-544-1076
202-544-0378 Fax

Michael D. Thurnherr
Program Coordinator
Test Positive Aware Network
1340 West Irving Park Road
Box 259
Chicago, IL 60613
312-404-8726
312-404-1040 Fax

Vivian Torres
Coordinator
Vivian's Place
505 West Market Street
Newark, NJ 07107
201-481-1412
201-481-1339 Fax

Zoila Torres-Feldman
Great Brook Valley Community Health
Center
32 Great Brook Valley Avenue
Worcester, MA 01605
508-852-1805
508-853-8593 Fax

Sylvia Trent
Bureau of Primary Health Care
Health Resources and Services
Administration
5600 Fishers Lane, Room 9-12
Rockville, MD 20857
301-443-8113
301-443-4786 Fax

Mirielle Tribie, MD
Deputy Director
The League Against AIDS
1500 NW 12th Avenue, Suite 1029
Miami, FL 33136
305-585-7480
305-547-4001 Fax

Dorothy Triplett
Centers for Disease Control
and Prevention
Mail Stop D21
1600 Clifton Road, NE
Atlanta, GA 30333
404-639-0906
404-639-0910 Fax

Bernard Turner
National Community AIDS Partnership
1140 Connecticut Avenue, NW, Suite 901
Washington, DC 20036
202-429-2820
202-429-2814 Fax

Carlos Vega-Matos, MPA
AIDS Program Director
COSSMHO
1501 16th Street, NW
Washington, DC 20036
202-387-5000
202-797-4353 Fax

Jonathan Wadleigh
Committee of Ten Thousand
c/o Boston AIDS Consortium
677 Huntington Avenue
Boston, MA 02115
617-432-3243
617-432-2494 Fax

Beth Weinstein, MOT, OTR
President
Dynacare
4309 SE 64th Avenue
Portland, OR 97206
503-774-1238
503-774-0156 Fax

Jim Welch, RN
AIDS Activities Coordinator
Delaware Division of Public Health
P.O. Box 637
Dover, DE 19903
302-739-5617
302-739-6617 Fax

Elaine Wells
National Hemophilia Foundation
110 Greene Street
New York, NY 10012
212-431-8541

Richard Westcott
Washington University CAB
ACT UP St. Louis
5335 Del Mar, #3C
St. Louis, MO 63112
314-361-6918

Roy Widdus, PhD
Executive Director
National Commission on AIDS
1730 K Street, NW, Suite 815
Washington, DC 20006
202-254-5125
202-254-3060 Fax

Jacqueline C. Wilkerson
Director, AIDS Advocacy
AIDS National Interfaith Network
110 Maryland Avenue NE, Suite 504
Washington, DC 20002
202-546-0807
202-546-5103 Fax

Jane Wilson
Regional AIDS Coordinator
U.S. Public Health Service
1185 Federal Building
1961 Stout Street
Denver, CO 80294
303-844-6163
303-844-2019 Fax

Alison Wojciak
Social and Scientific Systems
6101 Executive Boulevard, Suite 200
Rockville, MD 20852
301-230-3150

Arnette Wright
Bureau of Primary Health Care
Health Resources and Services
Administration
5600 Fishers Lane, Room 9-12
Rockville, MD 20857
301-443-9371
301-443-4786 Fax

Jifunza Wright, MD
Johns Hopkins School of Hygiene &
Public Health
624 North Broadway
Hampton House, 8th Floor
Baltimore, MD 21205
410-955-3943
410-955-9088 Fax

Susan Yarin
Manager
Pharmaceutical and Research
Communication
Bristol-Myers Squibb
345 Park Avenue
New York, NY 10104
212-546-5709

Allen Zaklad
CHI Systems, Inc.
Gwynedd Plaza III
Bethlehem Pike
Springhouse, PA 19477
215-542-1400

Pedro Zamora
Peer Educator
Body Positive
175 NE 36th Street
Miami, FL 33137
305-576-1111
305-576-0604 Fax

Heshie Zinman
AIDS Information Network
32 North 3rd Street
Philadelphia, PA 19106
215-922-6814

Johnson, Bassin & Shaw, Inc.
8630 Fenton Street, Suite 1200
Silver Spring, MD 20910
301-495-1080
301-587-4352 Fax

Nancy Albrecht
Wendy Child
Susan Haught
Lura Myers
Helene Quick
Jerri Shaw

Prospect Associates
1801 Rockville Pike, Suite 500
Rockville, MD 20852
301-468-6555
301-770-5164 Fax

Anne Chun
Connie Herndon
Bea Jakubowski
Don Mullins
Elaine Murray
Pamela Pine
Dale Singer
Jane Snyder
Shannon Stout

THE WHITE HOUSE
WASHINGTON

December 17, 1993

Honorable Gerald Johnson
Mayor, City of DeRidder
200 South Jefferson Street
DeRidder, LA 70634

Dear Mayor Johnson:

Thank you for sharing information on your efforts to establish an AIDS awareness program in DeRidder. Leadership at the community level by public figures like yourself can help make the job of stopping AIDS and HIV transmission much less controversial.

It sounds like you are already off to a very good start, but I'd suggest the following sources of additional assistance in your efforts:

- The National Community AIDS Partnership
Ms. Paula VanNess, Executive Director
1140 Connecticut Avenue, NW Suite 901
Washington, DC 20036-4001 / 202-429-2820
- The Centers for Disease Control (CDC) National AIDS Clearinghouse
(including the Business Responds to AIDS Resource Service)
1-800-458-5231
- The National Leadership Coalition on AIDS
Mr. B. J. Stiles, Executive Director
1730 M Street, NW Suite 905
Washington, DC 20036 / 202-452-8845
- U.S. Conference of Mayors
Ms. Mara Paternoster, AIDS Program Director
1620 "I" Street, NW
Washington, DC 20006 / 202-293-7330

Please accept my very best wishes for successful AIDS awareness in DeWidder, and my thanks for your leadership.

Sincerely,



Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

Be sure Buck sees the letter -
(he may want to edit mine!)
Der Mr Johnson -

Thank you for sharing info on
any efforts to establish an
AIDS awareness program in
De Ridder. You may get some
ideas or assistance from

CAN (Psalms 124:1-2)

NLCA (BQ stiles)

in addition to the LA HD.

Best wishes, & please stay in touch.



GERALD JOHNSON
MAYOR



DEC - 3 1993

OFFICE OF THE MAYOR
200 SOUTH JEFFERSON STREET
DE RIDDER, LOUISIANA 70634
(318) 462-2461
FAX (318) 463-2352

30 November 1993

Ms. Kristine Gebbie
Executive Office of The President
750 17th Street N.W., Suite 1060
Washington, D.C. 20503

Dear Ms. Gebbie:

I saw you on the Today Show this morning and I certainly agree with your remarks.

As you will note by the attached copies of newspaper clippings, I am trying to create an AIDS Awareness Program here in DeRidder.

DeRidder is located just fifteen miles south of the Fort Polk Military installation. Consequently we have a big turn over of citizens from time to time. At any rate, I would appreciate any help your office would be able to provide.

Thank you for taking the time to respond to my request.

Sincerely,

GERALD JOHNSON
Mayor

GJ/bjw

Enclosure

Task force of volunteers to prevent AIDS being formed

By Ben Darby
City-Parish Editor

DeRidder Mayor Gerald Johnson Monday began working to create an area AIDS prevention awareness task force.

During a meeting last week of citizens concerned with the increasing incidence of area HIV/AIDS cases, Johnson said he would "start the ball rolling" on an area task force.

"As I see it, our first priority would be to get the word out about AIDS, a killer for which there is no known cure," Johnson said. "It's tragically simple. Once you get AIDS, there is no turning back. I have good friends with family members who have suffered losses to AIDS."

"At the same time, it must be understood that AIDS isn't gotten from drinking fountains. Two of the main ways it is trans-

mitted are through non-monogamous sexual activity and using needles more than once in illicit drug activity," Johnson said.

Johnson said he is looking for a cross-section of area society to work with a volunteer AIDS prevention awareness task force. "I will be asking members of the medical, religious, military and school communities to help with this effort."

"In recent meetings on this subject, we have discussed bringing in outside help in getting organized. That's fine, but we need to quickly get to the point where we know exactly what we are talking about and what we are doing. Getting the word out about this tragic matter, is, after all, an urgent necessity here as well as everywhere else," Johnson said.

See AIDS P. 2A

AIDS

Continued from P. 1A
son said.

Those who have attended recent local meetings on the subject agreed that youth are probably more likely to listen to a peer or someone who either has AIDS or has a family member or close friend who has it. They agreed that it needs to be emphasized that total sexual abstinence is the only full-proof preventative in non-monogamous relationships.

Other growing problems in this area are with teen pregnancies, other sexually transmitted diseases and alcohol and drug abuse, "which are too often tragically intertwined, only compounding the problem," Johnson said.

For every known case of AIDS, there are 10-to-15 unknown cases, according to national statistics. With about 35 known AIDS cases in Beauregard Parish, that means there could be more than 400 cases out there, in a parish of no more than about 30,000 residents.

One of the originators of the idea for an area task force is the Beauregard Parish Health Unit's Jackie Lester. Speaking for herself, she told a meeting recently that, on Jan. 1, Louisiana was ninth in the nation in the number of AIDS cases and, today, is fifth. By the year 2000, the state is expected to be first in the nation, at current growth rates.

Lester said that four of 10 Louisiana teen-agers are known to be HIV-infected. The virus has reportedly mutated so often and become immune to drugs that it can become full-blown AIDS in as little as two years, even as newer drugs prolong life with no cure in sight. Also, one victim can now get it more than once with new strains cropping up.

Tuberculosis is on the rise again as a result of HIV infections and illicit drug activity. It costs about \$30,000 to treat a normal TB case. It costs as much as \$300,000 to treat an HIV-affected TB case because of prolonged care costs.

Persons interested in working with an AIDS prevention awareness task force are asked to call DeRidder City Hall at 462-2461.

BEAUREGARD NEWS

30 NOV 93

Mayor will form AIDS awareness task force

By Ben Darby
City-Parish Editor

DeRidder Mayor Gerald Johnson has volunteered to "start the ball rolling" on a local AIDS awareness task force.

Saying, "I have good friends with family members who have suffered losses to AIDS," Johnson's offer came during a Tuesday night city hall meeting of residents concerned about the rise of AIDS, HIV and other sexually transmitted diseases in DeRidder and Beauregard Parish.

Meeting organizer Jackie Lester, with the Beauregard Parish Health Unit, said, speaking for herself, there are about 35 known cases of AIDS in the parish today. To that number can be added a national average of 10-to-15 more unreported cases of AIDS for each known case.

Beauregard Parish has about 30,000 residents.

Lester said that, on Jan. 1, Louisiana was ninth in the nation in actual number of AIDS cases and today is fifth. By the year 2000, the state is expected to be first, at current growth rates. She also said that four of 10 teenagers in Louisiana are known to be HIV-infected with no cure in sight for the deadly disease.

Lester pointed out that the HIV virus has mutated so many times and become immune to so many drugs that it can materialize as full-blown AIDS in as little as two years, even while new drugs prolong life. Also, the same person can now get it more than once with new strains cropping up.

Meeting participants agreed that youth are more likely to

listen to a peer or someone who either has AIDS or has a family member or close friend who has it when taking the necessary precautions — with total sexual abstinence the only recognized full-proof preventative in non-monogamous relationships.

Other growing problems in Beauregard Parish are teen-pregnancies, other sexually transmitted diseases and alcohol and drug abuse, Lester said, adding that the problems are too often related and intertwined.

Tuberculosis is on the rise again from HIV infections and illicit drug-related activity. To treat a normal TB case would cost about \$30,000. To treat an HIV-affected TB case would cost about \$300,000, Lester said, because of prolonged care costs.

See AIDS P. 2A

AIDS

Continued from P. 1A

Participants agreed that a community wide effort needs to be made to inform all ages about AIDS and other sexually transmitted diseases. They noted that parents, as well as the youth, need to do all they can to make themselves aware of the diseases.

Talks to social, professional, civic and religious groups will soon be in the planning stages with professional and lay speakers on tap for presentations about AIDS and other sexually transmitted diseases.

BEAUREGARD NEWS
25 NOV 93

THE WHITE HOUSE
WASHINGTON

December 17, 1993

Xenda Lindel
830 17th Street #2
Des Moines, IA 50314-1126

Dear Ms. Lindel:

Thank you for sharing your thoughts. I agree with you that we need to spend more time teaching children to value themselves and others. Please stay in touch.

Sincerely,

A handwritten signature in dark ink, appearing to read "Kristine M. Gebbie". The signature is fluid and cursive, with a large initial "K" and a long, sweeping underline.

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

DEC 13 1993

December 6, 1993

Kristine Gebbie
200 Independence Avenue SW
Washington, D.C. 20201

Gentle person:

Our country is currently concerned about a high and rising rate of crime among children. It is that issue to which I speak.

My credentials are that I am the mother of four adult children, a daughter and three sons, none of whom is a perfect citizen at all times, each of whom carries within him or herself all the love and caring I had to give. It seems to have been enough. However, for millions of children, the love and caring of parents is not enough, and these children, emotionally bereft, are those whom we see committing crimes we cannot afford to tolerate.

I do not believe new prisons and more policemen will solve this problem for our country. Our values as a country do not include protecting the lives of our most precious resource. We do not nurture our young, as a society. We do not value the roles of parents as those who have the greatest influence on these tiny individuals. My perception is that we value monetary success above personal growth and development. Our institutions, such as schools and churches, seek to form youngsters into the kind of people we think we "want." That does not seem to be working; witness the crime rate among children.

So we send our children away from us repeatedly, to school, lessons, camp, church, day-care, their rooms, or the neighborhood, the streets. For millions(?) of children there is little stability and perhaps no safe place. You know, it's difficult to even want to learn when your soul aches because of the fight that went on before you left for school or were taken to the sitter, or, were left to fend for yourself while adults (who also ache) seek some comfort of their own.

When I hear about our various "wars" against whatever is popular to "war" against, I wonder that we choose to use this most violent of metaphors to describe our need to change ourselves. War is traditionally about territory. What territory is it about which we now fight? The minds and bodies of children? Nonsense! (Take a look at that word, non- *sense*. An accurate perception in my opinion.)

I have done my own spiritual and emotional work. I continue to grow and change with each day. I have had contact with experts in the field of child-rearing through workshops and books. I do not understand, when our lack of regard for and interest in our children is so clearly the essence of this problem, why those who have power--social workers, supervisors, directors, legislators, cabinet members, and presidents--do not ask these wise men and women for help. Oops! Money. We'd have to pay these folks, and perhaps put into action some of their ideas about how to help

parents (even disadvantaged ones) nurture their children so they would not need to be on the streets with guns and knives.

And money is tight now--not tight enough to prevent our spending it on prisons and policemen, however. My question is how can you justify spending billions of dollars imprisoning people and ignore the very real need for children to value themselves enough to also value others?

I seriously suggest that John Bradshaw, Starhawk, Susan Forward, M. Scott Peck, Jean Houston and the hundreds of others like them be invited to share their ideas about how we might begin to heal our society.

I will gladly visit with you about my notions of how we might begin to approach some of the people I believe could assist our country as we near the beginning of the 21st century.

Sincerely,

A handwritten signature in cursive script that reads "Xenda Lindel". The signature is fluid and elegant, with the first name "Xenda" being more prominent than the last name "Lindel".

Xenda Lindel

830 17th ST #2
Des Moines, Iowa 50314-1126

Home (515) 244-0199
Work (515) 247-4782

THE WHITE HOUSE
WASHINGTON

December 17, 1993

Deenie M. T. Dudley, Clearinghouse Manager
Office of HIV/AIDS, Prevention and Education Services
Department of Health
Airdustrial Park, Building 9
P.O. Box 47840
Olympia, WA 98504-7840

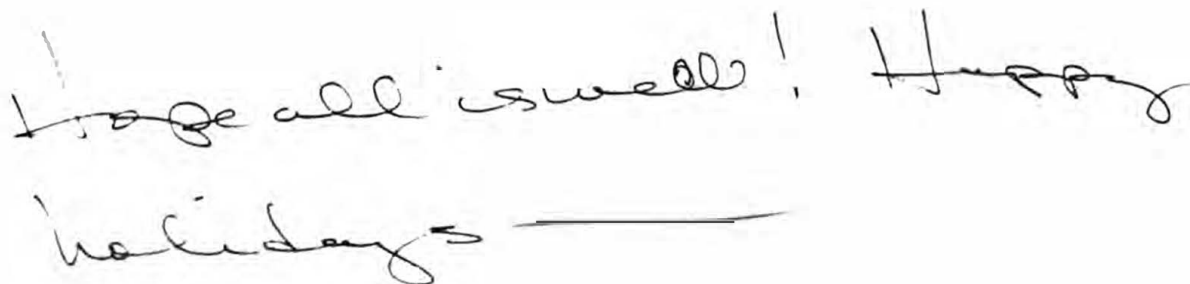
Dear Ms. ~~Dudley~~ 

Thank you for sending the abstract on condom promotion. I appreciate your continued support.

Sincerely,



Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator



— DEC 13 1993

12/2/93

Dear Kristine —

Just a note from the
"home front" (other Washington)
to say thanks for speaking
out on condom use, sexuality
as part of the human condition,
etc. The "Rural" teleconference was
great. I found this abstract in our
clearinghouse files while
researching a question from a
local health department, and
thought you might be able to
use it, someday, someday.

Best wishes for the
holidays —

Deenie Dudley ♀

— 206-586-3887

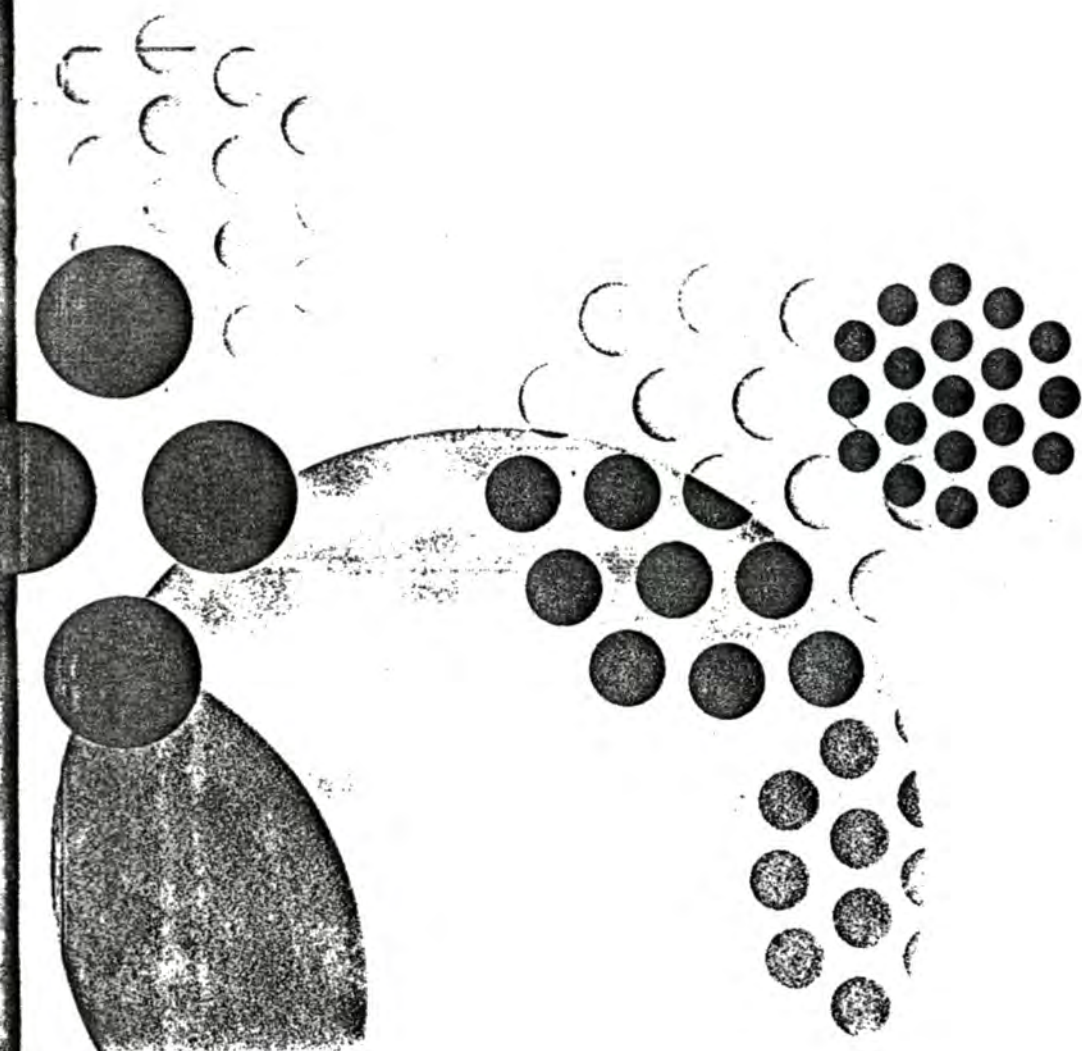
VIII International Conference on AIDS/
III STD World Congress
Amsterdam, The Netherlands
19-24 July 1992



A WORLD
UNITED
AGAINST
AIDS

FINAL PROGRAM & ORAL ABSTRACTS

HARVARD-AMSTERDAM
CONFERENCE



VOLUME 1

TuD 0575

CONDOM PROMOTION DOES NOT INCREASE SEXUAL INTERCOURSE AMONG ADOLESCENTS

Hausser, Dominique; Michaud, Pierre André

University Institute of Social & Preventive Medicine, Lausanne, Switzerland

Introduction: Since 1986 the Swiss Public Health authorities have run the STOP-AIDS preventive campaign. An important part of this effort is directed towards adolescents. Both locally and nationally, various actions have developed that put the emphasis on regular and steady condom use.

Objective: to measure trends in attitudes and behaviors over a three years period, particularly in terms of sexual activity.

Methods: A same self-administered questionnaire was used in 1987 and 1990. It was distributed in several professional centers of the canton of Vaud, to two samples of apprentices 16 to 19 years.

Results: The proportion of adolescents engaging in sexual intercourse has remained the same over the three years period:

	boys (n=944)	1987	girls (n=325)	boys (n=524)	1990	girls (n=277)
% no sexual intercourse	23 ± 3		34 ± 5	20 ± 4		26 ± 6
at least one intercourse	77 ± 3		66 ± 5	80 ± 4		74 ± 6

Likewise, the average number of partners is the same (Boys: 1 partner: 20%, 2-4 p.: 40%; 5p.: 40%; Girls: 1 partner: 40%; 2-4 p.: 40%; 5p.: 20%). Condom use has increased, especially among girls:

	boys (n=720)	1987	girls (n=210)	boys (n=415)	1990	girls (n=200)
% use of condoms	77 ± 3		59 ± 7	87 ± 3		80 ± 6
regular use of condoms	22 ± 3		10 ± 4	34 ± 5		27 ± 6

Conclusion: During the observed period, the Swiss AIDS prevention strategy focussing on condom use did neither increase the sexual activity of apprentices nor the number of sexual partners, but condom use was enhanced both among boys and girls. Each year, thousands of adolescents are entering an active sexual life: thus such interventions have to be maintained.

MICHAUD Pierre André, IUMSP, Rue du Bugnon 17, 1005 Lausanne,
Switzerland, phone (41) 21 313.20.48, fax (41) 21 313.20.35

THE WHITE HOUSE

WASHINGTON

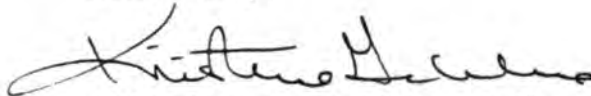
December 17, 1993

Allan M. Salzberg, M.D., Ph.D.
Chief of Staff
Veterans Affairs Medical Center
Bath, NY 14810

Dear Dr. Salzberg:

Thank you for sharing your article on simulation models. This information may prove useful to my staff and I as we work to end this epidemic. Please stay in touch.

Sincerely,

A handwritten signature in dark ink, appearing to read "Kristine Gebbie", with a stylized, flowing script.

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator



Office of the Chief of Staff

VAMC BATH NY 14810

(607)-776-2111 x 1300

FAX (607)-776-2111 x 1671

NOV 22 1993

10/29/93

Kristine Gebbie
Director of AIDS Policy
Executive Office of the President
750 17th St. NW
Suite 1060 Wash DC 20503

Dear Ms. Gebbie,

I thoroughly enjoyed and agreed with your talk at the opening session of ICAAC in New Orleans. It was suggested that I write to you to inform you of our work. We are engaged in using mathematical simulation techniques to analyze the effects of policies which lead to widespread voluntary detection of carriers coupled with fully funded HIV therapy. This is an area that has been almost totally ignored.

The enclosed reprint illustrates that wide spread early therapy might profoundly ameliorate the epidemic and save money at the same time. This paper which I presented at ICAAC (paper 1115) is a model of intermediate complexity and is somewhat approximate. However, it was suggested that you might be interested in a novel approach to HIV. Admittedly it is still theoretical, but the model incorporates biological and sociological data. The mathematics also indicates that "backcalculation" to obtain HIV incidence has serious problems.

The enclosed graphs are the output of a far more sophisticated and complex model which we just debugged. The policy change begins slowly in 1994 and is less intense than in the previous paper. Almost all of the approximations have been removed, and the source code is over 3000 lines of code. We are willing to share the code and work with you in any manner you feel will be useful. We plan to present the model this Thursday to Dr. Sten Vemund at NIAID. As you can see it corroborates the simpler model's conclusions.

A third paper which Dr. Duncan MacRae Jr. is presenting at the First National Retroviral Conference in DC in December corroborates the view that antiretroviral therapy slows the rate of progression of HIV disease. It is consistent with the data of Cooper in Australia, Graham et al for late disease and Hamilton's VA data for AIDS development. It indicates why it is extremely necessary to overemphasize CONCORDE as this study probably does not have the statistical power to detect the small expected (modeled) effects between the groups. These results are in concordance with those of I Longini of Emory University who read our paper and agreed with it. This paper also indicates that early treatment is preferable.

About the authors. I am presently Chief of Staff and hold an MD and Ph.D. (see resume). Dr. MacRae is a Chaired Professor of Sociology/Political Science and Policy analysis at the University of North Carolina. He has authored over 60 papers and books.

Thank you for your attention,

Sincerely,

Allan M. Salzberg MD, PhD

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Policies for Curbing the
HIV Epidemic in the United
States: Implications of a
Simulation Model

17pgs

Policies for Curbing the HIV Epidemic in the United States: Implications of a Simulation Model

ALLAN M. SALZBERG¹ and DUNCAN MACRAE JR²

¹Veterans Affairs Medical Center, Bath, NY 14810 and University of Rochester School of Medicine and Dentistry, Rochester, NY 14627, and ²University of North Carolina at Chapel Hill, Chapel Hill, NC 27599, U.S.A.

Abstract—An 8-compartment simulation model, with monthly steps and with different infectivities for 4 pre-AIDS phases of HIV, simulates the U.S. epidemic from 1976–2005. The use of AZT or other antiretroviral drugs is introduced under the assumptions that it halves the rate of conversion to AIDS, and that, with behavior change, it reduces transmission coefficients by 2/3. Two policy scenarios are projected. They assume that 66 and 100% of HIV-infected persons whose CD4 count is less than 500 are identified by voluntary testing and are treated with AZT by the end of 1993—which might be approached with full subsidy of medical treatment and protection against discrimination. Without such policies, we project over 100,000 new AIDS cases and 110,000 HIV infections in 2005, and a \$14 billion annual cost. Maximum use of AZT could reduce these numbers to 50,000, 45,000 and \$10 billion, respectively. Such policies might draw support from the infected, the uninfected, economizing officials and pharmaceutical companies.

INTRODUCTION

The choice of policies for reducing the effects of HIV/AIDS in the United States requires estimation of policy effects, reconciling political conflicts, and coping with budgetary shortages. We here examine policies of subsidized AZT treatment (a concise term for all antiretroviral therapy) for HIV-positive persons, together with this and other incentives for voluntary testing of persons at risk, using a model of the epidemic. We show projected effects of such policies in terms that are relevant for various interested groups, and suggest conditions under which these groups might join in support of such a policy. Possible budgetary savings are also examined. Substantial efforts have been made to aid policy discussions by modeling the epidemic and projecting policy effects [7]. Effects of extensive use of AZT do not, however, seem to have been sufficiently explored.

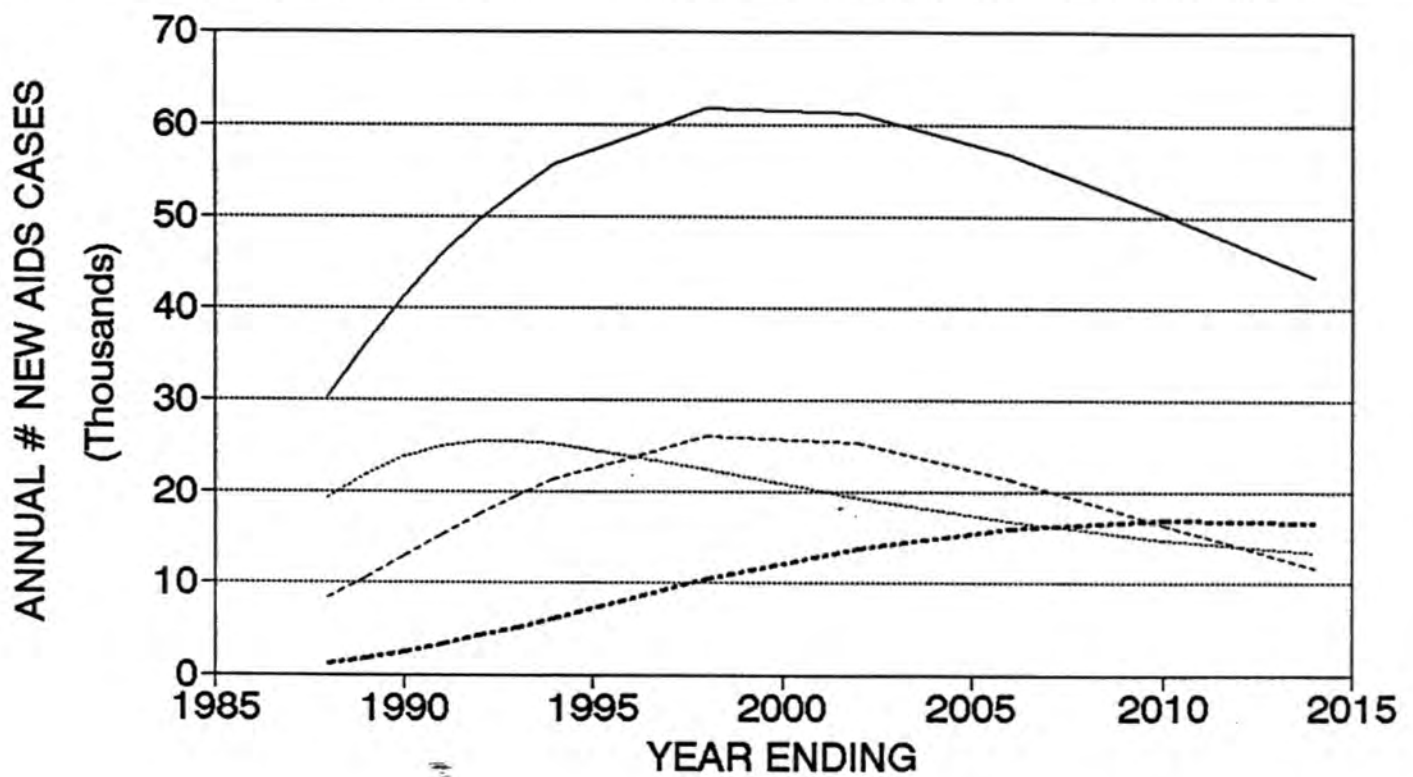
The paper is divided into three sections. The first presents a simulation model of HIV that describes and projects the course of the epidemic in some detail. This basic model has been found to be in quantitative agreement with both reported AIDS cases and Centers for Disease Control (CDC) AIDS projections through 1994. The model's estimates of HIV prevalence are consistent with CDC estimates through 1991 (1–1.5 million in 1991) [25, 26, 29]. The second section shows and analyzes computed effects of identifying and treating substantial fractions of the HIV-infected population, presuming that this can be achieved by voluntary testing and fully subsidized AZT treatment. The third section summarizes possible sources of political support for such a policy by various interested groups.

THE MODEL

We employ a multi-compartmental Markov model with time-dependent infectivity, which is an extension of a recently published model [29]. The structure of the model and the parameters proposed are the result of numerous trials constrained by three criteria: (a) empirical fit to CDC AIDS data and HIV estimates; (b) general conformity of parameters and outputs to independent estimates in the literature, where available; and (c) simplicity where omission of a feature does not

PROJECTED REPORTED AIDS INCIDENCE

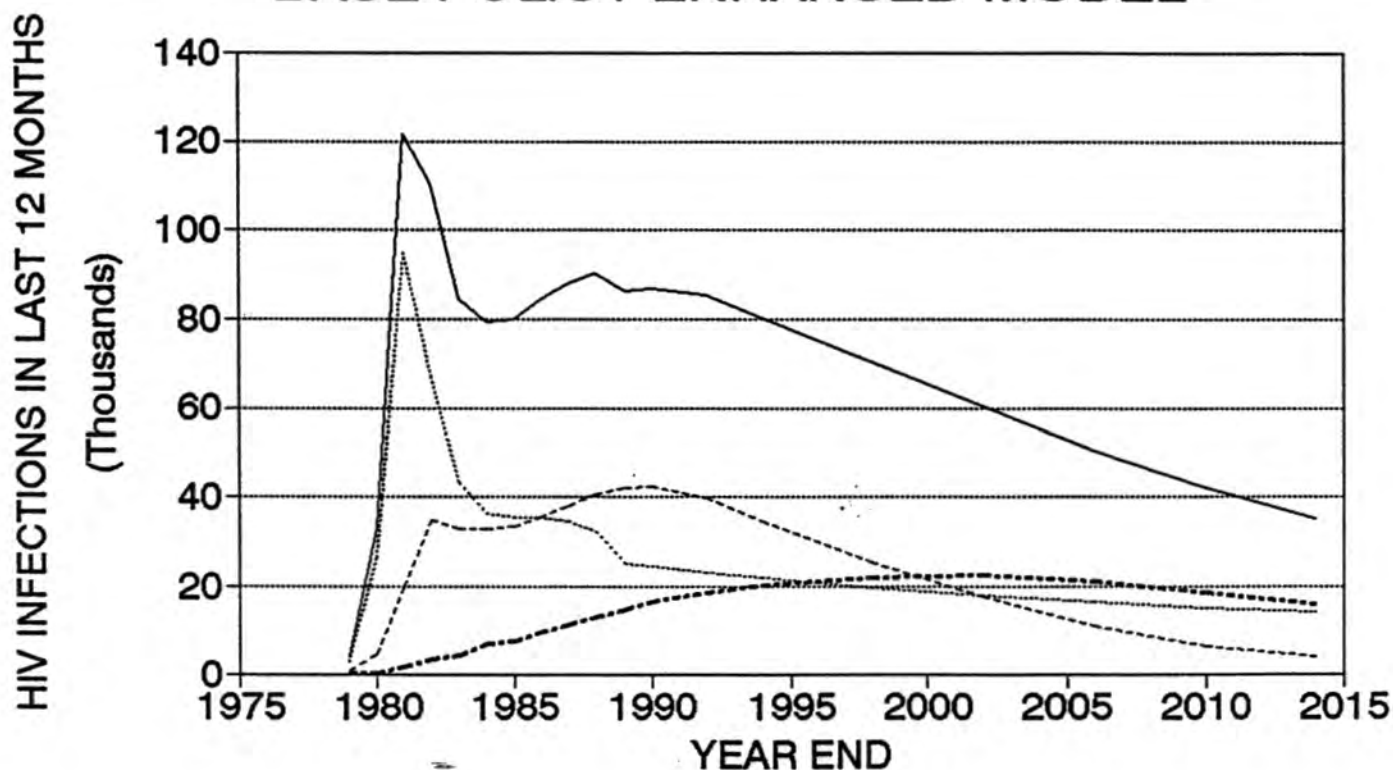
PRESENT POLICY CASE-ENHANCED MODEL



..... GAYS IVDU's HETEROSEXUALS — TOTAL

PROJECTED HIV INCIDENCE

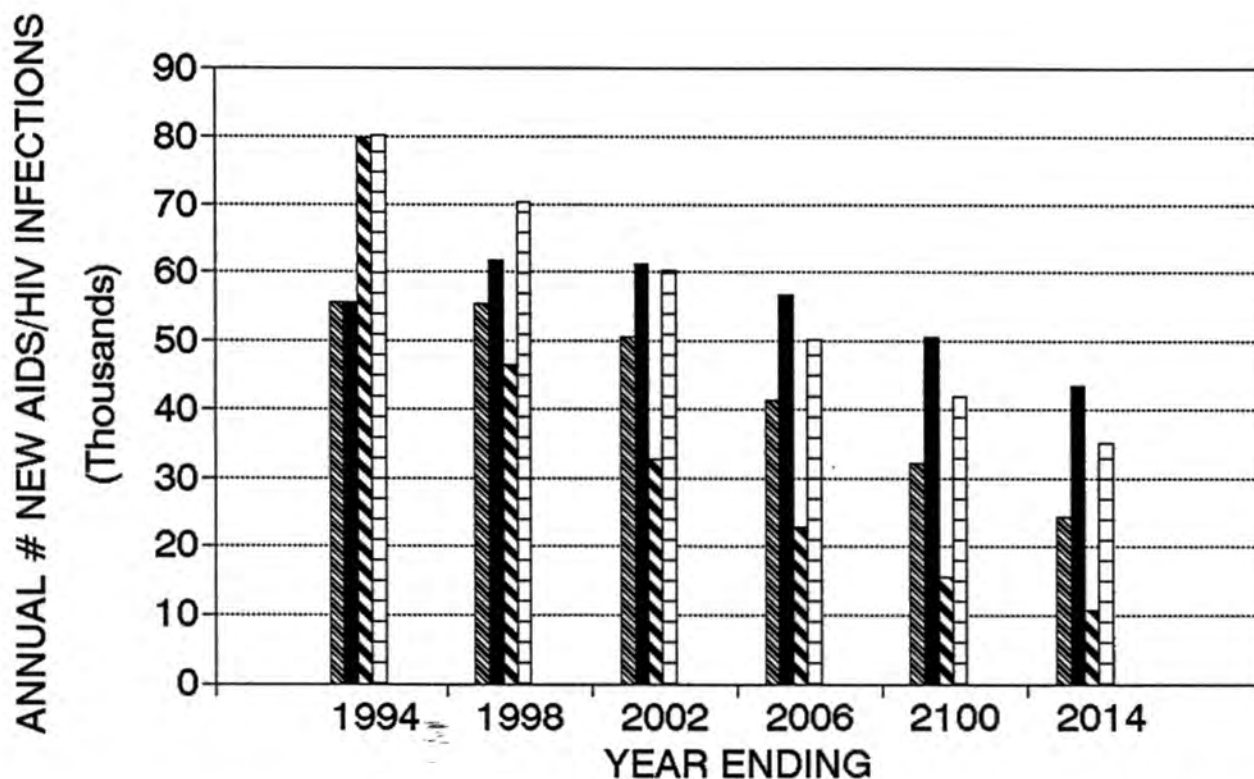
BASE POLICY ENHANCED MODEL



GAYS IDUs HETEROSEXUALS TOTAL

PROJECTED IMPACT OF POLICY CHANGE

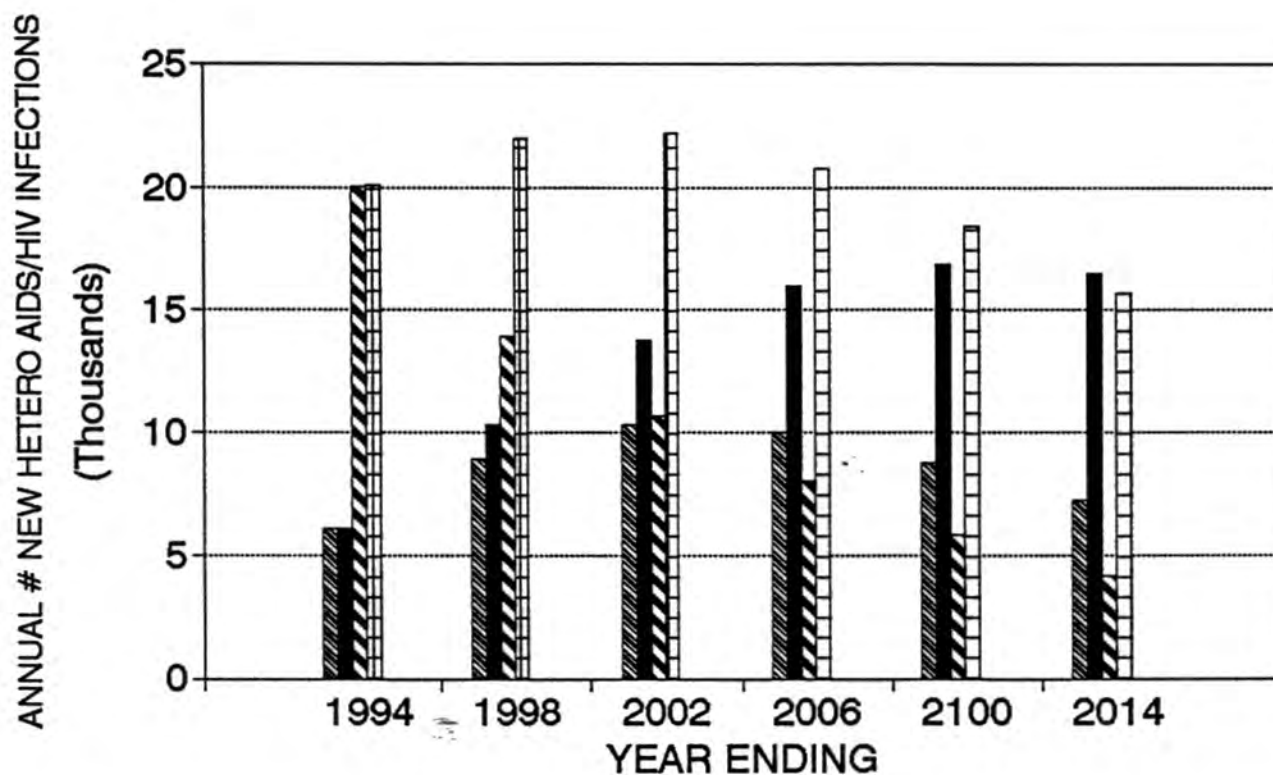
MODEST INTERVENTION BEGINNING IN 1994



■ AIDS INC(NEW) ■ AIDS INC(BASE) ▨ HIV INC(NEW) □ HIV INC(BASE)

PROJECTED IMPACT OF POLICY CHANGE

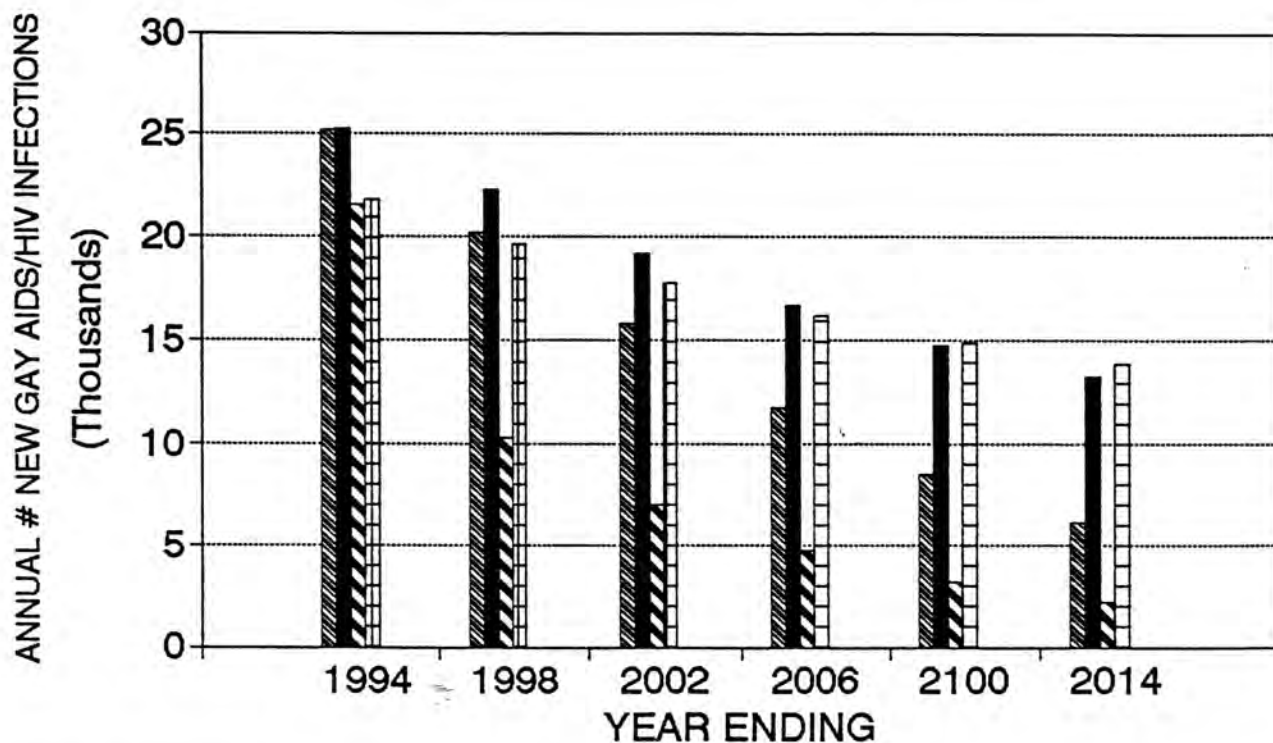
MODEST INTERVENTION BEGINNING IN 1994



 AIDS INC(NEW)
  AIDS INC(BASE)
  HIV INC(NEW)
  HIV INC(BASE)

PROJECTED IMPACT OF POLICY CHANGE

MODEST INTERVENTION BEGINNING IN 1994



AIDS INC(NEW)
 AIDS INC(BASE)
 HIV INC(NEW)
 HIV INC(BASE)

ALLAN M. SALZBERG, M.D., Ph.D.

6708 Pheasant Lane
Bath New York 14810
Home- (607) 776-6122
Office- (607) 776-2111 x1300

EDUCATION

- 1956 - 1960 Cornell University, Ithaca, New York
B.A. Chemistry, Minors Mathematics/Physics.
- 1960 - 1963 University of Minnesota, Minneapolis, Minn.
Ph. D. Physical Chemistry/Plasma Physics
Minor Mathematics.
- 1970 - 1973 University of Maryland, School of Medicine,
Baltimore, Maryland. M.D. 1973.
- 1977 - 1978 University of Pennsylvania, Philadelphia, Pa.
School of Medicine, Department of Preventive
Medicine(Core requirement for M.P.H. to
complete eligibility for Aerospace Boards).

PROFESSIONAL TRAINING

- 1973 - 1975 Mount Sinai Hospital, New York, New York
Resident in Medicine and Radiotherapy.
- 1975 - 1975 Naval Aerospace Medical Institute, Pensacola, Florida.
Aerospace Medicine and Jet Flight Training.
- 1980 - 1981 Veterans Administration Medical Center, Washington, D. C.
Senior Resident in Internal Medicine.
- 1991-1993 Completed Physicians in Management Seminars I-III (College of Physician
Executives) as well as the Chief of Staff Executive Leadership Institute
(Department of Veterans Affairs)

BOARDS

1979 Board Certified Preventive Medicine/Aerospace Medicine.

1981 Board Certified Internal Medicine.

EMPLOYMENT

1986-Present Chief of Staff VA Medical Center Bath NY, previously Chief Medical Service Miles City Montana. Supervises All clinical services. Adjunct Associate Professor of Medicine - The University of Rochester School of Medicine.

Research:

AIDS Epidemiology and modeling. Antibiotic and Antiviral pharmacokinetics and computerized dosing . Member Physicians Advisory Group of the Quality Management Institute of the DVA.

Former Technical Advisor, CYBERMED Corp., Bath, New York

1981 - 1985 Private Practice Internal Medicine,
Senior FAA Flight Examiner

1979 - 1980 Science Applications Incorporated, La Jolla, CA. Special Assistant to the Senior Vice President on Strategic Defense Systems.

1977 - 1979 United States Navy, LCDR MC
Medical Director of Research at the Naval Air Development Center
Warminster Pa.
High Acceleration Studies and Human Factors Research

1975 - 1977 US Navy, Flight Surgeon USS Enterprise Western Pacific Deployment.

1970 - 1975 Consultant Science Applications Incorporated.

1968 - 1970 Air Force Operations Analysis Office, Headquarters USAF, Pentagon,
Senior Analyst
Operations Research Analyst . Work centered on Strategic Defense,
Electronic Warfare, Lasers, Weapon Accuracy, ABM Design (based in part
on the Patriot), Effects of Nuclear Weapons.

1968 - 1969 Montgomery College, Takoma Park, Maryland
Lecturer, Department of Chemistry.

1965 - 1968 Center for Naval Analysis Arlington, Va..
Senior Staff Scientist. Operations Research.
ECM, Fleet Anti-Air Warfare, Nuclear Effects.

1963 - 1965 Hercules Powder Company Cumberland, Md..
(Allegany Ballistics Laboratory). Senior Chemist, Solid Fuel Rockets.

LICENSED BY NATIONAL BOARDS

1974 New York
1977 California
1977 Pennsylvania
1979 Virginia

PROFESSIONAL SOCIETIES

New York Academy of Science
American Medical Association
Medical Society of Virginia
American Institute of Physics
American Chemical Society
Operations Research Society of America

FELLOWSHIPS

1956 New York State Regents Scholarship
1960 New York State Medical Scholarship
1961 Mobile Oil Summer Fellowship
1962 USAF Summer Fellowship

SPECIAL RECOGNITION

1967 Letter of Commendation from Admiral Elmo
Zumwalt for Electronic Warfare Studies.
1968 Letter of Commendation from Admiral K.L.
Masterson for study of Airwar in Southeast Asia
1969 Outstanding Performance Award USAF for
Nuclear Studies, Electronic Countermeasures,
Lasers and Antiballistic Missile Research
1969 Letter of Commendation for work on the survivability of
the National Airborne Command Post General R.Gould USAF
1976 Letters of Commendation from Canadian Department of Defense
for Hazardous Medical Rescue at Sea

1987 Nominated for The Presidential Commission on HIV

COMMUNITY

1988-9 Chairman and Founder, General Nelson A. Miles Foundation
Miles City, Mt.

THE WHITE HOUSE

WASHINGTON

December 17, 1993

Diane R. Lamar Yellow Robe
General Delivery
Glorieta, NM 87535

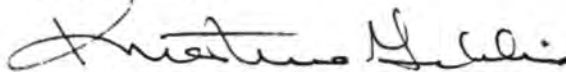
Dear Ms. Yellow Robe:

Thank you for sharing information on the play "The People." I have forwarded the information to the National Minority AIDS Council and the National Association of People With AIDS, who might have an interest in your play. In case you need to reach them, their addresses are:

National Minority AIDS Council
300 I Street, N.E., Suite 400
Washington, D.C. 20002

National Association of People With AIDS
1413 K Street, N.W., Suite 800
Washington, D.C. 20005

Sincerely,



Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

~~... of ... AIDS.~~



The honorable Christine Gebbie
AIDS TASK FORCE; CLINTON ADMINISTRATION
1600 Pennsylvania Avenue
The White House
Washington, D. C. 20500
November 30, 1993

DEC - 7 1993

Dear Ms Gebbie:

Hope this letter arrives on a good day for you. We watched the interview on T V with Katie Couric regarding the current status of the fight against AIDS. It was mentioned that in recent memory, various media have not put forth very much in the way of AIDS commentary. May we offer some solutions:

Nothing seems to grab the imagination of the citizenry like performing arts. William S. Yellow Robe, Jr. one of the foremost Native American Playwrights in the country, now an Instructor in Creative Writing at the Institute of American Indian Arts in Santa Fe, was commissioned in 1989 to write a Play about AIDS as it might happen on an Indian Reservation. The Play was presented as a staged reading at The Illusion Theatre in Minneapolis, Minnesota in 1989. The audience was very moved, however, further funding for publicizing and submitting this play for developed production, video and film potentials were not available. The crux of the story deals with a Father, who cannot accept his son's "perversions" and is willing to isolate him from his family and tribe, placing him in a remote cabin to die of AIDS. Other family members prevail upon him and modify the situation to create a reconciliation and peace-making attempt, both with Father and the Almighty, in the Indian Way.

This Play is copyrighted as "The People" with the Library of Congress. It seems to us that one of the major reasons why people do not "look" at AIDS and are in a state of denial, { Even, teenagers are now moving toward a "cult of chasity", rather than attempt "safe" sex} is due more to the fact that people can readily see AIDS is not only going to "kill", but that the STIGMA, regardless of method of transmission is in fact, not controllable. That factor in social control has dominated the human race for centuries and I do not think we are weighting this factor, sufficiently, in our thinking about this Epidemic. This stigmatization is probably much heavier than we've lately been led to believe by "PoP ArT", ie MADONNA, JACKSON, ETC,

page two

CULTIC SEX AND VIOLENCE. Despite all, we have been and remain one of the more puritanical cultures, at heart, in the world. This last twenty-five years as been an experiment and "morality" reassessment by the American people. I speak as one with a degree and two years of graduate school in Anthropology, although I wear many hats, not least being the Business Contact for William S. Yellow Robe, Jr. The Playwright, alluded to above, regarding his Play on AIDS. Mr. Yellow Robe is not "Gay", he simply recognizes that compassion and understanding are the real moral virtues, and is able to dramatize this message without lecturing. Yellow Robes writing is noted for this ability to tell the story and convey the message subliminally, without it being "mouthed" by the characters. The themes on which he writes are varied and not always Native American. Can you see AIDS in Russia? How will we deal with that? We can't just "dive into their lives" after the fact. We need to start establishing rapport on "neutral ground" with a sure fire success. Yellow Robe's Musical Book, "HARVEST" addresses the world of a three generation, Montana Ranch family, (white), who must deal with their love of the land and country, yet must accept that their son has married a "city girl" and there maybe no-one left to "work the farm", let alone "afford to do so", (aside). This is a "giant" in musicals, rivaling "OKLAHOMA". It toured six states and put The Montana Repertory theatre in the Blue Ink for the first time, in many years. However, Mr. Yellow Robe is Native American, and while the enclosed resume speaks to his awards!, nevertheless, choices in Theatre are made politically.

We have rewritten the music, and can translate into Russian. It is now, reminiscent of Russian folk music themes, (The original song writer, who is a "white" lawyer, native of "the white supremacy attitude toward Indians", riddled town of Conrad, Montana has since, refused to pursue further association with the "Play").

We see this musical as having great parallels with the Russian, love of the land. (I personally, was first married and had children with a Russian National political emigre and I can read and write Russian to a modest degree, am a musician, as well. I can see a wonderful diplomatic advantage to cementing relations with the Russian people on a more personal level using this Musical as a "tour" in Russia. I might add that, "capitalism is cruel", and my knowledge of these people, and their history prompts me to predict, an increasingly severe "reversal of direction" toward nostalgia for the ability of "the old communist regime to feed the people, regardless". { I'm well aware that, Stalin starved to death 40 million Russians and nearly, wiped out the cossacks, and kalmuks, among others}. We must get a rapport between the peoples of our country, and Russians, so that they can see we, too, have had to struggle for what we've achieved). Mr. Yellow Robes Play, HARVEST does just that.

If any of this is of interest to you, please write us.

Thank you,

Hane

Diane R. Lamar Yellow Robe
General Delivery,
Gloreita, New Mexico 87535

805-757-2374

WRITE
P.O. Box 374
Valier, Montana
59486

General Delivery
Glorieta, New
Mexico
87535

Directing and Production
arranged by calling:
Diane Lamar Yellow Robe
(406)-279-3432
(406)-279-3424

505-757-2374

WILLIAM S. YELLOW ROBE, JR.

DIRECTING CREDITS
(Partial listing)

DRAMATIC:

"THE COUNCIL", (Director) Honolulu Theater for Youth, Pamela Sterling-Artistic Director), (Tour of all the islands), January---1992.

"THE INDEPENDENCE OF EDDIE ROSE", (Assistant Director), Montana Masquers Playwriting Festival, University of Montana, Missoula, Montana, June---1987.

OPERA:

"THE MAGIC FLUTE", (Stage Director), San Antonio Festival, San Antonio, Texas, June---1991.

COMEDY:

"TAKING AUNTY TO THE WAKE", (Director) Northern Montana College, Havre, Montana, May---1991.

"TAKING AUNTY TO THE WAKE", (Director), Purple Mountain Playhouse, St. Ignace, Montana, July---1989.

ORIGINAL WORKS
(Staged Readings)

"THE STAR QUILTER" and "MOMA'S SONG", (Director) Crystal Theater, Missoula, Montana---1992

"THE STAR QUILTER" and "MOMA'S SONG", (Director) American College Theater Festival, Pullman, Washington---1992

FOR YOUNG AUDIENCES

"THE CHIEF'S LOST DAUGHTER", (Director) Two Eagle River High School, Dixon, Montana---1987

"GRIZZLY BEAR TEACHES MAN", (Director) Two Eagle River High School, Dixon, Montana---1987

OTHER SKILLS

Actor, Playwright, Instructor, Lecturer.

Children's Theatre epic goes to the root of our troubled times

By Joe Adcock

P-I Theater Critic

Whew! This is children's theater?

Most of the characters are animals. But Mickey Mouse or Ninja Turtles they are not.

They are figures in an epic that begins in pre-history and warns of the possibility of post-history. William S. Yellow Robe Jr.'s "The Council," which premiered Friday night at Seattle Children's Theatre, is, literally, terribly interesting.

Review

The Council. By William S. Yellow Robe Jr. Seattle Children's Theatre. Through Feb. 10. Tickets \$7.75 and \$13.25.

The terrible part is the undertow of tragedy. Humankind, as a species, seems destined to destroy itself, its habitat and its fellow creatures.

The interesting part is the way Yellow Robe touches on ecology, biology, history, anthropology, human relations, gender relations, inter-species relations and natural religion.

If there is any hope in this dire panorama, it is the idea of intuitive attunement to the ways of nature, spiritual apprenticeship to animals.

"The Council" burrows to the root of contemporary troubles.

The action starts in pre-homo sapiens times. A certain order prevails.



FRED ANDREWS

Man, played by Eric Jensen, introduces fire to members of The Council in a play by that name at Seattle Children's Theatre. With Man are, from the left, Woman, Tiger, Panda, Lizard and Lion.

Director Diane Schenker's cast of seven actors wear gray longjohns to which identifying details are appended: feathers, furs, fins, flippers. A beak means bird, a leathery tail means lizard. Jose J. Gonzalez lumbers as a panda. Babo Harrison quivers as a flamingo.

At first man, played by Eric Jensen, just seems to be a very poorly equipped new species. After a forest fire, caused by man's carelessness, the cute incompetent starts to seem like a monster.

By the time Todd Jamieson — playing a take-charge, follow-me kind of guy — harangues his fellows with male-supremacist, human-supremacist propaganda, one is almost ashamed to be human.

Costume designer Paul Chi-Ming Louey fits Jamieson out with a flowing cloak. It suggests some archetypal Judaeo-Christian-Muslim-Mandarin-Aztec patriarch. His "man shall have dominion over

all" diatribe is familiar, sinister stuff.

Incurable optimists are fascinated by whales and dolphins. If

we save the whales, then maybe the whales will save us. For all his refusal to deny bleak facts, Yellow Robe has a streak of this optimism.

In his final scene, an orca whale intentionally beaches itself. It wants to tell man something.

Yellow Robe holds out the suggestion that man may not be entirely impervious to the orca's lesson.

Yellow Robe (who in fact looks a bit like a whale) has something important to say. He says it eloquently.

The eloquence can undermine the show's integrity: Fur and feather costumes, leather shoes?

Exploiting other species, huh? Plastic scenery? Polluting earth and atmosphere, huh?

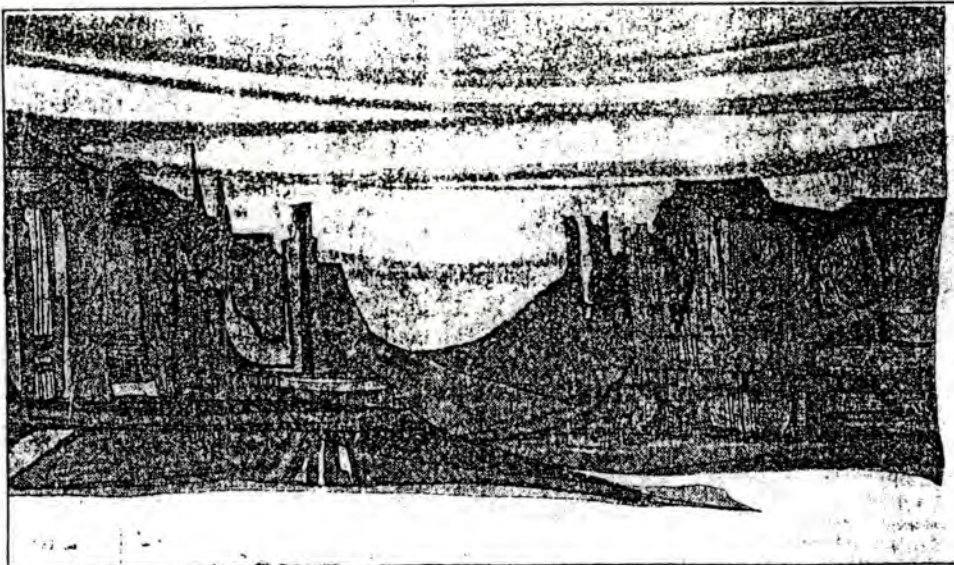
Yellow Robe is an Assiniboine Indian from Montana. His animal fable is reminiscent of traditional Indian lore. He brings to mind Chief Seattle's 1854 letter to President Franklin Pierce:

"We will consider your offer to buy our land. If we decide to accept, I will make one condition: The white man must treat the beasts of this land as his brother. I am a savage, and I do not understand any other way. . . ."

"For whatever happens to the beasts soon happens to man. All things are connected."

MUSIC

Festival's 'Magic Flute' crosses cultures



ARTISTRY: Amado Peña designed the sets for "The Magic Flute."

By **DIANE WINDELER**
Classical music critic



You've heard of being "at sixes or sevens" - confused. Director William S. Yellow Robe Jr. found himself "at threes or fours" as he searched for parallels between Native American ethos and Mozart's fantasy and Masonic symbolism while creating the San Antonio Festival's ground-breaking Native American view of "The Magic Flute."

As he explained it during a rehearsal break last week, "Threes appear throughout the opera: three ladies, three spirits, three temples ... but Native American

mythology is built on elements of four: four winds or four human components (heart, mind, soul and body)." The number three is regarded as jarringly out of balance, so that Yellow Robe has made such subtle adjustments as adding a fourth (non-singing) lady.

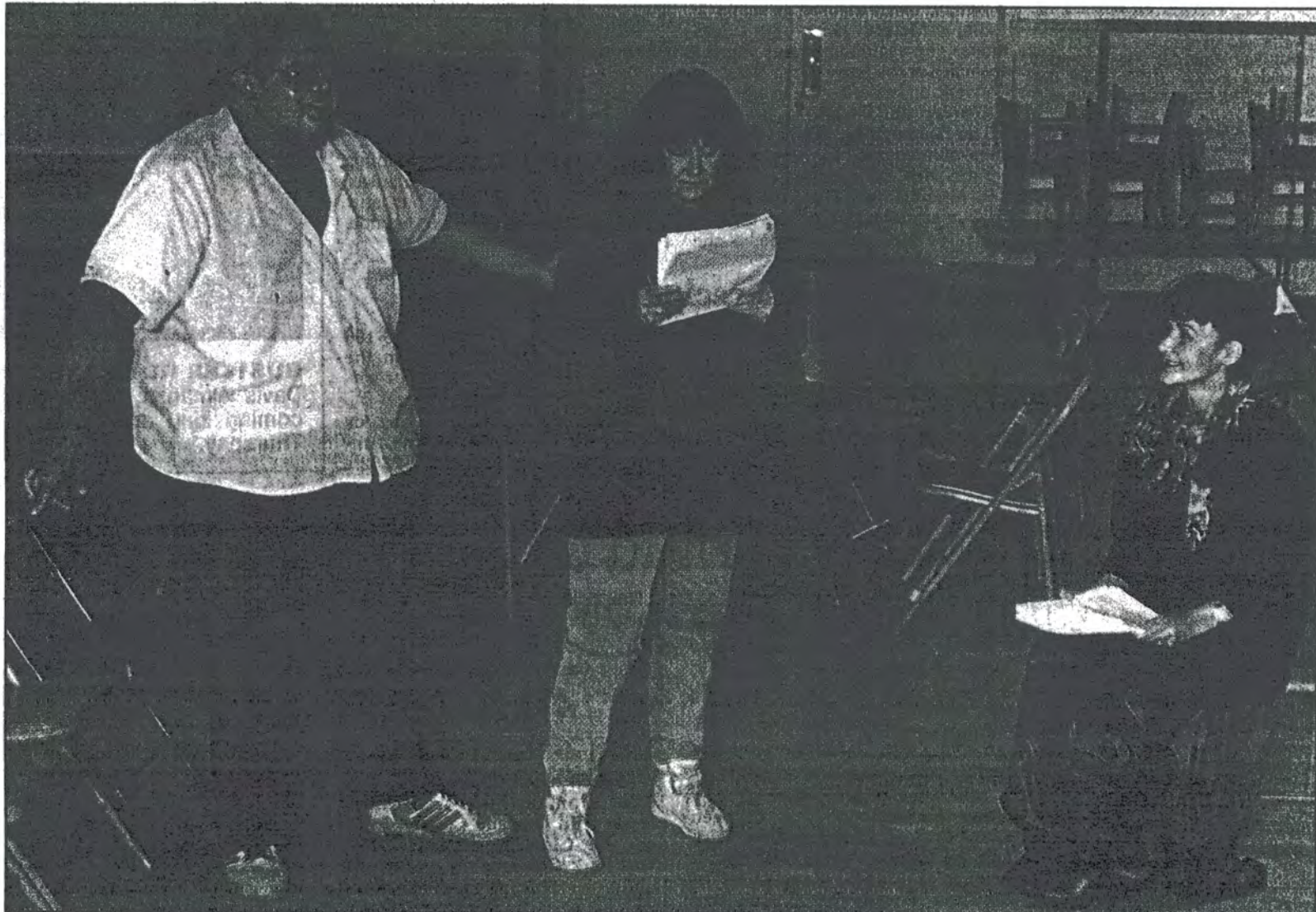
This is only one way in which he, with the acknowledged assistance of his wife, Diane (a musician/anthropologist who studied at the Eastman School), and music director William McGlaughlin, has reconciled a clash of cultures - going from German to English to Native American idioms, such as traditional sign language - without denigrating either the Schikaneder libretto or Mozart's sublime

Please turn to MAGIC FLUTE/J9

[other side] 501

Great Falls Tribune
Friday, October 9, 1992

Quilting together a production



William Yellow Robe directs a rehearsal of his play "The Star Quilter," to be performed Saturday at 7:30 p.m. in the Chapel Theater, 1601 2nd Ave. N. Actresses in the scene are Linda Hughes and Suzan Marie.

Tribune Photo by Stuart S. White

AWARDS AND HONORS

Received by

WILLIAM S. YELLOW ROBE, JR.

*NATIONAL

FIRST NATIVE BOOK AWARD FOR DRAMA, 'Returning the Gift',
University of Oklahoma, Norman, Oklahoma--1992.

NEA PLAYWRIGHT FELLOWSHIP, National Endowment of the Arts, Theater
Program, Washington D.C.--1991

JAMES ARTHUR BALDWIN PLAYWRITING AWARDS-HONORABLE MENTION,
University of Massachusetts, Amherst, Massachusetts--1990.

PRINCESS GRACE FELLOWSHIP, Princess Grace Foundation-USA,
New York, New York--1989.

JEROME FELLOWSHIP, Minneapolis Playwrights' Center, Minneapolis,
Minnesota--1988.

OUTSTANDING YOUNG MEN OF AMERICA, Outstanding Young Men of
America, Montgomery, Alabama--1988.

OUTSTANDING YOUNG MEN OF AMERICA, Outstanding Young Men of America,
Montgomery, Alabama--1987.

CIVIC

1991 ABC AWARD, A Better Community Organization, Poplar,
Montana.

ACADEMIC

PETER LEFT HAND AWARD, and the MERITORIOUS PARTICIPATION
University of Montana, Missoula, Montana-1986

TIME MAGAZINE COLLEGE ACHIEVEMENT AWARD-NOMINEE, Time Magazine
New York, New York-1986.

VIRGINIA AND ALEXANDER DEAN SCHOLARSHIP, and a MERITORIOUS
PARTICIPATION AWARD Department of Drama/Dance, University of
Montana, Missoula, Montana-1985

WILLIAM S. YELLOW ROBE, JR.

Playwright

Home: P.O. Box 374, Valier, Montana 59486 (406)-279-3432

PRODUCTIONS (Partial Listing)

- 1992 **THE COUNCIL**, Full-Length Play, Honolulu Theater
 for Youth, Honolulu, HI (Tour of all islands).
- 1991 **THE COUNCIL**, Full-Length Play, Seattle Children's
 Theater, Seattle, WA.
- 1990 **THE INDEPENDENCE OF EDDIE ROSE**, Full-Length Play,
 Seattle Group Theater, Seattle, WA.
- 1988 **WINK-DAH**, One Act Play, American Conservatory
 Theater (ACT), San Francisco, CA.
- 1987 **SNEAKY**, One Act Play, New World Theater,
 University of Massachusetts, Amherst, MASS.

READINGS (Partial Listing)

- THE STAR QUILTER**, One Act Play, Montana Human Rights
Network, Great Falls, MT-1992
- MOM-MA'S SONG**, and **THE STAR QUILTER**, Two-One Act Plays,
American College Theater Festival, Pullman, WA-1992
- THE PENDLETON BLANKET**, Full-Length Play, Mark Taper Forum's
PlayLab-90, Los Angeles, CA-1992

PUBLICATIONS (Partial Listing)

- SNEAKY**, A One Act Play, in Slantsix, New Rivers Press and
the Minneapolis Playwrights' Center, Minneapolis,
Minnesota-1990
- THE BURNING OF UNCLE**, A Short Story, in Dancing on the Rim
of the World, University of Arizona Press-1991

Awards and Organizations

(Partial Listing)

First Native Book Award-Drama

*Former Literary Manager, Seattle Group

NEA Playwright's Fellowship

*Former Regional Vice President, LMADA

Princess Grace Fellowship

*Member of the Dramatists' Guild Inc.

Jerome Fellowship

Drama's enemy is poverty, alcohol

THE INDEPENDENCE OF EDDIE ROSE.

By William Yellow Robe Jr.

Directed by Tim Bond. Cast: M. Cochise Anderson, Phyllis Brisson, Sheri Foster, Jose Gonzales, Mitch Hale, Winston-Jose Rocha-Castillo, Ah-Bead Soot. Presented by the Group Theatre at the Glenn Hughes Playhouse as part of the Goodwill Arts Festival through Aug. 5. For reservations and information call 543-4327.

By Freddie Brinster
Journal American Theater Critic

At last here is a Native American play that refuses to beat the tom-toms of political and historical issues or cater to white fascination with Indian spirituality. Instead, it reveals the Indian where he lives — in his home.

There, in his miserable shack on the reservation, he wages a desperate battle for survival and self-respect. The enemy is not the white man per se in this drama, but poverty and alcohol.

In *The Independence of Eddie Rose*, the portrayal of the effects of alcohol on Native American family life is visceral and uncompromising in its honesty. So much so that at the end of the first act, the opening-night audience sat silent and motionless for minutes before it could bestir itself for intermission indulgences.

Written by William S. Yellow Robe, the play is The Group's contribution to the

Goodwill Arts Festival and is performed at the Glenn Hughes Playhouse.

Eddie of the title is a stalwart, appealing youth. His father abandoned the family years ago after heaving Eddie against the wall. His mother is an alcoholic. His little sister Theia is being looked at "funny" by Mom's rowdy boyfriend.

When Mom is sober she exudes maternal affection. She brushes Theia's hair tenderly and coos, "my pretty girl."

When under the influence she is vicious and manipulative. And seductive toward Eddie. She kisses and caresses him, murmuring soddently, "My beautiful boy — don't you love me?" Eddie squirms. He tears himself away and visits his grandmother's grave. In despair he begs her for help and wails, "I don't know what I have to do — I can't see anymore."

The situation appears hopeless except that Eddie's got an aunt who's tough and caring and outspoken. He's also got the legacy of his people including empowering rituals that push and affirm the transition from boyhood to manhood.

Author Yellow Robe is an Assiniboine from Montana and has based his play on an amalgam of his own and others' experiences. However, one moment strains our credulity. That's when Eddie's friend Mike also complains of being seduced by his own mother. It seems like Oedipal overkill. In every other

See **Eddie Rose** on B3



'The Independence of Eddie Rose' portrays effects of alcohol.