



Regional Community Briefings on HIV/AIDS

A Report From

The Office of National AIDS Policy

December 1996

THE WHITE HOUSE

WASHINGTON

Dear Friends:

Following the historic White House Conference on HIV and AIDS, the Office of National AIDS Policy and the Presidential Advisory Council on HIV/AIDS decided to conduct a series of regional AIDS policy briefings in locations around the country. These briefings were designed to update concerned community members on the progress we were making in Washington on national issues related to the epidemic. They were designed to allow government officials to hear directly from people around the country about their concerns, their questions, and their ideas.

In four months, we visited 12 U.S. cities in eight states, held 17 public "town hall" briefings, visited 39 AIDS service organizations, and met with numerous newspaper editorial boards. In total, nearly 4,000 people participated, providing us with vital information, feedback, and suggestions.

Such an undertaking would not have been possible without strong partnerships with organizations that serve on the front lines of the HIV/AIDS epidemic. The National AIDS Fund and Funders Concerned About AIDS were the chief sponsors of this venture, providing important advice and support. The Council of Fashion Designers of America and the Henry J. Kaiser Family Foundation offered crucial support as well.

These briefings provided essential information that has guided AIDS policy decisions at the national level. They helped to shape decisions on such issues as funding for AIDS drug assistance, support for youth peer counseling programs, changes in Social Security disability eligibility procedures, support for housing programs for people with AIDS, and a host of other concerns.

The briefings also served to shine a spotlight on the many excellent AIDS organizations, foundations, and partnerships that are serving local communities. Federal officials, state and local government officials, members of the Presidential Advisory Council on HIV and AIDS, and other local citizens were able to see, first-hand, the remarkable work that is performed every day. The relationships that were formed during these visits will continue to enrich all participants in the future.

The following report attempts to give you a flavor of these meetings. It is also designed as a testament to the important work being done in communities across this country to improve and protect the lives of our fellow citizens.

Sincerely,

Patricia S. Fleming
Director
Office of National AIDS Policy

Chapter I

On December 6, 1995, President Clinton convened the first-ever White House Conference on HIV and AIDS. More than 300 individuals participated in the conference along with senior members of the Clinton Administration and representatives of more than a dozen Federal agencies involved in the national response to HIV/AIDS.

This historic meeting provided an opportunity for a national dialogue between those who are directly and indirectly affected by the epidemic of HIV/AIDS, those who care for them, and those who advocate on their behalf. This exchange of ideas and information has helped to guide Federal policy decisions.

During the course of the White House Conference, it became clear that an ongoing dialogue is needed to continue the collaboration and cooperation of that day.

Meeting the next day, the Presidential Advisory Council on HIV and AIDS asked the Clinton Administration to "initiate and maintain regular face-to-face meetings with HIV service providers, people living with HIV/AIDS, and their advocates to ensure consistent and ongoing communication and partnership with community members on the front lines of the AIDS epidemic."

In January 1996, the Office of National AIDS Policy (ONAP) joined with the Presidential Advisory Council on HIV and AIDS (PACHA), the National AIDS Fund (NAF), and Funders Concerned About AIDS (FCAA) to initiate a series of

Regional community briefings on HIV/AIDS policy developments that would provide an opportunity for face-to-face meetings. The objectives of these meetings were:

- (1) To update affected communities on policy development at the national level and hear directly from them about their concerns and ideas;
- (2) To provide Federal officials with an opportunity to observe, first-hand, the work of community-based AIDS service organizations (ASOs);
- (3) To provide community-based ASOs an opportunity to discuss concerns and ideas with Federal officials involved in the national response to HIV/AIDS;
- (4) To meet with media representatives to help focus local coverage of the impact of the epidemic on local communities; and,
- (5) To encourage greater participation in local activities by corporate and foundation leaders in those communities.

The public-private partnership that helped create this series of briefings was also essential to their success. Community partners of the National AIDS Fund and Board Members of Funders Concerned About AIDS provided important assistance in identifying local AIDS programs and concerns and in reaching out to the affected community to ensure participation.

Senior Clinton Administration officials, including Health and Human Services Secretary Donna E. Shalala and Housing and Urban Development Secretary Henry

R. Cisneros, committed their agencies to full participation in this project.

Representatives of the National Institutes of Health, Centers for Disease Control and Prevention, Health Resources and Services Administration, Office of HIV/AIDS Housing at HUD, and HHS regional offices participated in all of the visits.

Each briefing featured the following elements:

- Meetings with local leaders from the corporate and foundation communities;
- Visits to several AIDS service organizations, including programs that provide care, prevent the transmission of MV, conduct community-based research, provide housing assistance, and deliver substance abuse treatment and prevention;
- Meetings with local media representatives, including editorial boards; and,
- Open, public briefings for ASOs, members of affected communities, and the general public.

The schedule of visits was as follows:

- February 15-16: Dallas and Ft. Worth, Texas
- April 17-19: New York, New York, and Newark, New Jersey. May 7-8: Miami and Ft. Lauderdale, Florida.
- May 21-25: San Diego and San Francisco, California.
- June 20-21: Chicago, Illinois.

- July 23: Cleveland, Ohio
- July 30-31 Los Angeles, California.
- August 6-7: Charlotte, North Carolina.

Participants

The following organizations participated in and helped to support the series of regional briefings.

Federal Government Agencies

Office of National AIDS Policy, The White House
Domestic Policy Council, The White House
Department of Health and Human Services
Department of Housing and Urban Development
Health Resources and Services Administration
Centers for Disease Control and Prevention
National Institutes of Health
Food and Drug Administration
Substance Abuse and Mental Health Services Administration

Sponsors

Presidential Advisory Council on MV and AIDS
National AIDS Fund
Fundors Concerned About AIDS

Major Supporters

Council of Fashion Designers of America-Vogue Initiative/New York City
AIDS Fund of The New York Community Trust
Henry J. Kaiser Family Foundation

Community Supporters

AIDS Funding Collaborative (North Carolina)
American Dental Association
Board of Cuyahoga County (Ohio) Commissioners
Broward Community Foundation (Florida)
Broward AIDS Partnership
California Community Foundation
Cleveland Foundation
Dade Community Foundation (Florida)
Donors Forum of Chicago AIDS Affinity Group
Eaton Corporation (Cleveland, OH)
Equitable Foundation (New York NY)
Foundation For The Carolinas
George Gund Foundation (Cleveland, OH)
Levi Strauss Foundation (San Francisco, CA)
Marshall Field's (Chicago, IL)
NationsBank
New York Life Insurance Company
NYNEX (New York, NY)
Regional HIV/AIDS Consortium (North Carolina)
San Diego Community Foundation San Diego Grantmakers AIDS Collaboration
South Florida Community AIDS Partnership
Tarrant County Community AIDS Partnership (Fort Worth, TX)
University of North Carolina at Charlotte
United Way of Central Carolinas, Inc.
United Way of Greater Los Angeles
United Way Services of Cleveland

Chapter II

In total, these regional briefings included visits to 39 community-based AIDS service organizations, eight meetings with local corporate and foundation funders, five meetings with editorial boards, and nine public briefings.

An estimated 2,000 individuals attended and participated in the public briefings and another 1,000 participated in meetings arranged during site visits.

There was a very strong level of local interest in a continuing dialogue with Federal officials, members of the Advisory Council, and local funders.

Based on these visits, several clear points emerged:

- Communities clearly appreciate the infusion of additional resources to the Ryan White CARE Act. There has been an increase in the number of programs being supported and in the types of services offered to communities;
- Communities are very supportive of programs like the Ryan White CARE-Act, Housing Opportunities for People with AIDS, and AIDS prevention programs.
- Ryan White CARE, Act planning councils and CDC AIDS prevention planning groups are giving community members a seat at the

table and a voice in the decisions that affect them; and,

- Medicaid remains a vital source of medical care for people living with HIV/AIDS and the Ryan White CARE Act is also a growing source of such care.

Among the several themes and messages consistently communicated by community members there was:

- A growing concern about the cost and availability of emerging treatments for HIV disease.

The slow pace of some states in adding protease inhibitors to their AIDS Drug Assistance Program (ADAP) formularies caused considerable concern in affected communities;

- A strong desire for greater funding for HOPWA. Communities and ASOs are being very enterprising in their use of HOPWA funds, supporting the creation and renovation of AIDS-specific housing, providing rent support, paying for nutrition services, and providing end-stage care in non-institutional settings. The demand for these services is growing and funding is not yet keeping pace;
- A growing concern about the impact of substance abuse on communities and on the spread of HIV. Many of the communities we visited are operating syringe exchange programs or are

considering such programs. There is strong desire for the provision of Federal funds for such programs;

- A clear need by minority-based ASOs for greater resources and technical assistance to cope with a rising demand for their services;
- A continuing set of problems related to obtaining Supplemental Security Income (SSI) benefits, especially among women of color; and,
- A shortage of care and prevention services targeted to adolescents, particularly young men who have sex with men, and women, especially women of color.

Follow-Up

The Office of National AIDS Policy and relevant Federal agencies are committed to following up on issues raised at these regional community briefings.

Community participants raised a range of issues that include problems with state and local governments to specific problems with Federal agencies, to more general policy issues and concerns.

In many cases, there was immediate follow-up by relevant agencies with the involved ASOs. In others, there was follow-up with relevant state and local agencies in which Federal officials served as a conduit of information.

Finally, Federal policy has clearly been influenced by the testimony heard at town meetings and other venues.

Some examples of that influence are:

- Testimony in Dallas, Miami, and New York regarding the cost and inaccessibility of AIDS drugs led to the President's decision to request additional emergency funding for the AIDS Drug Assistance Program (ADAP) in Fiscal Year 1996 and in FY 1997;
- Testimony in San Francisco, Los Angeles, and several other cities regarding the growing need for HOPWA funding led HUD Secretary Cisneros to request a amendment for FY 1997;
- Testimony in Newark regarding problems being experienced by grandparents who are caring for their grandchildren who are affected or infected by HIV led to the creation of the "Grandparents' Project," which is designing a package of proposals to address those concerns;
- Testimony in many cities regarding ongoing problems with eligibility for SSI and SSDI benefits led ONAP to convene a meeting with officials of the Social Security Administration and client representatives from those cities to identify problems and solutions;
- Federal officials assisted the Minority AIDS Task Force on AIDS in Harlem in obtaining a much-needed approval from a local community board to construct a new housing facility for families affected by HIV/AIDS;

- The Health Resources and Services Administration (HRSA) dispatched a regional official to the Center for Haitian Studies in Miami to assist that ASO in correcting billing problems that were resulting in delays in payment of Ryan White CARE Act funds; and,
- Issues raised by officials at the Los Angeles County Medical Center were brought to the attention of the Health Care Financing Administration, which included specific assistance for AIDS clinics in Los Angeles in the county's Medicaid waiver plan.

Chapter III

Following are reports from each regional trip, including a list of events, a list of participants, and a discussion of the issues raised in those communities.

Dallas/Fort Worth, Texas February 15-16, 1996

List of Events

Participants:

Patricia S. Fleming, Director, Office of National AIDS Policy
Carol H. Rasco, Assistant to the President, Domestic Policy
B. Thomas Henderson, Member, Presidential Advisory Council on HIV/AIDS
Tarrant County Community AIDS Partnership

Site Visits:

Dallas

AIDS Services of Dallas
AIDS Resource Center of Dallas
Welcome House

Fort Worth

Health Education Learning Project

Media:

Meetings with the Editorial Boards of the Dallas Morning News and Fort Worth Star Telegram

Regional Briefing:

Public Forum (100 participants)

Highlights

The Dallas community has a strong partnership involving ASOs, local foundations and corporations, and private givers. AIDS Services of Dallas, which operates housing programs for individuals and families affected by AIDS, has particularly strong ties to local businesses and givers.

This partnership is not as strong in minority-based organizations, which are coping with a rising demand for services and a shortage of funds.

Welcome House, which provides substance abuse treatment, HIV prevention, and housing services to African-Americans living with HIV and recovering from substance abuse, provides a remarkable range of services to its clients. Welcome House's record has made it a model for other new minority-based ASOs.

Project HELP in Fort Worth has very strong connections to parents and students in that community. It provides AIDS education to adolescents based upon a peer counseling model. It, too, has achieved remarkable results on a very tight budget. The visit to Project Help received extensive local media coverage for the excellent work being done by its staff and volunteers.

Participants at the regional briefing were quite concerned about the rising cost of AIDS care, especially the prices of new drugs recently approved by the FDA. There was also concern expressed about limitations on AIDS education curricula in area schools.

New York, New York/ Newark, New Jersey April 17-19, 1996

List of Events

Participants:

Patricia S. Fleming, Director, Office of National AIDS Policy
Donna E. Shalala, Secretary, Department of Health and Human Services
Roberta Achtenberg, Senior Advisor, Department of Housing and Urban Development
Jeremy Ben Ami, Deputy Assistant to the President, Domestic Policy
Jack Whitescarver, MD, Deputy Director, Office of AIDS Research
Stephen Abel, Member, Presidential Advisory Council on HIV/AIDS
Mary Boland, Member, Presidential Advisory Council on HIV/AIDS
Tonio Burgos, Member, Presidential Advisory Council on HIV/AIDS
Debra Fraser-Howze, Member, Presidential Advisory Council on HIV/AIDS

Site Visits:

Minority Task Force on AIDS
Gay Men's Health Crisis
God's Love We Deliver
St. Claire's Hospital
Hispanic AIDS Forum
Brooklyn AIDS Task Force
Casa Betsaida
National Pediatric and Family HIV Resource Center

Media:

New York Times Editorial Board

Briefings:

ASO Executive Directors (200 participants)
Public Forum, The Equitable (300 participants)
Funders Briefing, New York Life (100 participants)

Highlights

Our visits to eight ASOs in three of the five boroughs of New York City and in Newark brought Federal attention to areas of the city that have been traditionally overlooked. As a result, programs in those communities received the recognition they deserve. These visits occasioned considerable interaction among ASOs that do not often have the opportunity to interact.

New York clearly continues to stagger under the impact of HIV/AIDS on the residents of that city. However, community-based programs are aggressively working to meet the needs of those residents and are benefiting from increased Federal resources, especially under the Ryan White CARE Act.

The meeting with ASO executive directors was very productive and focused on ways in which community-based organizations and Federal agencies can work to respond to the very real needs of this city.

The more general forum served as a release valve for a very frustrated community. There were strong expressions of anger about the inability of even increased resources to keep up with the rising demand for services.

The meeting with ASO executives raised similar issues but allowed for a greater exchange of information and ideas. ASOs were concerned by the increased competition for funds and the inability of some organizations in outer boroughs of New York City to compete for those funds. There were strong indications of increased cooperation and collaboration among organizations.

Miami/Ft. Lauderdale, Florida May 7-8, 1996

List of Events

Participants:

Patricia S. Fleming Director, Office of National AIDS Policy
Jeremy Ben Ami, Deputy Assistant to the President, Domestic Policy
Roberta Achtenberg, Senior Advisor, Department of Housing and Urban Development
Joseph O'Neill, MD, Associate Director for AIDS, Health Resources and Services Administration
R. Scott Hitt, MD, Chair, Presidential Advisory Council on HIV/AIDS
Broward AIDS Partnership
South Florida Community AIDS Partnership
San Diego Grantmakers AIDS Collaborative

Site Visits:

Children's Diagnostic and Treatment Center (Ft. Lauderdale)
Broward House (Ft. Lauderdale)
Health Crisis Network (Miami)
Center for Haitian Studies (Miami)

Media:

Sun Sentinel
South Florida Media Coalition

Briefings:

Public Forum, Miami Science Museum (300 participants)
Funders' Briefing, Dade Community AIDS Foundation (20 participants)

Highlights

The visit to Miami and Fort Lauderdale was extremely productive and positive. There was strong praise for the recent increase in Ryan White CARE Act funding for the City of Miami.

Both Miami and Ft. Lauderdale are coping with a rising demand for services but a very different demographic picture. Miami (Dade County) faces several additional challenges including multi-lingual populations, rising use of intravenous drugs, and a growing list of individuals and families seeking housing. Ft. Lauderdale (Broward County) is also coping with the dual epidemics of HIV and drug abuse. There are multi-cultural responses to HIV in both communities that aggressively reach out to communities of color.

A central challenge in Miami is providing care to women; resources for that population are rising but not as quickly as the numbers affected. During the public forum there were very strong expressions of concern about the rising level of negative public debate.

The meeting with the South Florida Media Coalition was particularly beneficial. The Coalition was formed to highlight the

impact of HIV/AIDS on the state and local community and the response of local residents and organizations. Our meeting resulted in extensive local media coverage.

San Diego, California May 21, 1996

List of Events

Participants:

Patricia S. Fleming, Director, Office of National AIDS Policy
Art Agnos, Department of Housing and Urban Development
Alexandra Levine, NM, Member, Presidential Advisory Council on HIV/AIDS

Site Visits:

Mamma's Kitchen
San Diego Youth and Community Teen Theater
Balboa Naval Hospital

Briefings:

Public Forum, Lyceum Theater (200 participants)
Fundraising Briefing, San Diego Community Foundation (30 participants)

Highlights

San Diego faces many challenges in meeting the needs of its HIV-affected population. Multi-lingual programs are essential to meet the needs of this population. A considerable concern is meeting the needs of adolescents and young adults, especially young gay teens. Our visit to the San Diego Youth and Community Teen Theater exhibited the strength of community-based programs

using peer education and modeling and dramatic demonstrations. A visit with HIV-infected members of the armed services was particularly poignant, coming on the heels of the repeal of the Dornan Amendment, which would have required the discharge of such individuals. Service members were grateful for this action but quite nervous about subsequent efforts. They are also exasperated by the restrictions imposed upon their service, in particular, the prohibition against overseas deployment. Since such service is important to receiving promotions, these service members are frustrated in their career advancement.

San Francisco, California May 23-24, 1996

Participants:

Patricia S. Fleming, Director, Office of National AIDS Policy
Carol H. Rasco, Assistant to the President, Domestic Policy
Jeff Levi, Deputy Director, Office of National AIDS Policy
Roberta Achtenberg, Senior Advisor, Department Housing and Urban Development
David Feigel, MD, Acting Director, Division Director of Antiviral Drug Products, Food and Drug Administration
Jack Whitescarver, MD, Deputy Director, Office of AIDS Research
Mark Feinberg, MD, Office of AIDS Research
Helene Gayle, MD, Director, Center for MV/STD/TB Prevention, Centers for Disease Control and Prevention

Joe O'Neill, MD, Associate Administrator for AIDS, Health Resources and Services Administration

Regina Aragón, Member, Presidential Advisory Council on HIV/AIDS

Nicholas Bollman, Member, Presidential Advisory Council on HIV/AIDS

Steve Lew, Member, Presidential Advisory Council on HIV/AIDS

Michael Rankin, MD, Member, Presidential Advisory Council on HIV/AIDS

Benjamin Schatz, Member, Presidential Advisory Council on HIV/AIDS

Site Visits:

San Francisco

Lavender Youth Recreation and Information Center

San Francisco General Hospital Community Consortium

Rafiki House

Oakland

VA Medical Center

AIDS Project East Bay

Briefings:

Oakland ASOs (75 participants)

Public Forum (350 participants)

Funders Briefing, Levi Strauss Foundation (75 participants)

Highlights

With considerable input from local members of the Presidential Advisory Council on HIV and AIDS, the San Francisco public forum was enlarged to include five breakout sessions on prevention, research, drug development, housing, and care.

A brief protest disrupted the opening session but participants reported that they had useful discussions with Federal

officials and PAC members on key issues of concern.

The meeting was convened shortly after FDA's approval of the second and third protease inhibitors and there was considerable concern regarding the ability of uninsured and underinsured individuals to obtain access to such treatments.

Audience members urged an expansion of the AIDS Drug Assistance Program (ADAP). Other major concerns included: a lack of affordable housing and lengthy waiting lists for HOPWA-supported housing; a desire for greater focus on the needs of gay/bisexual men, especially young men of color; the need for greater research into alternative and complementary medicines; support for needle/syringe exchange programs; and, a need for greater resources to meet the growing demand for services among women and communities of color.

Chicago, Illinois June 20-21

Participants:

Patricia S. Fleming, Director, Office of National AIDS Policy

Joe O'Neill, MD, Associate Administrator for AIDS, Health Resources and Services Administration

Al Noonan, MD, Regional Health Administrator, Department of Health and Human Services

Robert Fogel, Member, Presidential Advisory Council on HIV/AIDS

Site Visits:

South Side Help Center

Project VIDA

Bonaventure House

Media:

Chicago Tribune

Briefings:

Public Forum, American Dental Association (100 participants)

Funders Briefing, Marshall Field's (100 participants)

Highlights

We visited a remarkable program on the South Side of Chicago that is stretching a small budget quite far. One reason for this is that it is the only ASO in that part of the city. This fact was communicated directly to representatives of the City's Health Commissioner who had joined us on our visit.

The South Side Help Center conducts peer counseling education of adolescents and young adults including teen mothers. It also provides AIDS education in the local housing projects.

Project VIDA is another peer counseling program aimed at young Hispanic men and women. During the funders' briefing, concerns were raised about the state of Illinois' plans to reduce the number of drugs covered by its ADAP program in order to pay for coverage of one protease inhibitor. The issue was also raised with the Editorial Board of the *Chicago Tribune*, which later editorialized that the state should add new funding to the program rather than cutting back on existing coverage.

Cleveland, Ohio

July 23, 1996

Participants:

Donna E. Shalala, Secretary, Department of Health and Human Services

Helene Gayle, MD, Director, Center for HIV/STD/TB Prevention, Centers for Disease Control and Prevention

Joe O'Neill, MD, Associate Administrator for AIDS, Health Resources and Services Administration

Robert Fogel, Member, Presidential Advisory Council on HIV/AIDS

Site Visits:

Kamana Place

MetroHealth Medical Center

Stopping AIDS is My Mission

Briefings:

Public Forum, Health Museum (200 participants)

Funders Briefing, Eaton Corporation (150 participants)

Highlights

There was a tremendous community response to the visit of Secretary Shalala, who is a Cleveland native. Major issues raised included the cost of the new protease inhibitors, the impact of the epidemic on women and youth, syringe exchange programs, and the use of Ryan White CARE Act funds for funerals.

Cleveland had only recently become a Ryan White Title I grantee but had previously received assistance from the state through its Title II grant.

The visit to Stopping AIDS is My Mission provided an excellent example of peer education by young people ranging in age from 8 to 17.

Kamana Place offers residents transitional housing that prevents homelessness and connects people to a continuum of care.

The visit to MetroHealth Medical Center provided an additional opportunity for people living with AIDS to discuss their experiences and ask questions of federal officials.

Los Angeles, California July 30-31

Participants:

Patricia S. Fleming, Director, Office of National AIDS Policy

Joe O'Neill, MD, Associate Administrator for AIDS, Health Resources and Services Administration

Gary West, Deputy Director, Center for HIV/STD/TB Prevention, Centers for Disease Control and Prevention

R. Scott Hitt, MD, Chair, Presidential Advisory Council on HIV/AIDS

Ed Gould, Member, Presidential Advisory Council on HIV/AIDS

Alexandra Levine, MD, Member, Presidential Advisory Council on HIV/AIDS

Altagracia Perez, Member, Presidential Advisory Council on HIV/AIDS

Site Visits:

AltaMed HIV Services

Project Angel Food

Los Angeles Free Clinic

Homestead Hospice and Health Shelter

Briefings:

Los Angeles County Board of Supervisors Public Forum, United Way of Los Angeles (200 participants)

Funders' Briefing, California Community Foundation (20 participants)

Highlights

Having visited Los Angeles earlier in 1995, we wanted to pay particular attention to the delivery of HIV Services and prevention messages to communities of color.

AltaMed HIV Services has compiled an impressive record of serving communities of color in Los Angeles. Key issues raised by AltaMed clients included difficulties in qualifying for SSI and SSDI benefits. ONAP is working with the Social Security Administration and AltaMed to address those issues.

The LA Free Clinic demonstrated its peer counseling program featuring dramatic presentations by high school students.

The public forum included a demonstration by the AIDS Healthcare Foundation, which focused on the reduction in Title I funding to Los Angeles for FY 1997. That issue was raised with the LA County Board of Supervisors, which indicated that the shortfall in Federal funds had been replaced with local funds.

Other issues included the need for more focus on gay youth and women, support for syringe exchange programs, and the growing demand for Services in communities of color.

Charlotte, North Carolina

August 6-7, 1996

Participants:

Patricia S. Fleming, Director, Office of National AIDS Policy

Joe O'Neill, MD, Associate Administrator for AIDS, Health Resources and Services Administration

Rob Janssen, MD, Acting Associate Director for Science and Prevention, Division of HIV Prevention, Centers for Disease Control and Prevention

Site Visits:

Brothers United for Change

House of Mercy

Cleveland County Health Department

Metrolina AIDS Project

Media:

Charlotte Observer

Briefings:

Public Forum, University of North

Carolina, Charlotte (300 participants)

Funders' Briefing, Regional HIV/AIDS

Consortium (300 participants)

Highlights

This trip featured AIDS Services in rural communities. There is an impressive level of community support for AIDS prevention and care. Key issues included transportation, AIDS education in schools, stigmatization, access to SSI and SSDI, and Services to women.

There is a shortage of housing facilities for people living with HIV/AIDS. The County Health Commission is working to

create satellite offices to care for people in isolated communities.

Participants in the town meetings indicated that the visit provided a rare opportunity for members of the community to interact with each other and to bring their concerns to the attention of Federal and state officials.

Chapter IV

AIDS Service Organizations

Dallas, Texas

AIDS Services of Dallas
800 N. Lancaster Avenue Dallas TX 75203
214/941-0523
Contact: Don Maison, Executive Director

AIDS Services of Dallas is Dallas' largest providers of housing for homeless individuals and families affected by HIV/AIDS. It operates two facilities with a third under construction that will include a total of 49 units with residents ranging from infants to people in their 50s. Nearly 60% of the residents are racial or ethnic minorities and more than 95% are below the Federal poverty line.

AIDS Resource Center of Dallas
2701 Reagan
Dallas TX 75219
214/521-5124
Contact: Jamie Shields, Director of Community Center Services and Education

AIDS Resource Center of Dallas provides social Services to low-income and moderate-income individuals and families. Services include HIV/AIDS education, gay/lesbian education and support Services.

Welcome House
1818 East Overton Road
Dallas TX 75216
214/421-3948

Contact: Carolyn Harper, Executive Director

Welcome House was founded in 1966 as a residential facility for recovering male alcoholics. In February 1992, Welcome House began serving people living with HIV and AIDS, providing housing, support, and referral Services. Volunteers and staff provide street outreach Services and weekly support groups. In September 1992, Welcome House began a housing program specifically targeted at African American women who are substance abusers and living with HIV.

Health Education Learning Project of Fort Worth
901 Lake Street
Fort Worth, TX 76102
817/332-7722
Contact: Beth Perry, Executive Director

The Health Education Learning Project is an HIV/AIDS education program aimed at young people in junior and senior high school and alternate schools in Tarrant County TX. HELP's "Wedge Project," consists of collaborative efforts between professional HIV/AIDS educators, teenage drama students from the Boys and Girls Club, a panel of people living with AIDS, and a professional sexuality educator.

New York, New York

Minority Task Force on AIDS
475 Riverside Drive, Suite 1374
New York, NY 10115
212/870-2691
Contact: Linda Campbell, Executive Director and Terri Caronia-Smith

The Minority Task Force on AIDS (MTFA) is New York City's oldest non-profit minority AIDS service organization. Created in Harlem in 1985, MTFA was established to address the HIV related needs of Black and Latino people with HIV/AIDS. MTFA employs a client-centered, community-focused approach to provide education, outreach, advocacy, supportive housing, and direct Services. MTFA seeks to improve and extend the quality of life for the individuals and families it services by encouraging self-determination.

Gay Men's Health Crisis
129 West 20th Street
New York, NY 10011-3629
212/807-6664
Contact: Mike Isbell, Deputy Executive Director

The Gay Men's Health Crisis (GMHC) is one of New York's largest and oldest AIDS service organizations providing comprehensive Services to people living with HIV and AIDS. They provide advocacy, outreach, education, meals, buddy program, hotline number for information, newsletter/publications, gay and lesbian counseling, alcohol and drug abuse counseling, support groups, acupuncture treatments, and recreational activities.

God's Love We Deliver
166 Avenue of the Americas
New York, NY 10013
212/294-8193
Contact: Kathy Spahn, Executive Director

God's Love We Deliver (GLWD) is New York's leading provider of life-sustaining nutritional support Services for people

living with HIV/AIDS. They provide 900 meals twice a day throughout the city's five boroughs and in nearby Hudson County, NJ; they provide nutrition education and counseling to people living with HIV/AIDS, their families and care providers; they provide an opportunity for volunteer Services to people who seek to respond directly and effectively to the AIDS crisis.

St. Claire's Hospital
415 West 51st Street
New York, NY 100 19
212/586-1500
Contact: Dr. Victoria Sharp

St. Claire's Hospital provides needy persons living with HIV/AIDS medical care. It is the largest ambulatory care program for HIV related disease on the East Coast offering medical, dental and psychosocial Services for HIV/AIDS patients, volunteer program, grant funded Services, clinical trials for experimental therapies, clinical education and outpatient clinic.

Hispanic AIDS Forum
886 West Chester Avenue
Bronx, NY 10459
212/741-9797
Contact: Dr. Annette B. Ramirez de Arellano, Executive Director

The Hispanic AIDS Forum in the Bronx is the largest Latino-run AIDS service organization in New York providing HIV prevention and education, risk reduction seminars, case management services, counseling, referral services, testing, medical care, drug treatment, and housing. They primarily address the needs of the Latino community.

Brooklyn AIDS Task Force
465 Dean Street
Brooklyn, NY 11217
718/783-0883
Contact: Elaine Greeley, Executive
Director

The Brooklyn AIDS Task Force provides various programs to ensure that all Brooklyn residents have access to HIV/AIDS related information and Services that include pastoral care, treatment readiness for recovering addicts between detoxification and rehabilitation center programs, safe sex education, women's health issues, outreach to community programs, and client intake Services.

Casa Betsaida
267 Hewes Street
Brooklyn, NY 11211
718/388-8262
Contact: Msgr. Bryan Karvellis, Executive
Director

Casa Betsaida is a 21-resident supportive permanent residence for homeless persons with AIDS in Kings County, the Borough of Brooklyn and the communities of Williamsburg, Bushwick and Greenpoint. It provides a place to live and receive counseling, meals, medical attention, case management and personal care. Most of the residents are Hispanic and from the area, enabling them to live close their families. Casa Betsaida works to maximize independent living through intensive case management, health and nutritional maintenance controlling substance abuse, seeking legal assistance and by providing individual and group counseling.

Newark, New Jersey

National Pediatric and Family HIV
Resource Center
Children's Hospital AIDS Program
University of Medicine and Dentistry of
New Jersey
15 South 9th Street
Newark, NJ 07107 201/268-8267
Contact: Mary Boland

The Children's Hospital of New Jersey services as the major pediatric clinical teaching site for UMDNJ New Jersey Medical School. In 1982, Children's Hospital was one of the first institutions to report AIDS in children. Located in an epicenter of the epidemic in women and children, the Children's Hospital AIDS Program (CHAP) was founded in 1986 to respond to the increasing numbers of HIV infected children seeking care.

Ft. Lauderdale, Florida

Children's Diagnostic and Treatment
Center
417 S. Andrews Avenue
Ft. Lauderdale, Florida 33301
954/728-8080
Contact: Dr. Susan Widmayer, Executive
Director

The Children's Diagnostic and Treatment Center is one of the nation's leading centers serving the needs of children with HIV/AIDS and their mothers. The Comprehensive Pediatric AIDS Project is a coordinated system of primary medical care and case management to over 1300 children, youth and families living with HIV disease in Broward County since 1991.

Broward House
P.O. Box 350367
Ft. Lauderdale, Florida 33335
954/522-4749
Contact: Tom Shidaker, Executive
Director

Broward House is one of the oldest housing programs for people living with AIDS in this country. Services include supportive housing in a 52-bed assisted living facility, case management, HIV education, homeless outreach, chemical dependency treatment, and independent housing for families with children affected with HIV.

Miami, Florida

Health Crisis Network
5050 Biscayne Blvd.
Miami, Florida 33137
305/751-7775
Contact: Alexandria Douglas, Acting
Executive Director

Health Crisis Network is Dade County's oldest AIDS service provider. It conducts a variety of prevention outreach/training activities in high-incidence neighborhoods, corrections facilities, and gay clubs at night. The network runs a Parent/Teen prevention project that educates teens and their parents about AIDS and also a mobile testing van that provides free anonymous testing services at several locations around Dade.

Center for Haitian Studies
8325 NE Second Avenue
Miami, FL 33138
305/757-9555
Contact: Laurinus Pierre, Executive
Director

The Center for Haitian Studies is one of the few organizations in the country serving the Haitian immigrant population. It was founded in 1988 and provides direct Services to people living in Dade County who are affected by HIV/AIDS. CHS has an estimated 400 HIV/AIDS clients currently enrolled in its Services. The majority of these clients do not qualify for public assistance programs because of their legal status.

San Diego, California

Mama's Kitchen
1875 2nd Avenue
San Diego, CA 92101
619/233-6262
Contact: Carolyn McFarlane, Executive
Director

Mama's Kitchen is currently sending 320 hot dinners, 320 lunches and 320 weekend grocery bags to clients with AIDS who are too ill or too impoverished to care for themselves. Seventy volunteers drive 35 delivery routes each day, ensuring access to our service to all areas of San Diego County.

San Diego Youth & Community Services
3255 Wing Street, Suite 550
San Diego, CA 92110
619/225-9305
Contact: Rodney von Jaeger, Executive
Director

The San Diego Youth & Community Services provides transitional housing for runaway youth. The Teen Connection Theater is an AIDS peer education program made up of runaway youth living in this transitional housing providing HIV/AIDS information using dramatic skits.

Balboa Naval Hospital
San Diego, CA
619/532-6047
Contact: Barbara Graham

Balboa Naval Hospital provides HIV/AIDS services to active as well as non-active military personnel.

San Francisco, California

Lavender Youth and Recreation
Information Center (LYRIC)
127 Collingwood Street
San Francisco, CA 94114
415/703-6157
Contact: Ken Bukowski, Executive
Director

Founded in 1988, the Lavender Youth Recreation and Information Center (LYRIC) is the San Francisco/Bay Area's community center for lesbian, gay, bisexual, transgender and questioning youth under the age of 24. LYRIC provides educational, social, recreational, and leadership development activities focused on decreasing self-destructive behaviors and increasing life skills among this youth population. Over 1,000 young people participate in LYRIC programming each year.

Veterans Administration Medical Center
427 13th Street
Oakland, CA 94612
510/267-7978
Contact: Michael Rankin, Chief,
Psychiatry and Mental Health Services

VA Medical Center provides psychiatric and mental health Services for veterans living with HIV/AIDS. Through individual counseling and support groups, veterans are provided with outlets for dealing with HIV/AIDS issues. The Center also provides counseling and support groups for significant others when appropriate. The Center's staff sees approximately 100 veterans on a consistent basis.

AIDS Project East Bay
651 20th Street
Oakland, CA 95612
510/834-8181
Contact: Valerie Papaya Mann, Executive
Director

The AIDS Project of the East Bay, provides direct support Services to over 800 people on site last year including benefits advocacy; case management; emergency fund vouchers; and housing case management. Of those served, over 80 percent were living in poverty, 70 percent were people of color, 40 percent were homeless, and 25 percent were women. APEB's Education & Prevention Department reached over 20,000 people in Alameda County last year alone, and conducted over 400 group HIV risk reduction discussions in the community.

San Francisco General Hospital
1001 Potrero Avenue
San Francisco, CA 94110
415/206-8100
Contact: Dr. John Stansel

Since opening one of the country's first outpatient clinics dedicated to AIDS in early 1983, the AIDS Program has been a leader in caring for HIV infected patients. Voted best in the nation for AIDS care for six consecutive years, the clinic provides Services to over 2,500 HIV infected patients in the City and County of San Francisco. The AIDS Program has emerged as a unique provider of clinical care, research and educational experiences.

Rafiki House
1648 Kirkwood
San Francisco, CA
415/641-5641
Contact: Larry Saxxon, Executive Director

Rafiki House is a 24-hour transitional housing facility for African American men and women living with HIV or AIDS. Rafiki House provides a stable, safe, comfortable and healthful environment to residents while helping them develop a long-term support system for living with HIV disease. Services provided include substance abuse counseling, housing case management, referrals to outside services, gender specific HIV/AIDS groups, and outpatient substance abuse treatment. Rafiki House is a component of the San Francisco Black Coalition on AIDS.

Chicago, Illinois

South Side Help Center
10420 Halsted Street
Chicago, IL 60628
312/445-5445
Contact: Betty Smith, Executive Director

The South Side Help Center provides HIV/AIDS education using peer educators and drug awareness. Counseling Services are also offered, incorporating safer-sex and substance abuse counseling. Teen pregnancy prevention strategies are also provided for area youth.

Project VIDA
2858 South Lawndale
Chicago, IL 60623
312/522-4570
Contact: Luule Vess, Executive Director

Project VIDA offers anonymous and confidential HIV-antibody testing and counseling, and distributes condoms to the Hispanic community. It trains peer educators to do outreach in the Hispanic community, focusing on safer sex and testing information. An outreach program targets gay, lesbian, and bisexual and HIV-positive youth.

Bonaventure House
825 West Wellington
Chicago, IL 60657
312/327-9921
Contact: Tim McCormack, Executive Director

Bonaventure House provides service-enriched supportive housing to men and women with AIDS. All residents were formerly homeless or on the verge of homelessness, often brought on by the

high cost of medical treatment and an inability to continue working. As a result, virtually all of its residents have few financial resources. Each individual has a private room with a semi-private bathroom and access to many programs. Services include three meals per day, medical and psychological case management, substance abuse recovery support, HIV/AIDS support groups, pastoral care, and recreational opportunities.

Cleveland, Ohio

Kamana Place
7910 Lake Avenue
Cleveland, OH 44102
216/651-6400
Contact: Louise Valentine, Executive Director

Kamana Place is a transitional housing program for people living with AIDS. It opened in 1991 to provide assisted living Services and support to persons living with AIDS who can no longer live alone, or who are homeless and in need of assistance with day to day activities. This facility offers single room accommodations for ten people.

MetroHealth Medical Center HIV Clinic
2500 Metro Health Drive
Cleveland, OH 44109-1998
216/778-7800
Contact: Dr. Robert Kalayjian, Director

The MetroHealth System provides quality health care to the residents of Cuyahoga County. MetroHealth Medical Center offers a sliding scale, based upon income, for medical services provided, and is able to offer discounted medications to patients who meet the lowest income criteria. The

HIV Clinic provides case management, treatment and other health care Services associated with the management of HIV/AIDS.

Stopping AIDS is My Mission
2561 East 59th Street
Cleveland, OH 44106
216/231-3475
Contact: Dr. Victoria Cargill

SAMM provides AIDS education and information for adolescents and young adults of color, particularly those in inner-city neighborhoods. SAMM was founded in 1987. SAMM has reached over 30,000 adolescents and young adults and is comprised of a research arm and service arm.

Los Angeles, California

AltaMed HIV Services
133 N. Sunol Drive
Los Angeles, CA 90063
213/980-4502
Contact: Al Ballesteros, Executive Director

AltaMed Health Services is a non-profit community based medical services corporation which has been in existence since 1969 serving primarily the Latino community. The HIV programs were formalized in 1990. Specific HIV programs include medical and support services to approximately 650 men and women at all levels of HIV disease. Comprehensive services include mental health, case management, prevention and education, HIV counseling and testing and home health care services. About 80 percent of the clients being served are Latinos and virtually all are indigent.

Annually, approximately 8,000 individuals are served through the various HIV services programs.

Los Angeles Free Clinic
8405 Beverly Blvd.
Los Angeles, CA 90048
213/653-1990
Contact: Mary Rainwater, Executive Director

The LA Free Clinic provides various medical and social services. Specifically targeted services for HIV/AIDS include Project ABLE, a peer HIV education program for high-risk youth and services for people living with HIV and AIDS.

Project Angel Food
7574 Sunset Blvd.
Los Angeles, CA 90046
213/845-1800
Contact: John Gile, Executive Director

Project Angel Food is a daily meal delivery program for people with AIDS throughout Los Angeles. Each day, over 800 hot lunches are delivered to people in need. These meals are carefully prepared and delivered by volunteers. Over 2,000 men, women, and children with AIDS will receive a meal from Project Angel Food this year. These meals are home cooked quality, and provide vital nutritional support for hundreds of people. For many clients, Project Angel Food is the only source of nutrition, and our volunteers are their only connection to the outside world. Since 1989, Project Angel Food operates under the premise that no person with AIDS should also face loneliness and hunger. More than 45 percent of Project Angel Food's clients are people of color. In addition, special menu items are

available for clients facing various AIDS symptoms, and for those on protease inhibitor therapy.

Homestead Hospice and Shelter
Waylon Flowers House
P. O. Box 931179
Los Angeles, CA 90093-1179
213/466-5411
Contact: John Meceri

Homestead Hospice and Shelter was established in 1987 to provide care to people living with AIDS in Southern California. Since that time, the agency has provided a home to more than 900 men and women living with HIV disease. The agency currently operates seven facilities with a total of 49 beds.

Charlotte, North Carolina

Brothers United for Change
P.O. Box 179
Clover, South Carolina 29710
803/222-5100
Contact: Rev. Walter White, Director

Brothers United for Change was started in 1994 under the auspices of the Clover Parish of the United Methodist Church. The program is a response to the critical situation in which young African American males find themselves with regard to their disproportionate number using drugs, committing crimes and high mortality rate -- black on black homicide being the prime cause of death. This program address HIV/AIDS using dramatic interpretation skits to inform young men of the dangers of alcohol and drug abuse and unprotected sex by encouraging self-esteem and a sense of responsibility for the future.

House of Mercy
P. O. Box 808
701 Mercy Drive
Belmont, NC 28012
704/825-4711
Contact: Sister Margaret Straney,
Executive Director

The House of Mercy provides physical, psychological and spiritual care and comfort to men and women living with HIV/AIDS in a six-county area surrounding Charlotte, NC. Founded by the Sisters of Mercy nearly five years ago, House of Mercy is the only licensed Family Care Home in the region devoted to people living through the incapacitating final stages of AIDS.

Cleveland County Health Department
315 Grover Street
Shelby, NC 28150
704/484-5241
Contact: Jimmy Hines, Director of Health
Education

CleCo provides prevention, education and outreach through health promotion, maternal and infant care, and dental and school health Services to the citizens of Cleveland County.

Metrolina AIDS Project
P.O. Box 23662
Charlotte, NC 28232
704/333-1435
Contact: Barbara Rein, Executive Director

Metrolina AIDS Project was founded in 1985 and is the region's leading provider of comprehensive case management, preventive education services and direct financial support to the people of Charlotte

and surrounding communities. MAP provides a multitude of services for people living with AIDS. The Agape Center provides childcare services to mothers whose children are living with HIV and/or mothers who are living with HIV.