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FAX TO: 202-456-2438
SEVEN PAGES

August 31, 1999

Ms. Sandra Thurman
Director
White House Office of National AIDS Policy
736 Jackson Place
Washington, DC 20503

Dear Sandy:

A scientific advisory committee—consisting of Drs. Max Essex, Phyllis Kanki, George Pavlakis, Edmund Tramont, and myself—suggested that we invite you to participate in one of our ongoing series of invitational think tank meetings, entitled *HIV Vaccines for Developing Countries: Prioritizing Vaccine Candidates for Human Trials*. This meeting will be hosted by the Harvard AIDS Institute, Monday, October 4 through Thursday, October 7, 1999, in Boston.

This meeting is the seventh in a series of meetings with the primary goals of developing a truly worldwide HIV vaccine and addressing cutting-edge scientific HIV-1 vaccine issues, especially as they pertain to developing countries. Our first meeting, held in July 1995, examined overall challenges and opportunities related to vaccines for developing countries. In April 1996, we focused on antigen design, and in October 1996, we explored designing vaccine efficacy trials. In April 1997, we considered issues concerning DNA vaccines, new vaccine adjuvants, and novel delivery systems. In April 1998, we addressed the role of immune correlates of protection in the creation of an HIV vaccine. During our sixth meeting in December 1998, we moved the series to Dakar, Sénégal—outside of the United States for the first time—to explore issues pertaining to the vaccination of the leading infectious killers of children. Throughout the series, the discussion has been focused to include perspectives, benefits, risks, and economic constraints of developing HIV vaccines for worldwide use.

One of the goals of *HIV Vaccines for Developing Countries: Prioritizing Vaccine Candidates for Human Trials* is to allow different viewpoints to be aired so that we can move closer to developing an effective HIV/AIDS vaccine development strategy. With this in mind, representatives of these differing perspectives will be provided with an opportunity to share their objectives and thoughts. For your information, a draft agenda and a list of invited participants are attached.

Those invited to the meeting include researchers with broad general knowledge in infectious disease pathogenesis, epidemiology, and vaccine development, as well as HIV experts, virologists, immunologists, behavioral scientists, and representatives of international organizations who are key players in the definition, funding, and implementation of such interventions.

Max Essex, DVM, PhD
Chair

Richard Marlink, MD
Executive Director

Neil Rudenstine, PhD
Chair
Policy Board

Maurice Tempelsman
Chair
International Advisory Council

Mrs. William McCormick Blair, Jr.
Co-Chair
International Advisory Council



HIV Vaccines for Developing Countries

August 31, 1999

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During this upcoming think tank, as in past meetings, open discussion and comparative analysis will be encouraged, rather than the common meeting format of participants' presentations of their own research with a limited question and answer period. Everyone will be asked to speak as we intend for this meeting to be both didactic and interactive. Considering the nature of this think tank, our hope is that all attendees will plan to participate throughout the meeting.

While our funding is limited for this effort, we would like very much to include you in this critical meeting, as your perspective is an important one. We would appreciate it if you could cover the costs of your stay at the conference venue, the MIT Endicott House, and your transportation to Boston with your organization's travel funds. This will allow us to underwrite the participation of individuals from developing countries. If, however, this is not possible, let us know, and we will work with you to try to accommodate your needs.

We hope that you will be able to join us for this important meeting. Please confirm your attendance by returning the enclosed fax form by September 10. If you have any questions, please feel free to contact Kimberly Hensle, manager of conferences (phone: 617-432-4400; fax: 617-432-4545; email: khensle@hsph.harvard.edu). Thank you for your consideration of this invitation.

Sincerely,

A handwritten signature in dark ink, appearing to read 'Ric', with a stylized flourish at the end.

Richard Marlink, MD

*HIV Vaccines for Developing Countries:
Prioritizing Vaccine Candidates for Human Trials*
DRAFT AGENDA

Monday, October 4, 1999

Dinner, Reception, and Call to Action

Tuesday, October 5, 1999

Welcome: M. Essex and R. Marlink

Overview: G. Pavlakis and E. Tramont, think tank co-chairs

Session I: Overview of HIV Vaccine Development to Date

Discussion:

- A. What is the status of current HIV vaccine efforts?
- B. What lessons can be learned from the past?

Session II: Requirements for a Worldwide HIV Vaccine

Discussion:

- A. What are the qualities of or requirements for a vaccine to be feasible for use in a developing country setting?
- B. What are the scientific qualities or requirements for a test site?
 - 1. demographic data
 - 2. technical capabilities
 - 3. demonstration of ability to conduct human studies
 - 4. political will
- C. What other issues should be considered for site selection?

Session III: Molecular Epidemiology and HIV Vaccinology

Discussion:

- A. How does the changing worldwide epidemic result in problems in test sites and cohorts?
- B. Are clades important for vaccine development or are they just an epidemiologic tool?
- C. What immunologic parameters are necessary?

Session IV: Existing Vaccine Choices

Discussion:

- A. What vaccine choices do we have?
- B. What is in the "pipeline"?
- C. What we do need?
- D. Why don't we have more candidates ready to test (i.e., what are the causes of the bottlenecks in the vaccine development pipeline)?

Session V: Lessons from Southeast Asia

Discussion: Case Study: Thailand

Session VI: Lessons from East Africa

Discussion:

- A. Case Study: Uganda

B. Case Study: Tanzania

Session VII: Lessons from Southern Africa

Discussion:

A. Case Study: Botswana

B. Case Study: South Africa

Wednesday, October 6, 1999

Session VIII: Lessons from West Africa

Discussion: Case Study: Senegal

Session IX: Elements of Success/Elements of Failure

Discussion:

A. What is the criteria for vaccines to be selected for testing in humans?

B. How are candidates selected?

C. How do organizations which focus on vaccine development decide which vaccine candidates to support?

D. Why do some efforts go forward, while others fail?

Thursday, October 7, 1999

Session X: Feasibility, Funding, and the Future

A. What kind of infrastructure, political support, or funding base is needed to develop a global strategy for AIDS vaccine design?

B. What is the role of international foundations in vaccine development?

C. Who funds vaccine design?

Session XI: Concluding Thoughts/Call to Action

Invited and Confirmed Participants to Date
HIV Vaccines for Developing Countries:
Prioritizing Vaccine Candidates for Human Trials

Jorge Beloqui, Grupo de Incentivo a VIDA, Brazil

Seth Berkley, MD, International AIDS Vaccine Initiative, USA

Natth Bhamarapravati, MD, Mahidol University at Salaya, Thailand

Deborah L. Birx, MD, Walter Reed Army Institute of Research, USA

William A. Blattner, MD, Institute of Human Virology, USA

Barry Bloom, PhD, Harvard School of Public Health, USA

Kenneth Bridbord, MD, National Institutes of Health, USA

Pedro Chequer, National Programme on STD/AIDS, Brazil

Richard B. Ciccarelli, Ph.D., Wyeth Lederle Vaccines, USA

Lawrence Corey, MD, University of Washington, USA

Victor de Gruttola, Harvard School of Public Health, USA

Assane Diop, MD, Ministry of Health, Senegal

Raphael Dolin, MD, Harvard Medical School, USA

Volker Erfle, MD, GSF-Institute of Molecular Virology, Germany

José Esparza, MD, PhD, UNAIDS, Switzerland

Max Essex, DVM, PhD, Harvard AIDS Institute, USA

Robert Gallo, MD, Institute of Human Virology, USA

Karen Goldenthal, MD, United States Food and Drug Administration, USA

Maurice R. Hilleman, PhD, SDc, Merck Research Labs, USA

Margaret Johnston, PhD, National Institute of Allergy and Infectious Diseases, National Institutes of Health, USA

Phyllis Kanki, DVM, ScD, Harvard School of Public Health, USA

Crispus Kiyonga, MD, Ministry of Health, Uganda

Michel Klein, MD, Pasteur Merieux Connaught, France

Tun-Hou Lee, SD, Harvard School of Public Health, USA

Myron M. Levine, MD, DTPH, University of Maryland School of Medicine, USA

Judith Lieberman, MD, PhD, Center for Blood Research, USA

Yichen Lu, Harvard School of Public Health, USA

Malegapuru William Makgoba, MBChB, PhD, President, Medical Research Council
Cape Town, South Africa

Stephen Marks, PhD, François Xavier Bagnoud Center for Health and Human Rights,
USA

Souleymane Mboup, PharmD, PhD, Université Cheikh Anta Diop, Sénégal

Gary Nabel, MD, Howard Hughes Medical Institute/University of Michigan , USA

Marian Neutra, PhD, Children's Hospital, USA

George N. Pavlakis, MD, NCI-Frederick Cancer Research Family, USA

Jerald C. Sadoff, MD, Merck Research Laboratories, USA

George Seage, Abt Associates, USA

John F. Shao, KCMC, Tanzania

Joseph Sodroski, MD, Dana-Farber Cancer Institute, USA

Edmund C. Tramont, MD, University of Maryland Biotechnology Institute, USA

David Weiner, MD, University of Pennsylvania School of Medicine, USA

Bruce Weniger, MD, Centers for Disease Control and Prevention, USA

Harvard AIDS Institute

Please fax by September 10 to +1-617-432-4545.

Attention: Kimberly Hensle, Manager of Conferences

_____ I would like to confirm my participation in HIV Vaccines for Developing Countries: *Prioritizing Vaccine Candidates for Human Trials*, to be held October 4-7, 1999 in Boston.

_____ I will not be available to attend the meeting.

Please complete the following:

Name: _____ Degrees: _____

Title: _____

Organization: _____

Address: _____

Phone: _____

Fax: _____

Email: _____

Notes: _____

Harvard AIDS Institute

Sandra L. Thurman
White House Office of National AIDS Policy
736 Jackson Place
NW Washington, DC, 20503

Dear Ms. Thurman,

We hope this message finds you well. In writing this letter, it is our sincere hope to impress upon you the significance of Harvard's ***Africa Now!*** summit taking place this November. This summit will help determine the building blocks for successful joint United States and African collaborations. National United States leaders, representatives from private industry, multilateral institutions, and private foundations will have the opportunity to listen and learn from the experience of African nations and African people living with AIDS. Following the summit, the Harvard community, the summit participants and its partners will initiate a revived global commitment with the release of a framework document intended to help us all confront the AIDS pandemic in Africa.

It is with great pleasure that I invite you to save the following dates for participation in ***Africa Now! A Leadership Summit to Define African Needs and Priorities*** sponsored by the Harvard AIDS Institute. This meeting is to be held Sunday, November 12 through Tuesday, November 14, 2000 in Cambridge, Massachusetts. As the Harvard AIDS Institute is a Joint United Nations Programme on HIV/AIDS (UNAIDS) Collaborating Center, we will work closely with UNAIDS, the World Health Organization, and the United States government to coordinate this summit. The work will compliment and continue the specific dialogues that have been ongoing with the United Nation's International Partnership against AIDS in Africa.

When United States President, William Jefferson Clinton visited the continent two years ago, he addressed the African renaissance. The seeds of democracy have taken root in many African nations, South Africa has triumphed over apartheid and many African nations have begun to develop market economies. Africans have reason to hope for a brighter future. Yet, with the dawn of a new century, millions of African lives are being lost to AIDS related illnesses. The sweeping spread of HIV and AIDS has resulted in the destruction of promising economies and the devastation of far too many families. The present United States administration recognizes that the AIDS pandemic unabated may lead to economic collapse and political instability. It is imperative now that the United States build a consensus to take effective and immediate action. Support and commitment from leaders in Africa and from all sectors in the United States must be mobilized. Guidelines must be created to determine how the international community, and specifically United States organizations, can work and collaborate in Africa.

Now is the time for us to unite against AIDS in Africa.

The goals of the ***Africa Now!*** leadership summit are to:

- Bring national leaders from the United States to the same table with key African leaders to establish the fundamental needs and priorities of Africa concerning AIDS. An inventory of present-day projects concerning AIDS in Africa will be matched with a needs survey of African countries prior to the summit;
- Complement and further advance the international efforts already underway by the United Nations, the United States government, and others;

- Create a framework document entitled "*Principles of Collaboration: A Guide for Global Partnerships When Confronting AIDS in Africa*"; and
- Formalize a tangible post-summit strategy and in doing so showcase the summit's findings to help prepare for an African-based AIDS Congress of Leaders.

Since the first appearance of HIV and AIDS cases, members of the Harvard community have been working resolutely to further AIDS research, enhance public health policy and improve relief efforts. This summit will draw upon the multitude of AIDS related expertise and experience at Harvard. Historically, the University has provided a haven for political leaders, economists, academics and scientists to express their thoughts, findings and vision to the world. Under the auspices of the University, we expect this summit to launch a renewed and truly concerted effort to help address the crisis in Africa.

Other collaborators involved in this summit include the Center for International Development at the Kennedy School of Government, the Corporate Council on Africa, the Faculty of Arts and Sciences of Harvard University, the François Xavier Bagnoud Center for Health and Human Rights at the Harvard School of Public Health, the Harvard Committee on African Studies, the Harvard School of Public Health, the Kennedy School of Government and the W.E.B. Du Bois Institute for Afro-American Studies at Harvard University.

Leaders with diverse interests and expertise will be brought to the summit table. Prior to the summit we will inventory both ongoing projects in Africa and what the African nations feel to be their fundamental priorities. The framework document and all materials will be circulated and jointly reviewed with the Office of the Secretary General of the United Nations in advance of the summit date. Confirmed summit participants include Foreign Ministers, Ministers of Health and past Presidents from Africa. Please join them, as well as other leaders from Africa and the United States, and experts in the field of AIDS research and international collaboration. Your perspective and participation will be most critical to the success of this endeavor.

This leadership summit will begin on Sunday, November 12 at 6.00pm with a special reception at the Harvard Museums of Art in Cambridge, Massachusetts. On Monday, November 13, participants will meet for an intensive private discussion at the Charles Hotel in Cambridge, that will continue on Tuesday, November 14. As this summit is meant to be a productive meeting, the number of participants will be limited.

We hope that you will be able to join us for this important leadership summit. A fax confirmation form is attached, for your convenience.

Additional details will follow this invitation. In the meantime, if you have any questions, please feel free to contact us or Bridin Byrne, conference coordinator, Harvard AIDS Institute. Ms. Byrne can be reached via telephone at (617) 432-4400, fax at (617) 432-4545, or email at africanow!@eci.harvard.edu

Thank you for your consideration of this "save the date". We look forward to welcoming you to Boston in November.

Sincerely,



Max Essex, DVM, PhD
Chair
Harvard AIDS Institute



Richard Marlink MD
Executive Director
Harvard AIDS Institute

Harvard AIDS Institute

Please fax by August 1 to +1-617-432-5222.

Attention: **Bridin Byrne**

_____ I would like to confirm my participation in ***Africa Now! A Leadership Summit to Define African Needs and Priorities***, Cambridge, Massachusetts, November 12-14, 2000.

_____ I will not be available to attend the meeting.

Please complete the following:

Name: _____ Degrees: _____

Title: _____

Organization: _____

Address: _____

Phone: _____

Fax: _____

Email: _____



Contact:

Andrew Shih

New York until 6/30: 212 584 5012
Durban, 7/6–7/13: (27 82) 858 0889

Michael Sinclair

Durban, 7/4–7/14: (27 83) 653 4271
msinclair@kff.org

*****MEDIA ADVISORY*****

loveLife YOUTH HIV PREVENTION PROGRAM TO BE FEATURED AT INTERNATIONAL AIDS CONFERENCE IN DURBAN

-- Multimedia Programs, Speakers, and “loveTrain,” the World’s Largest AIDS Prevention Billboard, Roll into Durban with Lifesaving Messages on HIV/AIDS --

What *loveLife*, South Africa’s youth HIV/AIDS prevention education initiative, will be prominently featured at the XIII International AIDS Conference in Durban:

- *loveLife*’s arrival will be heralded by the arrival of the *loveTrain*, the world’s largest moving billboard and a sexual health center
 - *loveLife* youth spokespeople will appear at the internationally televised conference opening ceremony with South African President Thabo Mbeki
 - The methods and success of *loveLife* will be discussed at a media briefing hosted by the American Medical Association (AMA)
 - *loveLife* representatives will be available throughout the conference week to discuss the need for and challenge of youth AIDS education
- **Media Briefing of the American Medical Association**
Saturday, July 8, 11h00–04h00, Holiday Inn Elangeni, 63 Snell Parade
 - **Arrival of the *loveTrain***
Saturday, July 8, 17h00, Durban Railway Station
 - ***loveLife* participants join in the conference Opening Ceremony**
Sunday, July 9, 19h30–20h30, Kingsmead Stadium

loveLife is designed to jump-start discussions of adolescent sexual responsibility and health, and aims to substantially reduce the HIV infection rate among South Africa’s 15-20 year olds in the next five years. *loveLife* couples frank sexual discussion with music, sports and other adolescent pursuits. The initiative primarily targets South Africans age 12-17 and spearheads a nationwide effort to set up adolescent-friendly sexual health services and outreach programs.

Information on *loveLife* and interviews with *loveLife* representatives are available throughout the Durban conference. Contact Andrew Shih at 212 584 5012 or (27 82) 858 0889.

DRAFT

O- Harvard
AIDS
Institute

CRISIS UPDATE

The Challenge of HIV and AIDS in Communities of Color

From

The Leading for Life

Campaign at the Harvard AIDS Institute

9/27/1999

DO NOT CIRCULATE

CRISIS UPDATE

The Challenge of HIV and AIDS in Communities of Color

INTRODUCTION

Part I THE CRISIS

Recommendations: Old and New

Recommendations by the National Commission on AIDS, 1992
Recommendations from the *Crisis Update*, 1999

Race, Society, and Community Influences

Racial Inequality and the HIV Epidemic
The Burdens of Race and Racism
AIDS in Communities of Color
Silence and Linked Fate
Homophobia and Fear of AIDS
Substance Abuse and HIV

The Challenge of a Coordinated Response

Prevention
Health Care
Clinical Trials

Part II COMMUNITY PROFILES

Communities in Acute Crisis

Young People of Color
Women
Rural Communities
Incarcerated Populations

The AIDS Epidemic: Demographics and Epidemiology According to Census Group Categories

African American Communities
Latino Communities
Asian American and Pacific Islander Communities
Native American Communities

Part III CRISIS RESPONSE

Programs in Place
Resource
References

CONCLUSION

INTRODUCTION

Since it was recognized more than 20 years ago, acquired immunodeficiency syndrome (AIDS) has disproportionately affected certain communities. Following its organization in 1989, the National Commission on AIDS (NCOA) alerted the President and Congress that “the message [concerning the epidemic of HIV and AIDS in the United States] was clear and alarming.” The commission warned that “far from over, the epidemic is reaching crisis proportions among the young, the poor, women, and many minority communities. In fact, the 1990s will be much worse than the 1980s” [National Commission on AIDS, 1989]. The commission’s 1992 report, *The Challenge of HIV/AIDS in Communities of Color*, defined the terms of the crisis even further, “The HIV/AIDS epidemic presents unique challenges to communities of color, and in this context, to all public policymakers.” Sadly, the commission’s finding is as true today as it was seven years ago.

Sidebar: June Osborn quote TBA.

From 1989 to 1992, NCOA conducted public hearings and site visits in an effort to gather information that would provide its members with a better understanding of the epidemic. A crucial component of the commission’s efforts was its examination of the trends of the epidemic in communities of color. Beginning in December 1990, the commission compiled “information and advice from hundreds of individuals within communities of color in forums that examined issues specific to African American, Native American, Hispanic/Latino, and Asian American/Pacific Islander communities.”

In their investigation of the epidemic’s effect within communities of color, commission members focused their attention on four racial and ethnic minority groups described by the U.S. Bureau of the Census: African Americans, Latinos, Asian Americans and Pacific Islanders, and Native Americans. NCOA wrote that within communities of color “the prospects for preventing and treating HIV disease . . . give cause for grave national concern, notwithstanding current efforts by many committed individuals inside and outside of government. The complex link between race, socioeconomic status, and poor

health has assured a difficult road ahead in our efforts to effectively confront the HIV epidemic in communities of color.”

The Challenge of HIV/AIDS in Communities of Color described and attempted to dissect the problems the HIV epidemic presents members of racial and ethnic minority communities. Rather than address the full scope of issues, the report included recommendations on key issues its members felt should be considered by the President and Congress during their formulation of HIV and AIDS policies.

- Surveillance practices
- Funding
- Prevention initiatives
- Technical assistance
- Primary care infrastructures
- Physician education
- Clinical trials
- Foster care programs for children affected by the epidemic

Today, the commission’s decade-old prediction of a growing HIV crisis among women and people of color shows no sign of subsiding. Without immediate and fervent attention, the HIV epidemic will continue to spread disproportionately among these populations. With the report, *The Challenge of HIV/AIDS in Communities of Color*, NCOA took an important step toward presenting the disparate manifestations of this disease in various populations. With this report, *Crisis Update: The Challenge of HIV and AIDS in Communities of Color*, we review the state of the crisis in these populations and issue another, more desperate, call to action.

Sidebar : Cornell West quote TBA.

Purpose of Update

In 1996, the *Leading for Life* campaign of the Harvard AIDS Institute began the process of reviewing the various components of the report, *The Challenge of HIV/AIDS in Communities of Color*. A group of individuals affiliated with the Harvard AIDS Institute re-examined the issues raised and recommendations made by NCOA in its original report. The contributors to this document, the *Crisis Update*, are not members of NCOA.

They are individuals from diverse backgrounds united by a common desire to combat the epidemic in our country's minority communities. Similar to the members of NCOA, the contributors to this report addressed essential issues important to the discussion.

The contributors to the *Crisis Update* sought to identify the progress, or lack of progress, our nation has made against the HIV epidemic with respect to specific populations—minorities, youth, women, rural individuals, and incarcerated individuals—and on specific issues—substance use, accessibility and quality of health care for people of color with HIV and AIDS, and efforts by legislators and government agencies. In addition to reexamining issues from NCOA's report, the contributors to the *Crisis Update* hoped to define new issues that have arisen in the past seven years, particularly issues of special and significant concern to racial and ethnic minority communities.

Following the completion of *Crisis Update*, staff at the Harvard AIDS Institute sent the report to a panel of <<number>> reviewers, some of whom were contributors to the original NCOA document. In addition to being asked to review the original NCOA recommendations, the reviewers were to be asked to examine the issues raised in this update and to suggest new recommendations, update the original recommendations, or both.

Recommendations: Old and New

Recommendations by the National Commission on AIDS, 1992

In the conclusion of its 1992 report, *The Challenge of HIV/AIDS in Communities of Color*, the National Commission on AIDS made 14 recommendations specifically targeting the issues addressed in the report. These recommendations were put forward “as a step toward focusing greater attention on the needs of these communities [of color] and facilitating the increased availability of critical resources.”

The 1992 recommendations, by category, were as follows:

Race and Socioeconomics

- Federal, state, and local governments should squarely confront problems associated with racial inequality and its effect on the public health. Public health officials should ensure that effective and equitable HIV policy, program, and funding efforts are brought to bear in communities of color.
- Public health officials should work with researchers, health professionals, and community-based service providers to gain a better understanding of the role of cultural and socioeconomic factors in the transmission of HIV, the disease process, and access to care. Information gleaned from these efforts should be taken into account in designing HIV prevention messages, services and programs, and in providing expanded treatment opportunities.

Prevention

- The Centers for Disease Control and Prevention should review the adequacy of demographic information regarding HIV/AIDS currently available by race, ethnicity, and nationality, particularly with regard to Asian Americans/Pacific Islanders and Native Americans. Additionally, the National Center for Health Statistics should make information available regarding HIV/AIDS knowledge, attitudes, beliefs, and behaviors among Asian Americans/Pacific Islanders and Native Americans.
- The Centers for Disease Control and Prevention should ensure that the prevention and education needs of persons of color who engage in high-risk behaviors are appropriately addressed by current and future prevention initiatives and funding efforts. Programs specifically targeted toward men of color who have sex with other men, toward injection drug users, and toward women are needed.

Programs in Place

Please take a moment and describe your innovative program or project that represents an effective approach to the challenge of HIV and AIDS in the targeted communities.

Are you offering a new program for the *National Crisis Update* or are you updating a program already featured? What is the name of the program?

Briefly describe the history of your program.

What is the population your program serves?

Why is your program effective?

For those programs already featured in the *National Crisis Update*, is the presentation of your program still an accurate representation of the scope of the work being done? How has it changed? What would you add or delete to your feature?

- Federal, state, and local governments should join forces with the private sector in providing long-term support to community-based organizations serving communities of color. As part of the effort, the U.S. Public Health Services should expand and promote comprehensive and integrated programs for technical assistance to and capacity building in these communities.

Health Care

- The President and the Congress should increase support for community-based primary care, including community health centers, migrant health centers, and clinics funded by the Indian Health Services to ensure delivery of prevention and care services, including those for HIV/AIDS.
- The President and the Congress should fully fund the Ryan White CARE Act and ensure that communities of color are adequately represented in the planning process and appropriately served by the resources available.
- The President and the Congress should provide additional incentives for health care professionals to work in underserved areas by increasing support for programs such as the National Health Service Corps and programs such as the Disadvantaged Minority Health Improvement Act of 1990 targeted specifically at increasing the number of minority health care professionals.
- Likewise, state and local jurisdictions should increase support for public hospitals and other locally supported components of comprehensive primary care systems that deliver HIV prevention and care services.
- Additionally, the Health Resources and Services Administration should assess the capacity of special initiatives, such as the Ryan White CARE Act and the Health Care for the Homeless Program, to develop and support a strong primary care infrastructure in communities of color.
- The federal government should provide adequate resources to community programs designed to improve access to health care and support services and to prevent the spread of HIV among adolescents. Passage of legislation similar to the proposed Comprehensive Services for Youth Act of 1992 would foster coordination and collaboration among educators, health care providers, and community-based organizations through the development and operation of citywide and statewide youth service center systems.
- The Agency for Health Care Policy and Research, the Health Resources and Services Administration, and the National Institute of Allergy and Infectious Diseases should conduct a review of current efforts to educate physicians on developments in HIV/AIDS care and aggressively pursue methods to improve the quality of

HIV/AIDS care. In order to ensure that people of color living with HIV receive the benefit of current developments in HIV/AIDS care, these agencies should strive to coordinate better the dissemination of information, target physicians who practice in communities of color, and work intensively with school and professional associations that have traditionally trained minority health professionals.

Clinical Trials

- The National Institutes of Health, in conjunction with other appropriate agencies within the Department of Health and Human Services, should intensify efforts to ensure access to HIV/AIDS clinical trial information, with regard to trial opportunities, the results of research efforts, and their significance for clinical management. Emphasis should be placed on reaching populations that have had poor or under-representative access to clinical trial opportunities. Efforts should include the collection and dissemination of trial-related research and information on new developments in treatment. Dissemination should be carried out in a manner that ensures that information is current, accurate, and comprehensible to target populations and the health professionals who serve them.

Social Services

- The federal government should work with the states to establish and support foster care programs for children with HIV infection and noninfected youth orphaned by the loss of parents to HIV/AIDS. Federal and state government should also support programs designed to assist family members in caring for children whose lives have been affected by HIV/AIDS.

NCOA's report AIDS also directed those interested to some of the commission's previous reports, which also contain recommendations relevant to the HIV epidemic in communities of color: *Americans Living with AIDS*, *HIV Disease in Correctional Facilities*, *The Twin Epidemics of Substance Use and HIV*, *The HIV/AIDS Epidemic in Puerto Rico*, *Housing and the HIV/AIDS Epidemic*, and *Resolution on U.S. Visa and Immigration Policy*. These reports provide vital information that must be considered by any policymaker and program planner who is serious about understanding the complexities of this country's AIDS epidemic.

Recommendations for the *Crisis Update*, 1999

The different organizations and programs listed in the "Addressing Community Needs" section of this report have inspired some of the recommendations made below. While individuals and organizations around the country have taken considerable steps in their local communities to address the areas of need pertaining to people of color, the aim of this report is to provide the motivation for a concerted nationwide action toward combating the epidemic among communities of color. Most importantly, this aggregate

effort must build from the efforts of each community to create an action plan that reflects its own unique history and culture.

TBA

The Epidemiologic Variable Called Race

In 1992, NCOA stated that, “racial inequality in the United States forms the backdrop against which efforts to deal with HIV/AIDS take place. Therefore, as a nation we have no choice but to take account of race if we are to alter the course of the epidemic. If we succeed, we will have learned much that is of importance to the whole country and of particular significance to those who would safeguard the public's health.”

The categorical descriptive *race* is routinely used in epidemiologic studies in the United States. Race has no fixed genetic basis. People who are called black in this country represent a genetic mixture of people from all over the world. Similarly, people who are called white represent a genetic mixture of peoples from all over the world excepting those with direct African (black) ancestry. [Ignatiev, 1994]. Therefore, although race is completely subjective or based on one individual's evaluation of another individual, the categorizations that result are generally taken as fact.

In fact, race is a powerful predictor of health outcome in the United States, with black people at higher risk than white people for many adverse health outcomes [Polednak, 1989; Secretary's Task Force, 1985]. Race-associated differences are routinely documented in the United States but for the most part remain poorly explained. This situation impedes efforts at primary disease prevention for those at highest risk: If the only known risk factor for a disease is race, and individuals cannot change their race, then there is nothing to be done concerning prevention of specific health problems.

Rather than simply attribute disease prevalence to race, researchers and intervention developers should consider how multiple factors such as poverty, nutrition, behavioral norms within a community, knowledge of how the local health care system works, and knowledge of how to apply for Medicare and Medicaid might influence a population's health status.

The Burdens of Race and Racism

It is clear that most disparities in health status are not genetic but are instead rooted in the context of a larger social environment in which the treatment of people differs at least in part, on the basis of the arbitrary categorization called race. In America, these disparities result in racism that operates on different levels: structural, interpersonal, and internal.

Structural racism refers to inequitable access to the goods and services of the society. While structural racism may have had its root in segregation, it is perpetuated in an integrated society that takes no active intervention on behalf of an individual or a community. Poor schools, poor housing, unemployment and underemployment, inadequate health care facilities, and toxic environments are disproportionately distributed because of structural racism. Communities facing this form of racism are often entrenched in a ceaseless cycle of poverty that affects health outcomes.

Interpersonal racism refers to assumptions made and actions taken by an individual as a reaction to another's race. Lack of encouragement by teachers, racial profiling by police, and sterilization by physicians are dramatic examples. For people with HIV, interpersonal racism may be manifest in a physician's disinclination to recommend a patient of color for a clinical trial. This type of racism is described as prejudice or discrimination.

Internal racism refers to the acceptance by the stigmatized races of what society teaches about their worth, abilities, and prospects. Internal racism includes not believing in others who look like oneself and not believing in oneself. A person who has internalized racism may exhibit low self-efficacy about their life chances and the corresponding need to protect their health.

Collectively, these three forms of racism have a profound and complex effect on the struggle to reduce HIV and AIDS in communities of color.

In presenting this *Crisis Update*, we are forced to present epidemiologic and demographic data on health in the categories in which they are collected. Thus, instead of discussing the HIV epidemic as it affects all our communities, especially our underserved communities, we must present epidemiologic data on minorities in the form that those data are currently available. The four standard racial and ethnic divisions are: African American (Black), Latino (Hispanic), Asian American and Pacific Islander (API), and Native American (comprising American Indians and Alaskan Natives).

In this report, the terms African American, Latino(a), Asian American and Pacific Islander (API), and Native American are used (except in citations where other terminology is used). The authors of this update recognize that these delineations are poor approximations for the diversity of people who exist within each demographic group, and that multiple factors, and not race alone, influence health status. In addition, as we explore race-associated differences in the HIV epidemic, we have tried to remain mindful of the ways in which the different levels of racism might explain these differences. By doing so, it is hoped that public health interventions developed from this report will account for the effects of race-consciousness and racism.

AIDS in Communities of Color

To understand AIDS in communities of color requires consideration of the social contexts in which the disease thrives and affects behaviors and practices. In 1992, NCOA recognized that social norms and structures of a particular racial or ethnic group might contribute to the spread of the HIV epidemic. In this update, we examine how norms and structures, such as differences in culture, socioeconomic and educational level, and moral perception, assist or impede the community's response to the epidemic.

Silence and Linked Fate

In *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics*, author Cathy J. Cohen [1999] notes:

A shared history of oppression, rooted in ideologies and systems of racial hierarchy, has motivated the development among black Americans not only of a common narrative of exclusion, self-reliance, and struggle, but also of shared consciousness and linked fate.

On a similar theme, NCOA stated in its 1992 report, "For these communities, disproportionate representation [in epidemic statistics] raises the fear that they will be saddled with the disease—blamed for it, stigmatized by it, and left to deal with it on their own."

The phenomena of shared consciousness and linked fate affects communities of color in at least two significant ways. One way is manifested through an exaggeration of the differences among communities. Members of minority communities see others,

particularly those in white communities, as significantly different. They believe they are “not like that” and can therefore ignore or disregard HIV-prevention messages. A second way is manifested through the minimization of intragroup variation. This makes it possible for minorities to live in a form of denial about the transmission risks that exist in their communities. It allows them, for instance, to wrongly declare, that in their community there are no instances of men having sex with men (MSM).

These perspectives can be devastating for communities of color fighting the AIDS epidemic. Rather than addressing difficult issues such as homophobia, drug use, and teen sexuality, discussion of these issues remains taboo. Unfortunately, things unsaid are not things undone. The effects of homophobia, drug use, and teen sexuality significantly affect the severity of the HIV epidemic in communities of color. A community’s inability to address these factors contributes both to the spread of the virus among high-risk groups within it and to the neglect that these groups experience from other members of the community. Gay white men, among whom the disease was first identified, were able to mobilize support in part because they were willing to talk about the taboos that put their community at risk. Communities of color must shed their collective conservatism on these topics and engage in open dialogue about the risk factors, and at-risk groups, within their communities.

Homophobia and Fear of AIDS

In communities throughout the United States, homophobia remains an overwhelming influence on people’s perceptions about the AIDS epidemic and their attitudes toward individuals with HIV or AIDS. Although homophobia and a fear of AIDS are separate issues, their relationship is complex and intertwines on issues such as fear of infection, moral beliefs concerning sexuality, level of AIDS knowledge, cultural stigma, and denial [O’Hare, Williams, and Ezoviski, 1996; Young et al., 1991; Larsen, Serra, and Long, 1990; St. Lawrence et al., 1990; Kelly et al., 1987]. Discrimination against gays and lesbians can prevent them from receiving accurate information about the disease and their treatment options.

Studies of health care providers’ attitudes show that their perceptions of gay people and their fear of HIV infection have a profound effect on the delivery of health services [Vermette and Godin, 1996; Yedidia, Berry, and Barr, 1996; Yedidia, Barr, and Berry, 1992, 1993; Shapiro et al., 1992; Bredfeldt et al., 1991; Gerbert et al., 1991; Hayward and Shapiro, 1991; Feldman et al., 1990; McGrory, McDowell, and Muskin, 1990].

Furthermore, such feelings and attitudes originate in the health care providers' "broader social experiences, not in their medical training," a circumstance that makes it difficult to reduce their unwillingness to treat people with HIV [Yedidia, Berry, and Barr, 1996]. A survey of home care providers showed that nurses "expressed lower feelings of moral obligation to provide home care" to gay patients compared to heterosexual patients [Vermette and Godin, 1996]. A separate study comparing the changes in the attitudes of physicians surveyed as fourth-year medical students and re-surveyed three years later as residents showed that, among those who initially expressed an unwillingness to treat people with HIV, physicians were more likely to demonstrate an increased willingness to treat HIV patients if they had received their training from faculty who had positive HIV-related attitudes or if, in the years between the surveys, they had become acquainted with a person living with HIV [Yedidia, Berry, and Barr, 1996].

Within the different racial and ethnic minority communities, homophobia is manifested in a variety of ways. Robert Fullilove of Columbia University's School of Public Health notes how the traditions associated with religion complicate the issue in African American communities. "The inability of [African American] ministers to raise HIV awareness in their communities is related to the church's age-old dilemma between serving those in need and recognizing homosexual behavior" [Washington, 1996]. In many instances, homophobia assumes an even more personal and intimate face than that of a minister when it stems from rejection and denial by family members. One young Latino man said, "When my cousin died of AIDS, his mother found it easier to think of him as having become infected through drugs rather than through sex with another man.... Because of homophobia, it's not uncommon for Latinos who have never done a drug in their lives to suddenly die of AIDS because of injection drug use" [Brewer and Kaczorowski, 1996]. In Asian American and Pacific Islander communities, discomfort about discussing sexuality in general can preclude openness about gay identity [Kaczorowski, 1996]. For Native Americans as for other groups, homophobia is often closely associated with the stigmatization of AIDS [Brewer, 1996]. While none of these issues are exclusive to any one community, the scenarios do raise the question of how individuals of different cultural backgrounds might face homophobia differently.

Homophobia and AIDS-phobia have detrimental consequences across all communities. Individuals too often allow their fear of AIDS to turn into irrational fear of people with AIDS [Kaiser Family Foundation, 1996]. These fears disrupt the efforts of communities

of color to address the epidemic and to treat all individuals with the respect and human compassion they deserve.

Substance Abuse and HIV

Substance use, whether injection or noninjection, constitutes a severe health risk for substance users, their sexual or needle-sharing partners, and their offspring. The risk of HIV infection associated with needles used to inject drugs has been noted since the early days of the epidemic. [Masur et al., 1981]. The use of noninjection drugs, recognized only in the past few years as a secondary risk factor in HIV infection, is of equal concern. Noninjection substances heighten the threat of infection by suppressing a person's inhibitions toward engaging in risky behaviors such as unprotected sex.

Despite consistent evidence for an association between substance use and HIV infection, the federal government has made little effort to address the problem in a concerted effort. In 1991, NCOA issued a special report pointing out the failure by the government to confront the "twin epidemics" of substance use and HIV infection.

The twin epidemics transcend all economic, geographic, and racial boundaries; everyone is affected. Substance use enhances the spread of HIV infection through the sharing [of nonsterile injection equipment] and the practice of unsafe sex related to crack, alcohol, and other substances. There has been an indisputable link between substance use and HIV transmission. Despite this insidious and indisputable link between substance use and HIV infection, the Office of National Drug Control Policy continues to virtually ignore it, and neglect the real public health and treatment measures which could and must be taken to halt the spread [of the HIV epidemic]. [National Commission on AIDS, 1991]

In the United States, the use of injection drugs is the second most frequently reported risk behavior among people with AIDS [Centers for Disease Control and Prevention, 1995]. Through December 1998, people of color accounted for nearly 75 percent of cumulative AIDS cases among injection drug users (IDUs) or IDU-MSMs. Of adult/adolescent AIDS cases attributed to injection drug use in 1998 alone, 50.1 percent of the cases were among African Americans and 23.6 percent were among Latinos [Centers for Disease Control and Prevention, 1999]. Among injection drug users in the United States, African Americans are 5 times more likely than whites to be diagnosed with AIDS [Day, 1998].

Needle exchange programs (NEPs) continue to be battlegrounds for politicians, public health officials, and community leaders. Despite overwhelming scientific evidence

supporting NEPs as an effective measure for reducing the spread of HIV without increasing drug use [See table on page 66], federal policymakers failed to repeal syringe restriction laws. A survey of syringe exchange programs (SEPs) by Paone and colleagues found that 52 percent of SEPs were legal (programs that operated in states without prescription laws or with exemptions to such laws), 16 percent were illegal but tolerated (programs that operated in states having prescription laws but that had received formal votes of support or approval from local elected officials), and 32 percent were illegal and underground (programs that operated in states having prescription laws and that had no local support) [Paone et al., 1999].

As of 1998, every state in the nation had some form of legal impediment to the sale or distribution of needles. Forty-seven states maintain drug paraphernalia laws that make possession of or transactions involving needles and objects intended for drug injection an offense subject to penalty. Eight states require valid medical prescriptions to purchase syringes from pharmacies, and 23 states maintain pharmacy regulations or practice guidelines to restrict needle access [Gostin, 1998; Gostin et al., 1997].

Studies have shown that discarded needles do not increase drug use in a community following the opening of a SEP, especially if the SEP has a one-to-one distribution policy [Khoshnood et al., 1998; Doherty et al., 1997]. Paone and colleagues found in their survey that SEPs with more formal and legalized ties with their community were more likely to provide valuable related services such as HIV testing, primary health care services, drug abuse counseling, and referrals for employment, STD treatment, birth control, or mental health services [Paone et al., 1999]. The legal status of a program is important to attaining certain public goals. Recent studies show that the non-needle-exchange services provided by SEPs have the effect of lowering SEP participants' risk of HIV infection and improving their likelihood of using primary health care services and enrolling in drug-abuse treatment programs [Altice et al, 1998; Brooner et al., 1998; Porter and Perez, 1998]

The following table presents the findings from seven federally funded needle exchange studies, each of which concluded that NEPs reduce HIV infection without promoting an increase in drug use. Despite this evidence and support for repealing the ban on federal funding of needle exchange voiced by Dr. David Satcher, Surgeon General; Dr. Harold Varmus, Director, National Institutes of Health; Dr. Anthony Fauci, Director, National Institute of Allergy and Infectious Diseases; Dr. Alan Leshner, Director, National

Institute on Drug Abuse; Dr. Claire Boome, Acting Director, Centers for Disease Control and Prevention; and Dr. Helene Gayle, Director, National Center for HIV, STD, and TB Prevention, and by scientific and public health groups such as the American Medical Association, American Public Health Association, National Academy of Sciences, American Nurses Association, and the American Academy of Pediatrics [Pelosi et al., 1998], the federal government has not moved to repeal the ban.

Conclusions and Recommendations of U.S. Government-Funded Reports on Needle Exchange Programs (NEPs)			
Reporting Agency	NEPs reduce HIV transmission	NEPs do not increase drug use	Revoke federal Needle Exchange Funding Ban
National Commission on AIDS, 1991	Yes ¹	Yes	Yes
General Accounting Office, 1993	Yes ²	Yes	N/A ³
University of California, San Francisco, 1993	Yes	Yes	Yes
Centers for Disease Control and Prevention, 1993a	Yes	Yes	Yes
National Academy of Sciences, 1995	Yes ⁴	Yes	Yes
Office of Technology Assessment, 1995	Yes	Yes	N/A ³
National Institutes of Health, 1997	Yes	Yes	Yes

Source: Schipper, Earl J., News From the National AIDS Fund, September 1996; National Institutes of Health Consensus Panel, Interventions to Prevent HIV Risk Behaviors, 1997

¹ "Legal barriers precluding needle exchange lead to increased HIV transmission."

² "Research suggests promise as an AIDS prevention strategy."

³ Reviewed data without making policy recommendations.

⁴ "Reducing the proportion of contaminated syringes in circulation will reduce HIV transmission."

In failing to recognize these data and respond to the urgent crisis of HIV infections among IDUs, their sexual partners, and their children, the federal government fails to live up to its responsibility to protect public health. Equally at fault are communities of color who refuse to acknowledge and deal with the grave effects of injection drug use. The injection drug epidemic, like the HIV epidemic, requires a coordinated response from public, private and nonprofit entities.

Alcohol Use and HIV Infection

According to the National Institute of Alcohol Abuse and Alcoholism, there are two major links between alcohol use and increased vulnerability to HIV infection:

First, alcohol use may be a marker for a risk-taking temperament: those who drink alcohol may also engage in a variety of high risk activities, including unsafe sexual practices, as part of a 'problem behavior syndrome.' Second, alcohol may influence high-risk behaviors at specific sexual encounters by affecting judgment and disinhibiting socially learned restraints. These are not mutually exclusive interpretations. [National Institute of Alcohol Abuse and Alcoholism, 1992]

Studies of alcohol's effect on behavior confirm the role it plays in increasing one's risk of HIV infection. A recent study found that young HIV-positive men were more likely to engage in unprotected anal intercourse with an HIV-negative partner or a partner whose serostatus was unknown if they had been drinking alcohol [Purcell and Parsons, 1998]. Alcohol serves as a "gateway" both to the use of other substances and to the practice of other risk behaviors. The authors of *Risk and Recovery: AIDS, HIV and Alcohol* [Quackenbush, Benson, and Rinaldi, 1992] outline four reasons why alcohol use may increase one's risk of HIV infection.

- Alcohol distances one from adhering to the personal behavioral rules they normally follow such as never using injection drugs or always using latex barriers during sexual intercourse. Even a couple drinks can cause individuals to slip in their behavior.
- Drinking beyond one's alcohol tolerance level can cause blackouts. These lapses make it difficult for a person to remember events and to assess his or her risk of HIV infection.
- Studies have suggested a possible biologic susceptibility to HIV infection as a result of alcohol use. Alcohol may limit the body's normal immune response, facilitating infection by a foreign pathogen.

- Many alcohol users also use other substances. Other drugs, such as heroin, crack, or speed, have debilitating effects on a drug user's ability to make decisions about sexual encounters or injection drug use.

The correlation between alcohol use and increased risk of HIV infection is complex. Recognizing the cycle of alcohol and high-risk behavior will aid in the development of interventions geared toward those who tend to engage in high-risk behaviors regardless of alcohol consumption and those who are more likely to take sexual risks only when they are intoxicated [National Institute of Alcohol Abuse and Alcoholism, 1992].

Crack and HIV Infection

In 1991, the Division of Clinical Research of the National Institute on Drug Abuse funded an eight-city ethnographic study, *Crack pipe as pimp* [Ratner, 1993]. Concepts of HIV transmission as a result of non-injection drug use that existed prior to the publication of this article primarily focused on the sexual partners of IDUs. In 1988, Willard Cates, Jr., director of the Sexually Transmitted Diseases Division of the Centers for Disease Control and Prevention (CDC), established the connection between crack use and the increased risk of HIV infection. This connection has come to be known as “sex-for-crack.” Goldsmith remarked in 1988 that “the crack house of today has become what the gay bathhouse was yesterday with regard to all sexually transmitted diseases” [Goldsmith, 1988].

The sex-for-crack phenomenon arises most often out of compulsive or desperate situations such as the need for drugs or money to pay for drugs. Such lifestyle circumstances severely curb a person's ability to assess his or her risk of HIV infection. A 1997 study of crack-using versus noncrack-using men, primarily from the African American community, found that those who used crack reported more sexual partners in the past year, more sexually transmitted diseases (STDs) during their lifetime, greater frequency of sex-for-crack or sex-for-pay, and greater frequency of having sex with an IDU than noncrack users [Word and Bowser, 1997]. While there has been an increase in the incidence of condom use among sex-for-crack participants, the inconsistency of use can lead to an even higher rate of HIV infection in these particular communities. Even when crack users and suppliers recognize the importance of condom use, most “would prefer to spend their last dollar on crack rather than on a condom” [Bourgois and Dunlap, 1993]. In the Harlem study site, it was estimated that 16.6 percent of sex-for-crack

prostitutes contracted HIV solely through sexual contact. “The vulnerable and abusive lifestyles” of these individuals undermine their ability to insist on condom use while also multiplying their instances of sexual contact, two conditions that invariably promote STD transmission [Bourgois and Dunlap, 1993].

The incidence of HIV transmission among crack users cannot be adequately assessed by the present collection methods of CDC’s HIV Surveillance Unit. Current figures do not account for the possibility of transmission by multiple factors. The polysubstance-using habits of many crack users is evident in NHSDA results.

The influence that drug and alcohol use have on people’s direct and indirect vulnerability to HIV infection is a considerable issue that needs to be more assertively addressed in public health data collection, prevention and intervention programs, and drug abuse and HIV treatment programs. To effectively promote public health, efforts are needed in many communities to acknowledge and work through the stigma that surrounds substance use—from alcohol abuse to injection drug use.

The Challenge of a Coordinated Response

What the previous sections of this *Crisis Update* suggest is that the AIDS epidemic still requires an aggressive and coordinated response from both the public and private sectors if we are to eliminate racial disparities and reduce overall infection rates in communities of color. There has to be a coordinated response that includes dedicated and directed assistance from federal government agencies, elected officials, business executives, and community-based leaders, including religious leaders. Nothing less is acceptable. The alternatives are too dire. Communities of color cannot afford to lose their precious resources—mothers and fathers, daughters and sons, sisters and brothers—that make them sustainable.

The 1992 NCOA report included recommendations on three critical components of a coordinated response to the epidemic—prevention, health care, and clinical trials. In this section we review and assess progress in each of these areas.

Prevention

NCOA recognized in 1992 “that the Centers for Disease Control and Prevention (CDC) had worked hard to listen to, understand, and address concerns voiced by people of color. In many instances, the CDC had borne the burden of frustration individuals and communities have felt in the face of government failure to respond adequately to the threat of HIV in communities of color. In particular, the CDC had played an important role in responding to community suggestions on how to improve surveillance efforts and prevention activities.” When the CDC made preparations for a guide on community planning the following year, it relied heavily on the “experience and recommendations of health departments and non-governmental organizations; and the health promotion, community development and behavioral/social science literature” [Centers for Disease Control and Prevention, 1993c].

In December 1993, the CDC issued *HIV Prevention Community Planning Guidance*. The new proposal required the 65 state, local, and territorial health departments administering federally funded HIV cooperative agreements to convene community planning groups

(CPGs). The directive given to the CPGs was to develop plans on which the 1995 applications for continued funding would be based.

The *Supplemental Guidance*, implemented in 1994, delineated an approach that allowed for the development of more effective HIV-prevention efforts. According to this document, interventions were to be designed to increase the understanding of basic HIV-prevention information and principles. The emphasis of HIV prevention would be shifted from national education programs, such as the “America Responds to AIDS” campaign that had information that was often vague and written for an anonymous general public, to efforts in which there were diverse responses to the variety of cultural and social subcultures within the United States would be recognized. This new concept of prevention promotes holistic, culturally competent programs that are linguistically appropriate, economically feasible, and located in and delivered by members of the affected community.

A continuing challenge for HIV-prevention community planning is the need to recruit and retain more young, African American and Latino planning group members. Currently, 5 percent of members are under 24 years of age. Yet, it is estimated that half of all new HIV infections occur in youth under age 22. In 1998, both African Americans and Latinos were underrepresented in planning group membership compared with their representation in national AIDS epidemiology figures. As the AIDS epidemic evolves in local communities, HIV-prevention community planning will focus on quality needs assessment, adequate provision of technical assistance, and continued recruitment and retention of representative planning group members and health department staff [Centers for Disease Control and Prevention, 1998d].

In 1992, NCOA stated that “funds allocated by Congress and budgeted by the CDC for programs in communities of color have simply not been enough to support the intense and sustained national effort needed to ensure that effective prevention efforts reach these communities.” This is still true as we move into 2000. In 1999, the Congressional Black Caucus (CBC), with support and encouragement from community leaders, successfully lobbied for an additional \$156 million in the federal budget to address the AIDS epidemic in communities of color. This gesture by the CBC should serve as an example of how bold and vocal communities of color need to be about the AIDS epidemic.

There is no question that, given the epidemiologic data, showing that new infections are occurring largely unabated in communities of color, the need for targeted, culturally sensitive HIV-prevention programming still exists. The CDC along with private sector interest must continue to fund this activity at maximum levels. It is also critical that technical assistance and training be made available to community-based grantees. These individuals and groups are often the best suited to do the work but are also often unfamiliar with the processes and procedures for managing a federal grant. This type of technical resource is a critical component to fortifying HIV-prevention efforts.

Health Care

In 1998, more than 41 million Americans, 10 million more than a decade ago, were without any health care coverage at all [Kaiser Family Foundation, 1998]. The Bureau of Health Resources Development in its *Work Group on Health Care Access Issues for Hispanic Americans* report [1991] noted “A patient’s financial resources remain the most important factor in predicting the quality of health care received. Indeed, the correlation between socioeconomic status, race, and health has been widely researched, with the nearly unanimous conclusion that poverty is a marker for poor health and inadequate care. Most recently, Shapiro and colleagues reported that African Americans, Latinos, and people with low income, limited education, and no insurance had worse access to health care than did people who are not of those categories [Shapiro et al., 1998].

While it is important to consider other socioeconomic factors, it is clear that the exorbitant cost of HIV and AIDS treatment is a tremendous barrier to quality health care, particularly for the uninsured, underinsured, or Medicaid recipient, and, therefore, particularly for members of communities of color. In *The Challenge of HIV/AIDS in Communities of Color*, NCOA recognized “that access to care for people of color has been impeded both by a lack of sufficient health insurance coverage and by a dearth of appropriate health services.

“People of color historically have had difficulty in gaining access to and paying for primary care services. In many instances, limited income precludes the purchase of insurance. For example, individuals who are employed in low-paying or minimum wage jobs in the service industry often do not have any health insurance coverage, or at least

not adequate coverage. For those who are forced to rely on public programs, Medicaid eligibility criteria in some states are very restrictive. Persons living with HIV can attest to the difficulties they confront in the absence of insurance. Even those with insurance may exhaust the coverage and be left with limited government support and community assistance.”

Although the costs of inpatient care are staggering, estimates of total lifetime costs (for example, outpatient services, drug treatment, and out-of-pocket expenditures) for treatment of people with HIV or AIDS are considerably higher. One study estimated the all-inclusive lifetime cost of treating a person with HIV at \$119,000 (1993 dollars). This estimate breaks down to \$50,000 for care from time of HIV infection to the development of AIDS and \$69,000 for care from the development of AIDS until death [Hellinger, 1993]. A 1997 study evaluating cost and quality-of-life estimates found that the lifetime cost of HIV illness was upwards of \$195,000 [Holtgrave and Pinkerton, 1997]. In one study of low-income people with HIV, the majority of whom were African American and Latino, 49 percent reported having problems meeting the cost of care and 38 percent reported sometimes going without care because of the expense [Cunningham and Hays et al., 1995]. A recent study presented at the “XII World AIDS Conference” noted that African Americans and Latinos who are on Medicaid are highly likely to report difficulties with, dissatisfaction with, and discrimination by their health care providers [Rapkin et al., 1998].

Studies have confirmed a pattern of health care use by people of color with HIV that not only indicates an increased financial burden but shows a decreased survival time. Whites tend to use less expensive outpatient care at a significantly higher rate than people of color [Solomon et al., 1998; Fleishman et al., 1995; Mor et al., 1992]. In comparison, people of color have higher rates of more costly emergency room use and inpatient care [Fleishman et al., 1995; Fleishman et al., 1994; Mor et al., 1992]. These findings are largely attributable to differences in access to outpatient care and to the inconvenience that use of public clinics as opposed to private physicians brings. The result of these differences are potentially life-threatening delays in care for people of color. “The inconvenience associated with gaining access to the medical care clinic setting, with its frequent long waits, may be such a deterrent to care that minorities and [IDUs] delay seeking health care for elective problems until symptoms reach emergency proportions” [Mor et al., 1992].

General Barriers to Care

Simply eliminating financial barriers to care does not automatically bring universal access to or use of health care services. Fichtenbaum and Gyimah-Brempong demonstrated that the effect of having health insurance on individuals' use of health care services is different among different populations. They found that whites with Medicare and whites with Medicaid both made 2.3 more visits to physicians than whites with no insurance made. In contrast, African Americans on Medicare and those on Medicaid made only 1.0 and 1.4 more visits to physicians than African Americans with no insurance made. Thus, while insurance programs are meant to reduce the cost of visits to physicians so as to encourage people to seek health care when needed, this effect is less evident among African Americans than it is among whites [Fichtenbaum and Gyimah-Brempong, 1997].

Proximity to care is a considerable issue for individuals who are living with HIV and must be treated for a range of symptoms on a regular basis. A study with a low income and majority African American and Latino sample found that 55 percent of surveyed individuals traveled for longer than 30 minutes to their usual source of care, compared with between 9 and 12 percent of the general population in national surveys who traveled this far for care. In addition, 48 percent of the African Americans and Latinos in this sample had problems with clinic hours, compared with 23 percent of the general population in national surveys [Cunningham and Hays et al., 1995].

Individuals with HIV, particularly persons of color, who are able to access care may face additional barriers to the quality care they receive because of the attitudes of their primary care physicians. Several studies have documented the discomfort some health care providers feel in caring for HIV patients [Vermette and Godin, 1996; Yedidia, Berry and Barr, 1996; Yedidia, Barr, and Berry, 1992, 1993; Shapiro et al., 1992; Bredfeldt et al., 1991; Gerbert et al., 1991; Hayward and Shapiro, 1991; Feldman et al., 1990; McGrory, McDowell, and Muskin, 1990].

Louis Sullivan, former Secretary of Health and Human Services, noted that:

Our nation's minority communities have less access to care whether they are in urban areas or more rural areas, whether they are well educated or not, whether they are rich or poor. It means the barriers are not only economic, but social as well. Our poor citizens, and those in minority groups, even when they can afford it, often stay outside of the system. [Sullivan, 1997]

Dramatic disparities between the health of white and nonwhite peoples will continue to pervade our communities unless health and social service workers understand the myriad social forces that act behind the oversimplified differentiation of race. As a whole, minority communities are circumspect in their use of formal health care. This wariness is reinforced by incidents such as the Tuskegee experiment—a research project that for many people of color symbolizes the rampant disregard they believe the health establishment has toward them.

Since 1990, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act has made federal funds available to state and community organizations with the specific intent of providing a variety of services to people with HIV [Bureau of Health Resources Development, 1990]. “The CARE Act has served as an essential part of the safety net for people with AIDS” [AIDS Action Council, 1994]. In 1992, NCOA made the following recommendations regarding the Ryan White CARE Act.

Funds made available under the Ryan White CARE Act are the only resources targeted for addressing the crisis in HIV care brought on by the growing epidemic. The CARE Act provides critically needed relief to cities hardest hit by the HIV epidemic and to all states. Title I of the CARE Act distributes “emergency assistance” to metropolitan areas with more than 2,000 diagnosed AIDS cases. Each eligible area is required to establish an HIV planning council, whose task it is to set service priorities and to allocate health resources for health care and support services for the geographic area, across all affected populations and sub-populations. Title II of the CARE Act provides funds for states to respond to an array of primary care needs. Such state responses include the creation of HIV care networks in both urban and rural areas, drug reimbursement, COBRA premium payments, and the delivery of home care services. Each state must document that 15 percent of their funds are targeted to women and children with HIV/AIDS, the vast majority of whom are people of color. Title III of the CARE Act provides crucial early intervention, primary care, and mental health services through community migrant and homeless health centers, as well as sexually transmitted disease, family planning, and tuberculosis clinics.

NCOA reported that the CARE Act was not meeting expectations in part because of inadequate funding. This lack of funding was “particularly detrimental to communities of color, where resources are needed for financial relief of institutions providing care to under-served and indigent patients.” Further, the commission noted that “while comprehensive health reform is desperately needed in order to rescue a health care delivery system headed for collapse, full funding of the Ryan White CARE Act can help to fill the breach by creating cost-effective alternatives to hospitalization.”

When the original CARE Act expired on September 30, 1995, the President and Congress continued the Act in an amended form and with increased federal funding [Bureau of Health Resources Development, 1996a]. The growing federal commitment to the Ryan White CARE Act is apparent in the nearly fourfold increase in funding of Titles I and II between the years 1991 and 1996, and the threefold increase in funding since 1992 when *The Challenge of HIV/AIDS in Communities of Color* was published. At present, the President’s budget for FY 2000 appropriates <<\$XX>> billion toward Ryan White CARE Act programs through the HIV/AIDS Bureau of the Health Resources and Services Administration [Health Resources and Services Administration, 2000]. This elevated funding is in accord with that urged by NCOA in 1992.

Access to HIV Therapies and the AIDS Drug Assistance Program

Many studies repeatedly find people of color and people without private or other insurance are unlikely to receive early and appropriate treatment [Markson et al., 1999; Asch et al., 1998; Cook et al., 1998; Glick et al., 1998; Solomon et al., 1998; Stone, Hirschhorn, and Boswell, 1998]. Thus, findings by Palella and colleagues can be indirectly translated to an equation: lower survival for people of color and for poor, uninsured people if they are without insurance.

A recent study of 2,248 patients receiving HIV care found that only 65.6 percent of the patients reported receiving highly active antiretroviral therapy (HAART). As in previous studies, this study confirmed a difference in acceptance of HAART that was evident along the lines of ethnicity, gender, education level, and insurance. Patients who received HAART more often considered their provider’s advice an important influence on their decision to take medication. Patients who were not receiving HAART were more likely to believe antiretrovirals did not prolong or improve quality of life and that HIV could be fought without medication. From the data, investigators determined that not only must providers ensure underserved patients receive effective treatments but that efforts be

made to educate and counsel patients about treatment options and effects [Markson et al., 1999].

Inequities in drug therapy for individuals with HIV cannot be ignored. The appropriate treatment of all patients is a fundamental responsibility of the health care system. Efforts to address the differences in prescribing drugs are complementary to culturally appropriate educational efforts in affected communities. All people have a basic right to proper medical treatment, regardless of race, financial and insurance status, and degree of disease progression.

AIDS Drug Assistance Program

The AIDS Drug Assistance Program (ADAP) was created as part of Title II of the Ryan White CARE Act of 1990 to address the financial needs of people with HIV. Administered by the Division of HIV Services at the Health Resources and Services Administration, the program provides funding to the 50 states, the District of Columbia, and Puerto Rico for the provision of drugs for people with HIV who do not qualify for Medicaid and who either do not have private insurance or do not have insurance that covers the cost of HIV therapy. For FY 1998, the ADAP budget was expected to be \$510.2 million, with 76.6 percent federal funds and the rest through state contributions. The FY 1998 budget request represented a 38 percent increase over that of FY 1997 [Doyle et al., 1999]. The discovery of the increased effectiveness of drugs when taken in combination complicates the issue of access to therapy—the regimen's increased cost vastly changes the level of funding needed. Additionally, the improved health of people who live longer requires further services and drug assistance to maintain the health of more people for a longer periods of time [AIDS Drug Assistance Program Working Group, 1996]. The National ADAP Monitoring Project reports that ADAP expenditures are increasing faster than the growth in the client population because of the greater costs and use of combination therapy [Doyle et al., 1999].

Most ADAP programs already either have extensive waiting lists for drug assistance or, overwhelmed by the number of new applications, have cut off further applications for drug assistance. Twenty states have one or more current or projected restriction in their program, such as restricting enrollment, capping per capita expenditure, or limiting the ADAP formulary [Doyle et al., 1999]. Shayne and colleagues noted at the “XII World AIDS Conference” that “States that served higher proportions of minorities, but not women, are more likely to adopt rationing measures.” Race and ethnicity seem to be

significant factors in how states allot their ADAP budgets. Their investigators found marked differences in state ADAP programs.

ADAPs that reduced their drug formularies report larger numbers of Black clients. ADAPs with higher proportions of Hispanics were more likely to anticipate budgetary shortfall, and states with higher proportions of whites appear less inclined to introduce medical eligibility requirements for drugs. Areas with proportionally more whites generally served fewer clients. States with proportionally more females served proportionally fewer whites, more blacks, and more pediatric clients. These states also appear less inclined to limit access to PIs [protease inhibitors]. [Shayne et al., 1998]

Ryan White Reauthorization

The Ryan White CARE Act will soon be the subject of much scrutiny as the time approaches to reauthorize the legislation. During reauthorization, particular attention should be given to enhancing Title III of the legislation. This title allows for funds to flow directly to community venues used by people of color without requiring a pass-through by state or jurisdiction. History has shown that local “planning processes” are too often inequitable to communities of color. Additional attention should be given to changing the funding allocation between Titles I and II. While urban epicenters of the epidemic still exist, rural communities are struggling with an unprecedented number of HIV and AIDS cases. Finally, new drug therapies that can assist people in managing their illness must be fully funded under ADAP. It is unconscionable that drug therapies are the de facto domain of the rich in this country. Our leadership must not allow this.

The Need for Physician Education and Training

The AIDS epidemic also poses a challenge in terms of medical education. Many primary care physicians, particularly those trained before the onset of the epidemic, lack the skills and attitudes to implement the techniques of risk assessment and to provide the care required by a disease that has been in existence for less than two decades. The deficiency in knowledge about HIV and about risk assessment among many physicians is illustrated by the finding that physicians knowledgeable about HIV prevention tend to be young and have positive perceptions of homosexuals and IDUs [Gemson et al., 1991; Fredman et al., 1989]. Often, however, those physicians who do attempt HIV risk assessment and counseling are limited by their ability to discuss high-risk sexual behavior with patients [Curtis et al., 1995; Bowman et al., 1992; Carretta et al., 1990; Fredman et al., 1989].

NCOA made a number of recommendations concerning health care needs in communities of color. One of their recommendations targets physician education.

Physician training is a significant factor in the quality of care received by patients infected with HIV. Studies have shown that both physician and hospital experience with HIV and AIDS cases are correlated with increased patient survival [Kitahata et al., 1996; Bennett et al., 1992; Stone et al., 1992; Turner and Ball, 1992]. Though one likely explanation of this finding is selective referral—patients actively seeking caregivers with higher success rates—it is also plausible that the decrease in patient mortality is the result of a superior level of care that accompanies physician experience and training. Among patients enrolled in the New York Medicaid program between April 1987 and March 1990, there was “at least a 3-year lag before patients of primary care clinics received zidovudine [ZDV] therapy at the same rate as patients of AIDS specialists” [Markson, Cosler, Turner, 1994]. While this finding is specific to the state of New York and the prescription of ZDV, rather than newer antiretroviral treatments, it serves as an example of the need to educate primary care physicians in treatment innovations, as well as in risk assessment and prevention education approaches.

Housing Opportunities for People with AIDS Program (HOPWA)

Since the beginning of the AIDS epidemic, obtaining and maintaining appropriate, affordable housing has been one of the greatest challenges facing people living with HIV and their families. Without stable housing, people living with HIV cannot access care, prevent the early onset of illness, or maintain the most fundamental quality of life. While a great deal of attention has been paid to developing care services and treatments for HIV disease, much less attention has been paid to the fact that it is virtually impossible to link people to those care services and life-sustaining treatments if they do not have a stable place to live. A study by Arno and colleagues found that HIV-positive individuals who had no stable housing were far more likely to use emergency rooms than they were to use ambulatory care services [Arno et al., 1996]. Yet the barriers facing people living with HIV with regard to housing have been and continue to be staggering. Despite federal and state antidiscrimination laws, many people living with HIV face illegal discrimination in obtaining housing, or they face eviction when their illness is disclosed. Others lose their housing when, as a result of illness, lost wages, or medical expenses, they are unable to

pay their rent or mortgage. In addition, an increasing number of people living with HIV are already homeless when they become ill and find themselves shuffled between acute care hospitals, medically unsafe shelter facilities, and the streets, at an enormous cost to their health.

Even before the AIDS epidemic, people of color and single women with children formed a disproportionate portion of those populations that had low income and were likely to be discriminated against when finding and maintaining adequate, affordable housing. Thus as the epidemic continues to disproportionately affect people of color, especially women of color, the challenges with regard to housing grow even more complex. Without housing, it is virtually impossible to manage the complex requirements of combination drug therapy. Without adequate housing assistance, far too many individuals face the devastating dilemma of having to choose whether to pay for their medications or pay their rent or mortgage.

In 1992, NCOA's report on housing and the AIDS epidemic noted "The lack of affordable and appropriate housing is an acute crisis for people living with human immunodeficiency virus (HIV)...[H]ealth and medical aspects of the epidemic have overshadowed the frequently desperate need for safe shelter that provides not only protection and comfort but also a base in which and from which to receive services, care and support" [National Commission on AIDS, 1992b]. The commission cited studies showing that at any given time, one-third to one-half of all Americans with AIDS were either homeless or in imminent danger of losing their homes. Other studies cited found that at any given time, approximately 30 percent of people with HIV in acute care hospitals were there only because there was no other community-based residential alternative. The commission also reported that 15 percent of homeless people were HIV positive and that that number was growing rapidly [National Commission on AIDS, 1992b].

The first Congressional hearings on the housing needs of people with AIDS were held in 1990. Those hearings led to passage of the AIDS Housing Opportunities Act that same

year. That Act created the Housing Opportunities for People with AIDS (HOPWA) program. HOPWA is the only federal housing program specifically designed to address the housing needs of people living with HIV. Its purpose is to provide states and localities with the resources and incentives to devise long-term comprehensive strategies for meeting the housing needs of people with HIV and their families. Ninety percent of HOPWA funding is distributed by the Department of Housing and Urban Development directly to eligible metropolitan areas having at least 1,500 AIDS cases in a population in excess of 500,000 people and to states with 1,500 AIDS cases outside of any eligible metropolitan area [U.S. Code, 1990]. The remaining 10 percent is awarded on a competitive basis to projects of national significance or to nonformula jurisdictions for long-term planning. HOPWA is a flexible program—formula funds may be used to meet whatever a community's needs may be, from providing short-term transitional housing or rental assistance for low-income persons with HIV to building community residences or providing coordinated home care services. All planning, from selecting types of housing assistance to setting specific eligibility criteria, is done on the local level. Administrative costs are capped by law at 3 percent for formula grantees who administer the funds and 7 percent for the community-based project sponsors who actually provide the housing assistance [U.S. Code, 1990].

Although HOPWA was created in 1990, Congress did not fund the program until 1992 when it appropriated a mere \$50 million. Since that time, AIDS housing advocates have fought to keep the program alive and to increase federal funding. In 1998, HOPWA was funded at \$204 million. Of course, the number of states and metropolitan areas eligible to receive HOPWA formula grants has also increased. In 1992, only 17 jurisdictions qualified for formula grants; in 1998, 88 jurisdictions qualified.

It is now estimated that between 50 and 60 percent of all people with HIV will need assistance with housing at some point during the course of their illness [U.S. Department of Housing and Urban Development, 1998]. Past studies by the CDC found HIV infection rates of up to 21.4 percent in selected homeless populations [U.S. House of Representatives, 1998].

In 1998, HUD estimated that 130,000 persons living with AIDS and 75,000 persons living with HIV were in need of housing assistance. Yet HUD also estimated that 1998 funding for HOPWA was only sufficient to support the housing needs of about one-fifth of its population [U.S. Department of Housing and Urban Development, 1998].

In addition to the changing demographics of the AIDS epidemic, advances in the treatment of HIV present new challenges. Housing has become even more critical for people living with HIV; without it they cannot access the state-of-the-art combination drug therapies that have been proven to delay the progression to full-blown AIDS and to greatly improve the quality and duration of life. However, one of the results of the advancements in treatments is that more people with HIV are living longer, a situation that lowers the turnover in currently existing housing units and leads to an even greater demand for housing.

The decline in AIDS cases has created the perception among some policymakers that the epidemic is now manageable and that the need for public funding of AIDS housing programs has decreased. In fact, the faulty argument that “AIDS is decreasing so housing needs must be decreasing too” was the basis for a vote by the House of Representatives to eliminate a proposed increase in 1999 funding for the HOPWA program [U.S. House of Representatives, 1998]. The bottom line is clear: Unless Congress increases HOPWA funding, it will be impossible to meet existing needs, much less the needs of newly qualified and grandfathered jurisdictions.

HOPWA is the heart of the federal housing response to the AIDS epidemic. However, HOPWA is a comparatively small program in terms of funding and simply cannot address the entire housing problem facing people living with HIV and their families. Other important housing programs serving this population include the Stewart B. McKinney Homeless Assistance Grant program and the Section 811 program for people with disabilities. These programs are especially important to communities that do not receive HOPWA grants or where HOPWA funds are insufficient to meet the need.

Chronic underfunding and changes in attitudes toward the federal funding role in housing generally have combined to threaten the ability of any and all these housing programs to respond to the needs of people living with HIV.

HOPWA is not as well known or well funded as the Ryan White CARE Act. Housing issues in general have commanded far too little attention throughout the HIV epidemic. Too many people living with HIV—and most in need of housing—are disenfranchised, both in American society and within the context of the AIDS epidemic. Constant education and attention must be given to solving housing issues for people living with HIV and to advocacy on behalf of HOPWA and other housing programs. Otherwise, this country faces the specter of a growing division within the epidemic, one in which those with fewer resources and less access to housing experience a very different—and more deadly—version of HIV than those with more resources and greater access to housing and care.

Clinical Research Trials

The underrepresentation of minorities, particularly African Americans, in clinical research trials not only represents an injustice to communities already disproportionately affected by the epidemic but also presents a challenge to those seeking to generalize of trial results for all populations [Cunningham and Bozzette et al., 1995]. Minority participation in clinical trials is hampered by four factors:

- Minorities have poor access to health care in general. Even when access is not an issue, minorities have poor health-seeking behavior and often perceive an inhospitable health care system.
- Minorities perceive that they have experienced a history of medical abuse. The most prominent example of this is the Tuskegee experiment.
- Minorities have a history of distrust of the government that stems from the shared experience of slavery and the multitude of promises they believe the government has made and broken with them.

- There are too few researchers from minority populations making decisions on clinical trials at the upper levels of research. The failure to include people of color as principal investigators only fuels participants' suspicions of clinical trials.

The lack of minorities in AIDS clinical trials is also closely tied to problems of urban poverty. It is not only African Americans who are demonstrably less likely than whites to be enrolled in clinical trials. In a study on differences in clinical-trial enrollments, persons exposed to HIV through injection drug use and through heterosexual contact, persons with an average annual income of less than \$10,000 or with less than 12 years of education, and persons in public care or with no regular health care were all less likely to be included in clinical trials than were MSM, persons with annual incomes higher than \$10,000 or with more than 12 years of education, and persons with private care [Diaz et al., 1995].

A recent study of providers in a large public hospital with a diverse patient population and an on-site AIDS Clinical Trials Unit found that between 24 and 37 percent of the hospital's HIV care providers were reluctant to discuss clinical trials with patients whose primary language was Spanish, Haitian Creole, or other non-English language. Only 3 percent were reluctant to discuss trials with patients for whom English was their primary language [Stone, Mauch, Steger, 1998]. Although the providers reported no difference in their willingness to inform an African American versus a white patient about available clinical trials, 25 percent of the providers believed African American patients might be less interested in clinical trials because of suspicions about clinical research. The proportion of providers who felt the same about Latino or Haitian patients was 14 percent and 30 percent, respectively. The most cited reasons for believing these patients would not be very interested in clinical trials were that Latino and Haitian patients might be suspicious of clinical research or that they would have cultural beliefs about health that would preclude their participation [Stone, Mauch, Steger, 1998].

Although it is clear that avenues exist to make people aware of the availability of clinical trials, three things must be done concurrently by the National Institutes of Health (NIH) to produce equity in research trials. First, additional researchers from minority populations must be involved in the clinical-trial process, from the initial design stage through the implementation of the studies. Without, such measures, clinical trials will always be looked upon with suspicion by minorities. Second, resources and materials used to educate and recruit minorities to clinical trials must be circulated using methods

and venues accessed by people of color. For example, because many communities of color have an oral tradition of information sharing, the radio may be a better medium than the Internet for information dissemination. Third, people of color who are recruited to and who complete the lengthy informed consent process needed for participation in a clinical trial must be supported in their effort through the provision of relevant social services.

Young People of Color

Through December 1998, 64 percent of AIDS cases reported among individuals between the ages of 13 and 24 were diagnosed among young people of color [Centers for Disease Control and Prevention, 1999]. In the United States, it is estimated that one-half of all new HIV infections are among young people under the age of 25 and one-quarter are among young people under the age of 22 [National Cancer Institute, 1995; Rosenberg, 1995; Rosenberg et al., 1994]. This translates into two new HIV infections among young people every hour [Office of National AIDS Policy, 1996]. Although African Americans and Latinos make up the majority of young people of color with AIDS, Asian American, Pacific Islander, and Native American youths are strongly represented in certain geographic locations [Collins, C., 1997].

Young people's heightened risk of HIV infection can be attributed to a number of co-factors that define their life experience. Adolescence is a time when young people embark on life with a sense of freedom and experimentation. During this period of development, youths are in the process of separating emotionally from their parents and attempting to define who they are and what is important to them. Many teens grapple with peer pressure and self-esteem issues during this time. A number of adolescents use this period of their life to begin an exploration of their sexuality and to experiment with controlled substances such as alcohol. Far from being a care-free period, this period of development is characterized by a great deal of stress and turmoil for many young adults. Unfortunately, for too many teens, the family and community support systems that they desperately need during this time are either unable or unwilling to fully support them.

The search for love and recognition is a recurring theme in studies on youths and HIV. Discrimination by race, ethnicity, gender, sexual orientation, HIV status, or economic status strikes directly at the core of a young person's sense of personal value. In a guest

editorial for the *Journal of the Student National Medical Association*, Mario Cooper, founder of *Leading for Life*, appealed to minority medical students:

In broad terms, our challenge is not merely about AIDS. The question also centers on how we can instill in our children the self-respect and self-value that will enable them to protect themselves from HIV infection, drug addiction, dropping out of school, and teenage pregnancy. We must inspire our children through leadership, example, and spiritual development. Not one of us can afford to let those kids down. [Cooper, 1997]

The Office of National AIDS Policy also places a priority on this type of attention in its recommendations for addressing the HIV epidemic among youth. “Young people need to hear from parents and other adults that they are loved, valued, and have worth as individuals so they will internalize those feelings and believe they are worth protecting” [Office of National AIDS Policy, 1996]. By failing to love and care for our young people, we allow violence, substance use, and the HIV epidemic to devastate our younger generation.

Unfortunately, federal HIV prevention targeted at youths has often failed to address cultural differences and has ignored adolescent sexuality, especially gay sexuality among adolescents. Parental and public health advice often clash uncomfortably with images from popular culture when young people try to sort out the messages they receive. In the monograph *Dangerous Inhibitions: How America is Letting AIDS Become An Epidemic of the Young*, the author notes the confusing messages youths confront.

Our strange ensemble of youth-oriented media, advertising, and health promotion strategies adds up to a single dangerous mixed message: explore, risk, experiment, and be attractive—except when it actually comes to sex. Then our messages are muddled. Condoms, gay sex, and dynamics within relationships are often not explicitly discussed. Both antidrug and HIV prevention health messages using scare tactics and over-dramatization are summarily discarded by young viewers. Stern warnings to teens to avoid taking risks at all costs and “just say no” are speaking a language that is unlikely to succeed with adolescents in the 1990s. [Collins, C., 1997]

With growing rates of adolescent sexual activity, school and legislative prudishness about condom use and gay sexuality undermine necessary public health messages. It is also no

surprise that, faced with so many mixed messages, young people often develop skewed perceptions of their own risks for infection. Overconfidence is a large factor in young people's beliefs that they are not at risk of contracting HIV or STDs. For instance, many young people might mistakenly rationalize that because they are not gay, not having anal sex, and not promiscuous they are not at risk of HIV infection. Additionally, they may believe that someone with HIV would be visually identifiable, a characteristic they believe allows them to determine that they, and their partners, are safe [Collins, C., 1997; Michaels Opinion Research, 1997; Stevenson and Davis, 1994; Amaro and Gornemann, 1992]. Such excuses by youths do diminish their sense of risk and ultimately increases the likelihood that they will actually put themselves and their partners at greater risk.

Experimentation and peer pressure often lead to alcohol and drug use by young people. Since 1992, the number of 12- to 17-year-olds using illicit drugs such as marijuana and heroin has doubled [Substance Abuse and Mental Health Services Administration, 1998]. At least once in the month preceding the CDC's 1997 Youth Risk Behavior Survey, one-third of high school students surveyed nationwide had five or more drinks of alcohol [Centers for Disease Control and Prevention 1998f]. In 1997, on college campuses across the country, 52 percent of college students drank alcohol to get drunk. [Wechsler et al., 1998]. The staggering increase in substance use has strong implications for the spread of the HIV epidemic. Noninjection drug use and alcohol consumption impair an individual's abilities to reason and to communicate, which can lead to unplanned sexual intercourse, often without condoms and with relative strangers [Hingson and Strunin, 1992; National Institute on Alcohol Abuse and Alcoholism, 1992; Quackenbush, Benson, and Rinaldi, 1992].

The 1997 Youth Risk Behavior Survey reported that 1 in 4 Latino students and 1 in 5 African American students used alcohol or drugs prior to their last instance of sexual intercourse [Centers for Disease Control and Prevention, 1998f]. No figures were reported for APIs and Native Americans. Sex with concurrent substance use among young people under the age of 25, especially at peer-group social gatherings, translates into a high-risk situation.

Among the nation's growing population of homeless and runaway youths, the external pressures previously described are compounded by the struggle of day-to-day living. Street youths, a significant proportion of whom are gay and members of communities of color, are at high risk for contracting HIV [Office of National AIDS Policy, 1996]. They face violence, sexual abuse, and hunger daily. Homeless youths often trade sex for drugs, housing, and food. In such situations, determining one's risk of HIV infection is often not a priority [Sugerman et al., 1991]. Thus, two means of survival for these homeless youths, selling sex and injecting drugs, are paradoxically two of the most high-risk behaviors for HIV infection.

Sexually active adolescents do not use condoms consistently. The 1997 Youth Risk Behavior Survey reports that 64 percent of African American and 48.3 percent of Latino high school students used condoms during their last instance of sexual activity [Centers for Disease Control and Prevention, 1998f]. Most culturally directed outreach programs that aim to reduce sexual risk behaviors target African Americans and Latinos. While young people in these communities do initiate sexual activity earlier in their lives compared with young Native Americans and APIs, studies indicate that once youths from these latter communities begin to engage in sexual intercourse, they exhibit the same high-risk sexual behaviors that their African American and Latino peers do.

A survey of sexually active Native American youths found that only 40 percent of young men and 50 percent of young women regularly used contraceptive methods. Of those that used contraception, only 48 percent of young men and 24 percent of young women chose condoms as their preferred method [Blum et al., 1992]. A 1991 study of 153 heterosexual Asian American students at southern California universities found that while 77 percent reported having used condoms at some point, only 11 percent used condoms every time they engaged in sex. Additionally, 15 percent of the Asian American students had tried anal sex at least once [Cochran, Mays, and Leung, 1991]. While this study is regionally based and cannot represent national populations, it does show that Asian Americans are also in need of targeted sexual risk-reduction messages.

To exacerbate matters, condom use among young couples decreases dramatically after their first sexual encounter, particularly when the young woman of any given couple begins to take birth control pills. Oral contraceptives and long-term relationships can sometimes provide a false sense of security. One qualitative study of 54 sexual partners in four major cities examined the youths' sexual practices and beliefs. When the couples, who were predominantly African Americans and Latinos of middle-to-low socioeconomic level, were interviewed separately, interviewers found that in 25 percent of the couples, one partner believed the relationship was monogamous and "behaved accordingly, when in fact their partners privately admitted having sex outside of the relationship" [Michaels Opinion Research, 1997].

What is consistently noted in surveys of sexually active youths is the nature and timing of their discussions with their partner about sex, condoms, and partner history, if such discussions take place at all. Direct conversations about sex and condoms generally occur during or after first sexual intercourse [Michaels Opinion Research, 1997]. A 1992 survey of Native American adolescents attending schools in rural areas found that their reasons for not using contraceptives, including condoms, were that they did not think about protection or unexpected sex [Blum et al., 1992]. For most youths who have engaged in sex "not talking about the issue [of protected sex] was the path of least resistance" [Collins, C., 1997].

According to the Office of National AIDS Policy, "Millions of young people who have engaged in high-risk behaviors do not know their HIV status." For young people, particularly adolescents who have not left home for college or who are on the street, several factors including homelessness and a lack of health insurance, affect the likelihood that they will seek HIV testing.

First, many adolescents don't know how to arrange for HIV testing and where to go for such services. Second, adolescents do not have the money or means of transportation necessary to access some forms of counseling and testing. Third, school hours often coincide with the hours of counseling and testing facilities. Finally, parental consent requirements for counseling and voluntary testing also may

pose a barrier for many young people—especially those who know or feel they cannot communicate openly with their parents about this subject. [Office of National AIDS Policy, 1996]

Another significant obstacle for youths considering HIV testing is mandatory HIV names reporting that is already instituted in a few states. The recent legislative proposal by the federal government to require nationwide HIV names reporting will further curb people's willingness to seek HIV testing [Lambda Legal Defense and Education Fund, Inc., 1999].

On top of all these external barriers, young people also have a complex array of internal fears and apprehensions about HIV testing that lead to their delay in or complete avoidance of HIV testing. Young people are afraid of what positive results could mean for them, their futures, and their relationships with their family, friends, and partners. Fear of being tested for HIV stems from not knowing how to cope with a positive result, the difficulty of informing their partner, concern for privacy and confidentiality, and cost of testing. The act of seeking testing may also lead to stigmatization as young people may be quick to label someone as being gay or a drug user for having sought HIV testing. While it is not known exactly what proportion of HIV-positive young people are unaware of their serostatus, one report published in 1996 found that less than one-half of the adolescents tested at publicly funded HIV test sites returned for their results [AIDS Policy Center for Children, Youth, and Families, 1996].

Women

People are perhaps most vulnerable to HIV infection when they do not perceive their own risks. This vulnerability is particularly true of women who perceive themselves to be in a monogamous sexual relationship with a man. Many African American and Latina women may be at heightened risk for HIV infection owing to the sexual or drug-using behaviors of their regular sex partner. African American and Latino men who have sex with men outside of a primary relationship that is heterosexual are often unlikely to identify themselves as gay or bisexual. In fact, both African American and Latino men may be more willing to feign status as a drug user than admit to having engaged in sex with another man [Brewer, 1996; Lewis, 1996]. Homophobia in the African American and

Latino communities may be fueled by fear of STD and HIV infection, moral beliefs on sexuality, poor levels of AIDS knowledge, and cultural stigma. Homophobia may keep women from recognizing or acknowledging the risks their male sexual partners. In addition to their risks from partners who have sex with men, women who turn a blind eye to the drug-using behaviors of their male partners are at substantial risk of secondary HIV infection, even if the women are non-IDUs.

In one study, 40 percent of women with a regular partner and 68 percent of women with several partners believed their partners had had sex with someone else in the past year [Sikkema et al., 1996]. These researchers suggest that a woman's secondary risk of infection may be greater than if she were to directly engage in sexual relations with multiple partners. Although extrarelationship heterosexual activity may be accepted behavior among some men and women, social concerns about stigmatization and discrimination may prevent men who use drugs or who engage in male-to-male sex from disclosing the truth to their primary partner.

The greatest risk for HIV infection posed to non-IDU African American women appears to stem from having a primary male sex partner who has a history of multiple sex partners, injection drug use, or incarceration—three significant HIV risk factors [Mays and Cochran, 1998; Fullilove et al., 1990]. Some Latino men also have multiple sex partners, both male and female, concurrently. Because some Latinos differentiate sex into the “male” (insertive) and “female” (passive) roles, Latino men who take the male role in male-to-male sex may not identify themselves as gay or even bisexual. Moreover, for many Latinas, sexual intercourse is not meant to be a pleasurable act, and they are usually not expected to “[exhibit] knowledge about, and interest in, sexual behavior,” which precludes their initiation of discussions on condom use [Raffaelli and Suarez-Al-Adam, 1998].

Consistency of condom use also differs when the sexual activity is between primary or secondary partners. Of men surveyed at STD clinics, 90 percent of Latino men indicated

intent-to-use a condom with secondary or casual partners but only 54 percent of the men indicated intent-to-use a condom with their primary partners [San Doval et al., 1995].

The lack of female-controlled barrier methods and an imbalance of power dynamics in many male-female relationships are key concerns. Although female condoms exist, they are three times more expensive than male condoms and have not become a social norm in this country. This reality means women must request and/or negotiate the use of condoms with their male partners. Many women are hesitant to broach the topic of condom use because of fear that their partner will react negatively to their proposal, accuse them of infidelity or failure to trust their mate, and perhaps threaten them with bodily harm.

The economic status of many women also affects their willingness to insist on condom use during sexual relations. Women of meager financial means who must rely on men for partial or complete financial support have a weakened negotiating stance to demand safe sex: They must weigh the risk of disease against the risk of abject poverty for themselves and any children for whom they may be responsible.

The social desire of a woman to be “chosen” and “have a man” also affects her willingness to insist on condom use during sexual relations. Young women are reared to associate “having a man” with being desirable. Their self-worth is threatened if they don’t have suitors or a boyfriend, they feel that they are failing at being a woman. With this as the social norm in many communities, women are more likely to overlook contentious issues such as condom use to ensure that their relationships and status stay intact.

Finally, an often overlooked fact, is that women are sexual beings. In many communities, the “women as sexual beings” paradigm has not been embraced by elders who might discuss sexual risks with young women in an open and honest fashion. Consequently, women’s understanding of their risks and their options for HIV and STD prevention remains unknown to them.

Rural Communities

From the beginning of the HIV epidemic, both public policymakers and the public at large have tended to center their focus on the disease as it affects large communities of infected persons in New York and California. This view of the epidemic as primarily bicoastal, never touching “middle” America or the South, has unfairly skewed the perception of the problem away from rural communities. Even among rural health practitioners, it is common to find denial of HIV as a local problem [Voelker, 1998; Berry et al., 1996; Frasier and Gabel, 1996; Gold et al., 1994; Wasser, Gwinn, and Fleming, 1993].

Despite the urban focus on the disease, the CDC reports that the southern region, compared to other regions of the United States, accounted for the largest proportion of total AIDS cases through 1997 and accounted for 54 percent of all rural-based AIDS cases in the United States [Centers for Disease Control and Prevention, 1998e]. Reports by the U.S. Bureau of the Census indicate that 55 percent of the country’s African American population lives in the South compared to only 33 percent of the country’s white population [U.S. Bureau of the Census, 1997]. Each year between 1991 and 1996, the South led other regions of the nation in estimated deaths of persons with AIDS [Centers for Disease Control and Prevention, 1998e; Neal et al., 1996; Schable, Diaz, and Ward, 1996]. Coincidentally, an analysis of state surveillance data shows that a significant proportion of both persons of color, and those known to be living with HIV or AIDS, live in communities with populations under 100,000 [Lam and Liu, 1994; Rumley et al., 1991; St. Louis et al., 1991].

While rural communities suffer all the financial limitations, homophobia, substance use [Leukefeld and Godlaski, 1997], teenage pregnancy, and STD issues that their urban counterparts do, there are differences in the spread and care of persons with HIV in these communities. There are discrepancies between rural and urban regions in the health care services they provide and the AIDS awareness found among their health practitioners. A recent study sponsored by the Health Resources and Services Administration found that people living in rural communities have less access to HIV education. Additionally,

people living in rural communities may not perceive themselves to be at risk for HIV infection. This attitude is also found among rural physicians; they may not consider their patients to be at risk [Voelker, 1998]. For minority communities, these issues are particularly difficult and have led, in many cases, to a continued disparity between the level of care received by at-risk and HIV-infected persons in rural versus urban areas.

Many residents of small towns are attracted to their communities because of the opportunity for a greater familiarity with neighbors and a sense of personal closeness. This familiarity, however, creates significant problems of confidentiality and can lead to community stigmatization for individuals known to be or suspected of being HIV-positive [Frasier and Gabel, 1996; Gold et al., 1994]. Individuals with HIV and their families may go to great lengths to hide the fact of HIV infection from their community. They may drive to a city for treatment, hide in a car driven by another person when seeking care, or explain an individual's illness as cancer [Frasier and Gabel, 1996].

Although issues of confidentiality are important in both urban and rural settings, the relative anonymity offered by of a large metropolitan community is significantly different from the atmosphere of a rural community. Discrimination with regard to housing and employment are magnified in rural communities where jobs, shelter, financial security, and transportation are already limited [Berry et al., 1996; Rumley et al., 1991]. When services are offered in rural areas, they are "difficult for infected individuals to obtain without disclosing their serostatus" [Berry et al., 1996].

The rural community presents contradictions for many individuals diagnosed with HIV. The feeling of closeness and the network of familial support provide a strong contrast to the more morally conservative attitudes and beliefs that often prevail in small communities. This contradiction manifests itself in cross patterns of migration that have been noted among individuals with HIV. While many HIV-infected persons from small towns travel to the nearby city to seek better care or to avoid stigmatization within their local communities, individuals who live in urban centers and who are infected with HIV often migrate to rural homes and to their families for social support. [Berry et al., 1996;

Frasier and Gabel, 1996; Rumley et al., 1991]. One study of such migration in North Carolina found it was contributing to the doubling of HIV cases in rural regions, thereby increasing the patient burden on rural care networks and, consequently, serving to slow HIV case rates in urban areas [Rumley et al., 1991]. The movement of individuals with HIV, whether in terms of migration or simply travel from medical facility to medical facility, can be attributed to both the appeal and the conservatism of small communities.

Incarcerated Populations

The HIV epidemic in the United States is matched by a growing rate of incarceration. Between 1985 and 1995, the correctional population in this country increased by 78.5 percent. *Correctional Populations in the United States, 1995*, reported that by the middle of 1995, approximately 65 percent of state inmates and 56 percent of federal inmates were people of color [Bureau of Justice Statistics, 1997]. The exploding population of incarcerated individuals along with the parallel spread of HIV and other infectious diseases through the populations in the country's correctional system poses an even greater public health challenge than that already presented by daunting infection rates in the general U.S. population.

The frequent turnover of inmates in jails can make diagnoses and full provision of health care services extremely difficult. However, continuity of care and services not only ensures health maintenance for a discharged person but also decreases the likelihood of recidivism [Flanigan et al., 1998]. In order to stem the HIV epidemic among people moving through different correctional facilities, released inmates must not only have continuity of care and counseling but must be able to apply the risk-reduction skills they learned while in prison to their new "free world" circumstances [Inciardi, 1996; St. Lawrence et al., 1997].

The spread of infectious diseases through correctional facilities is a public health concern that affects not only inmates and facility staff members but also the families and communities to which these men and women return following discharge. On any given day in the United States, more than 6 million individuals are under correctional

supervision (on probation, in jail, in prison, or on parole) [Hammett, Gaiter, and Crawford, 1998]. In 1996, more 10 million people passed through the federal and state jail and prison system [Skolnick, 1998]. Because the majority of incarcerated people eventually return to their communities, correctional facilities provide an opportunity to treat and educate countless individuals who are often otherwise unreachable by public health educators and social workers. Too few facilities have taken the full opportunity for providing adequate health services and prevention education to those they house.

In a recent survey of all state and federal correctional facilities and 41 of the largest city and county jail systems, 96 percent reported at least some collaboration with a public health department. Of the facilities and systems surveyed, only 10 percent of the state and federal prisons and 5 percent of the city and county jails provided comprehensive HIV-prevention programs to their inmates [Hammett, Miles et al., 1998]. The result of this “missed public health opportunity” is an astonishingly high rate of HIV infection and AIDS-related morbidity and mortality in correctional facilities [Hammett, Widom, Kerr, 1996].

Conditions in Correctional Facilities

Not only is the rate of confirmed AIDS in prisons more than 6 times higher than the rate among the U.S. population [Maruschak, 1997] but several reports have documented a lack of sufficient HIV treatment services, counseling services, and prevention education, as well as poor discharge planning for continuity of care and counseling for inmates with HIV [Skolnick, 1998; St. Lawrence et al., 1997; Gaiter and Dell, 1996; Hammett, Widom, and Kerr, 1996; Inciardi, 1996; Canterbury et al., 1995].

The combination of risky behaviors within correctional facilities and poor health care for inmates with HIV yields a population of people of color who are at high risk of death from AIDS-related causes. The Bureau of Justice Statistics reports that between 1991 and 1995 more than one-third of the deaths in state prisons were attributable to AIDS-related causes. From 1991 to 1995, AIDS-related deaths in state prisons were second only to

deaths from “illness and natural causes” [Maruschak, 1998]. These figures point to the unavoidable crisis of HIV that has been allowed to build within correctional facilities.

Without more aggressive efforts by administrations in correctional facilities to work in collaboration with their health departments, HIV infection rates and AIDS-related mortality will continue to rise in prisons and jails. The result of the current lack of HIV prevention and care systems for inmates and those released presents a distinct public health threat to the inmates and to the communities to which they return.

The AIDS Epidemic: Demographics and Epidemiology According to Census Group Categories

The four communities of color have been adversely affected by HIV and AIDS for reasons ranging from institutionalized racism to cultural beliefs to lack of information. As the epidemic continues to grow, we confronted by the fact that neither the federal government nor community leaders have been successful in adequately addressing the barriers to effective care and education.

In an attempt to analyze and update the national response to the AIDS crisis, we have used the reporting framework offered by the 1992 National Commission on AIDS. As suggested in their report of that year, there are certain areas of concern: 1) Community Description, which describes the ethnic composition according to census categories; 2) Knowledge, Attitudes, Beliefs, and Behavior, which documents accounts of the cultural mores and beliefs about HIV and AIDS that affect a given population; 3) Demographics, which presents general statistics of the populations; and 4) Epidemiology, which presents the raw statistics of the epidemic and uses that data to conceptualize the severity of the epidemic.

The African American Community

Community Description

According to the 1992 NCOA report, "The African American community is the largest community of color in the United States, constituting 12 percent of the U.S. population and consisting of many different groups with different cultural backgrounds, religious beliefs and affiliations, and political views. It contains not only those whose ancestors were brought here as slaves in the early 17th century but also recent immigrants from areas as diverse as the Caribbean islands, Europe, and Africa. African Americans live all parts of the country and are found in every socioeconomic stratum. As many as half of all African Americans live in inner cities, in areas with pervasive poverty, poor schools, and inadequate social services, housing, and job

opportunities...the African American community is by far the most disproportionately represented with respect to HIV/AIDS.”

While this assessment is correct, it overlooks the deep sense of unity that exists in African American communities. During a recent Florida leadership meeting hosted by the Florida State HIV/AIDS Bureau, Mario Cooper, founder of *Leading for Life*, explained “We are a very homogeneous population, very conservative, positive thinking, family and community driven.”

Knowledge, Attitudes, Beliefs, and Behavior

In the African American community, both internal and external prejudices have affected beliefs and attitudes concerning AIDS. Within African American communities, prejudice (such as that against IDUs or gay men and lesbian women) has led to weak community support of its members living with HIV and to a great deal of silence on the issue. For instance, denial of bisexuality among some married African American men has been a factor in the HIV-infection rate among married African American women. In addition, hesitancy by African American communities to support needle exchange programs was a primary reason why it took the CBC more than a decade to formally recognize and act against the AIDS epidemic in the African American community. In addition to internal prejudice, African Americans face external prejudice that blames them for the AIDS epidemic. Some African Americans also believe AIDS as well as HIV prevention are efforts aimed at their genocide.

Over the past few years, African American communities have slowly begun to address the crisis wrought by the epidemic. As the impact of the epidemic is increasingly felt, African American religious leaders are altering their opinions and practices to break the silence and address the epidemic [Washington, 1996]. Such changes in attitude are reflected in the growth of faith-based AIDS organizations, such as The Balm In Gilead, a nonprofit organization that works to mobilize the black church to address the AIDS epidemic [Leading for Life, 1996]. On other issues, denial is decreasing and attitudes are becoming more tolerant. One study, for example, found an increase in tolerance of needle exchange programs, perpetually a sensitive issue among African Americans [Thomas and Quinn, 1993]. The recent Kaiser Family Foundation’s National Survey

of African Americans on HIV/AIDS found that 59 percent of those surveyed favored needle exchange programs [Kaiser Family Foundation, 1998b].

Among African American youth, a high percentage of adolescents engage in sex. The 1997 Youth Risk Behavior Survey of students indicates that 80.3 percent of young African American men and 65.6 percent of young African American women have had sex. In addition, African American students (38.5 percent) were more than twice as likely as white or Latino students were (11.6 and 15.5 percent, respectively) to have had four or more sex partners. With this data, however, it is important to note that 64 percent of sexually active African American students reported using condoms during their last sexual intercourse compared with 55.8 percent of white students [Centers for Disease Control and Prevention, 1998f].

Areas of misinformation regarding AIDS persist even though 72.7 percent of African American students surveyed in 1997 indicated that they had talked with an adult or family member about AIDS [Centers for Disease Control and Prevention, 1998f]. Of African American adults surveyed by the Kaiser Family Foundation, 27 percent wanted more information on the proper way to use a condom, 40 percent wanted to know what to discuss with a partner, and 46 percent wanted information on HIV testing. These numbers are significantly greater than the rest of the foundation's national survey of all Americans (13, 22, and 32 percent for the respective topics). Considering the results of the foundation's survey, in which 62 percent of parents reported the need for more information on what to discuss with children about AIDS prevention, it would seem important to ask whether adults are even able to impart accurate information to their children [Kaiser Family Foundation, 1998b].

The relationship of the African American communities to the larger society affects the communities' responses to the epidemic. Robert Fullilove, Associate Dean of the Columbia University School of Public Health, suggests that a "better model for examining what's going on with HIV in communities of color is not related to race . . . but to social realities that are the legacies of slavery and segregation" [Washington, 1996]. For instance, the added weight of discrimination and stigmatization is a great impediment to the African American communities' positive response to AIDS [Smith, 1991]. Fullilove states that the risk of HIV infection stems not

only from the dynamics of impoverished communities but also from a history of distrust of white society. Alvin Poussaint, professor of psychiatry at Harvard Medical School concurs adding that this distrust is based upon a reality in which many African Americans have suffered, and continue to suffer, as a result of practices within the mainstream medical establishment [Washington, 1996].

In 1989, Harlon Dalton, an African American member of the NCOA, explained in his article “AIDS in Blackface” why he believed African American communities had been slow to confront the epidemic.

What. . . accounts for the black community’s reluctance to grapple with AIDS? I have isolated five overlapping factors that I think explain a great deal. The first is that many African-Americans are reluctant to acknowledge our association with AIDS so long as the larger society seems bent on blaming us as a race for its origin and initial spread. Second, the deep-seated suspicion and mistrust many of us feel whenever whites express a sudden interest in our well-being hampers our progress in dealing with AIDS. Third, the pathology of our own homophobia hobbles us. Fourth, the uniquely problematic relationship we as a community have to the phenomenon of drug abuse complicates our dealings with AIDS. And, fifth, many in the black community have difficulty transcending the deep resentment we feel at being dictated to once again. [Dalton, 1989]

Rather than confronting the epidemic, many African Americans have avoided the issues out of distrust of mainstream society and denial that a problem actually does exist. For example, Poussaint points out that African Americans who subscribe to conspiracy theories that AIDS was created by whites as a tool for black genocide may do so as a way of avoiding responsibility for their inaction. Janet Mitchell, director of obstetrics and fetal medicine at Interfaith Medical Center in Brooklyn, states that another root of denial is the perception of AIDS as a disease of white homosexual men. She is careful to note, however, that not all responses interpreted as denial are in fact denial. “It’s just that, in our culture, you don’t hang dirty laundry in newspapers....Among ourselves, where there is trust, we acknowledge AIDS” [Washington, 1996].

Demographics

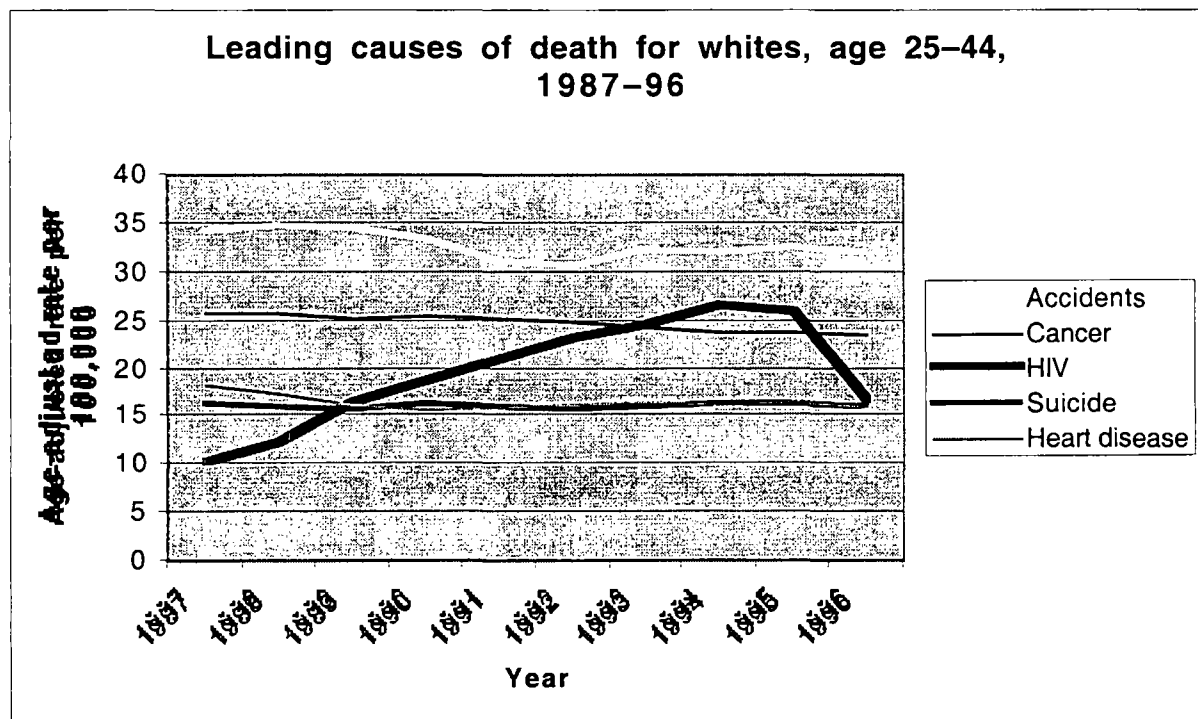
Self-identified African Americans (not of Hispanic origin) in the United States numbered just over 32.6 million as of July 1, 1998, making up 12.1 percent of the nation's total population. In 1998, the median age for African Americans, 30 years, was 8 years younger than that of the white population [U.S. Bureau of the Census, 1998].

The difference in socioeconomic status between the white population and the African American population is pronounced. Although the total number of whites living below poverty level was greater than that for any other racial or ethnic group, the percentage of African Americans living in poverty (26.5 percent) was three times that of whites (8.6 percent) [Dalaker and Naifeh, 1998]. This socioeconomic difference was also reflected in the proportion of individuals with health insurance. In 1997, 21.7 percent of African Americans, compared with 15 percent of whites, were not covered by health insurance [Bennefield, 1998].

In terms of family structure, African American households differ markedly from those of the white population. In 1997, female heads of household maintained 46 percent of all families in African American communities compared with only 11 percent of white families. In this same year, among African American families maintained by a single woman, the percentage below the poverty line was 42.8 [Dalaker and Naifeh, 1998].

In 1996, the age-adjusted mortality rate for the general population in the United States reached a record low. While African Americans had been disproportionately represented in rising mortality rates earlier in the 1990s [Gardner and Hudson, 1996], they showed a greater decline in mortality from 1996 to 1997 than most other racial and ethnic groups. In this same period, the death rate for African American men dropped 7 percent compared with 3 percent drops for both white and Asian men. The death rate for African American females dropped 4 percent compared with a 1-percent drop for white females. However, despite this positive trend, in 1997 African Americans continued to have an overall age-adjusted mortality rate per 100,000 (696.3) that was 1.5 times the rate for whites (456.6) [Ventura et al., 1998].

Since 1980, the 10 leading causes of death among African Americans have drastically changed. In 1980, HIV was not a recognized factor in deaths. In 1996, HIV-related mortality was the fourth leading cause of death for all African Americans. That same year, HIV was the leading cause of death for African Americans between the ages of 25 and 44, surpassing homicide, heart disease, accidents, and cancer [Peters, Kochanek, Murphy, 1998]. The following graphs display



the leading causes of death by year for African Americans and for whites.

Source: National Center for Health Statistics

Epidemiology

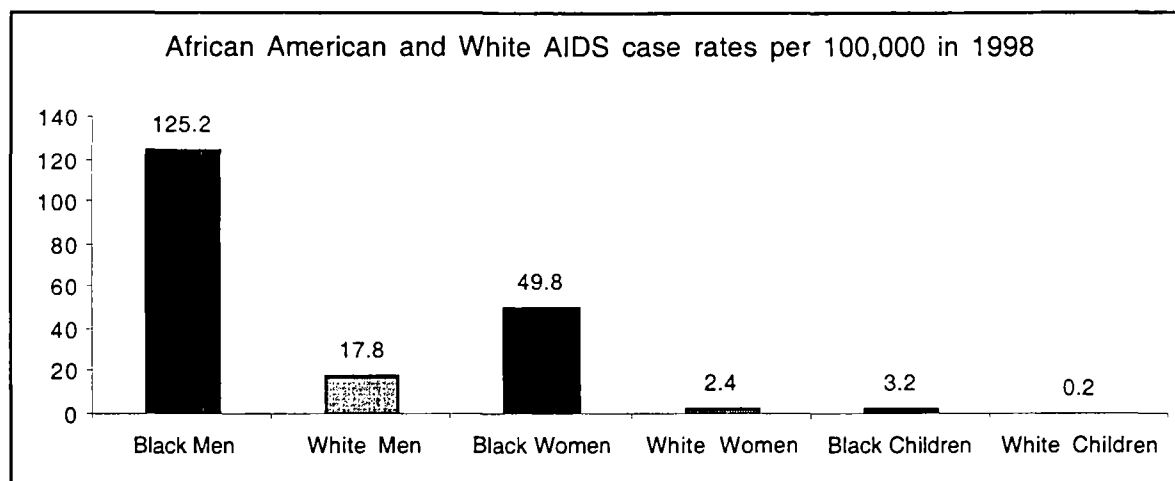
Annual and Cumulative AIDS Incidence

In the United States, there is an overwhelmingly disproportionate HIV infection rate among the African American population as compared with all other populations. It is estimated that 240,000–325,000 African Americans are infected with HIV. This estimate corresponds to approximately 1 in 50 African American men and 1 in 160 African American women infected with HIV [Centers for Disease Control, 1998a]. Although representing only 12.1 percent of the

U.S. population, African Americans accounted for a disproportionate 36.5 percent (251,408) of the 688,200 cumulative AIDS cases through December 1998. In 1998, the reported annual adult/adolescent AIDS case rate of 84.7 per 100,000 African Americans was more than 8 times that of whites and more than twice that of Latinos. In 1998 alone, African Americans represented 45.1 percent (compared to 33.4 percent for whites) of all AIDS cases reported in the United States [Centers for Disease Control and Prevention, 1999].

Although current HIV surveillance only includes reports from 32 states with integrated reporting systems (3 of these states only have confidential HIV reporting for pediatric cases or for children under age 6), a recent CDC review of 25 states with consistent HIV surveillance from January 1994 through June 1997, found that African Americans represented 45 percent of all AIDS cases reported in this period but accounted for 57 percent of all HIV diagnoses reported. Among young people between the ages 13 and 24, the percentage is even more disproportionate, with African American youth representing 63 percent of the HIV diagnoses in that age group [Centers for Disease Control and Prevention, 1998a].

Of the 251,408 cumulative cases of AIDS among African Americans reported through December 1998, 73.4 percent were among adult/adolescent males, 24.6 percent among adult/adolescent females, and the remaining 2 percent among children under age 13 (pediatric cases). The annual AIDS incidence rate for African Americans per 100,000 population in 1998 was 125.2 for men, 49.8 for women, and 3.2 for pediatric cases. Of the 43,267 AIDS cases reported for African Americans in 1998 alone, 67.8 percent were among men, 31.1 percent were among women, and 1.1 percent were among children under age 13 [Centers for Disease Control and Prevention, 1999].



Source: Centers for Disease Control and Prevention, 1999

African American Men

African American men accounted for 32.4 percent of all cumulative adult/adolescent male AIDS cases reported through December 1998 and 40 percent (14,740) of adult/adolescent male cases (36,886) in 1998 alone. The most common HIV exposure category for African American men was sex with another man at 38 percent of cumulative AIDS cases. Injection drug use was almost as common a cause, accounting for 35 percent of cumulative AIDS cases. Men who reported both types of exposure accounted for 8 percent of the cases [Centers for Disease Control and Prevention, 1999].

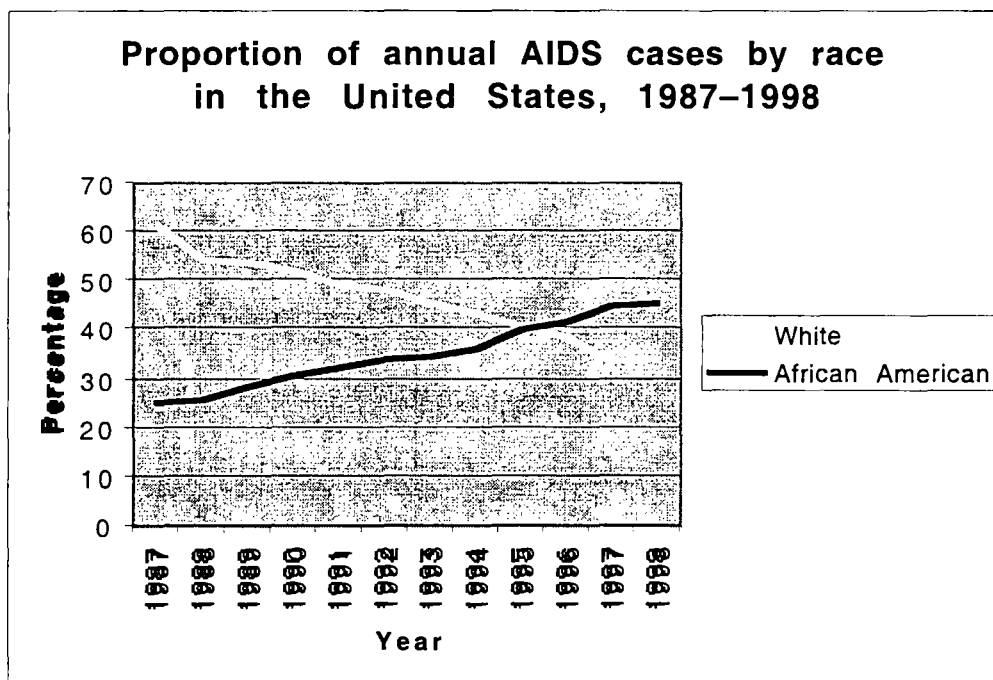
African American Women

One stark statistic in the epidemiology of AIDS is that African American females, while making up only 12.5 percent of all females in the United States [U.S. Bureau of the Census, 1998], represented 56.6 percent of cumulative AIDS cases among all adult/adolescent women reported through December 1998. They also represented 61.6 percent (6,775) of all new adult/adolescent female cases (10,998) reported in 1998. Forty-four percent of the AIDS cases in African American women were attributed to injection drug use. Heterosexual contact with an IDU accounted for another 15 percent [Centers for Disease Control and Prevention, 1999].

African American Children

African American children, in similar disproportion to the total pediatric population, represented 58.3 percent of the 8,461 cumulative pediatric AIDS cases (under age 13) reported through December 1998 and an even more disproportionate 62 percent of the cases reported in 1998 alone. Ninety-five percent of the 4,935 cumulative AIDS cases among African American children were attributable to perinatal transmission from mothers with HIV. Of the remaining cases of AIDS among African American children, 2 percent were caused by receipt of HIV-contaminated blood or tissue and another 2 percent were the result of undetermined exposures [Centers for Disease Control and Prevention, 1999].

Projections into the future from current statistical trends magnify the difference in the numbers of white and African American AIDS cases. While the annual AIDS rate per 100,000 has fallen for whites, the annual rate of AIDS diagnosis for African Americans has not improved. Although the proportion of African American and whites with AIDS appears to have stabilized, African Americans are still overrepresented in the annual number of AIDS cases.



Source: Centers for Disease Control and Prevention

AIDS Mortality

Rates of death from AIDS further demonstrate the extraordinarily disproportionate impact of the epidemic in African American communities. In 1996, the age-adjusted death rate from HIV infection per 100,000 population was 6 times higher for African Americans (43.3) than for whites (7.3). The age-adjusted HIV mortality rate in that same year for African Americans was 67.4 for men and 21.7 for women compared with 11.7 for white men and 1.8 for white women [Peters, Kochanek, Murphy, 1998]. The cumulative number of deaths for African Americans with AIDS as of December 1997 was 108,874 males and 32,733 females. Together these numbers represent 34.5 percent of cumulative AIDS deaths for all racial/ethnic groups. In 1997 alone, 9,526 African Americans, more than any other racial or ethnic group, died from AIDS-related causes [Centers for Disease Control and Prevention, 1999].

For African Americans between the ages of 25 and 44 in 1996, the HIV mortality rate per 100,000 (93.8) was more than twice the mortality rate from homicide and legal intervention, the second leading category of deaths for this cohort (43.4). The HIV mortality rate for African American men between the ages 25 and 44 (145.1) is more than 3 times higher than the leading cause of death (accidents) for white men between the ages 25 and 44 (45.9) [Peters, Kochanek, Murphy, 1998].

African American AIDS Cases reported in 1998, and Cumulative Totals through December 1998, United States

	<u>1998</u>		<u>Cumulative Total</u>	
	#	%	#	%
Adult/Adolescent Male				
Exposure Category				
Men who have sex with men (MSM)	4,553	(31)	69,741	(38)
Injection drug use	4,041	(27)	64,513	(35)
MSM and inject drugs	695	(5)	13,910	(8)
Hemophilia/coagulation disorder	20	(0)	528	(0)
Heterosexual contact:	1,491	(10)	13,162	(7)
<i>Sex with injection drug user (IDU)</i>	367		4,672	
<i>Sex with person with hemophilia</i>	—		11	
<i>Sex with transfusion recipient with HIV infection</i>	8		133	
<i>Sex with HIV-infected person, risk not specified</i>	1,116		8,346	
Receipt of blood transfusion, blood components, or tissue	57	(0)	1,006	(1)
Risk not reported or identified	3,883	(26)	21,739	(12)
Total	14,740	(100)	184,599	(100)
Annual rate per 100,000 population		125.2		
Adult/Adolescent Female				
Exposure Category				
Injection drug use	1,876	(28)	27,114	(44)
Hemophilia/coagulation disorder	11	(0)	98	(0)
Heterosexual contact:	2,419	(36)	22,800	(37)
<i>Sex with IDU</i>	675		9,200	
<i>Sex with bisexual male</i>	92		1,215	
<i>Sex with person with hemophilia</i>	4		69	
<i>Sex with transfusion recipient with HIV infection</i>	12		157	
<i>Sex with HIV-infected person, risk not specified</i>	1,636		12,159	
Receipt of blood transfusion, blood components, or tissue	71	(1)	1,183	(2)
Risk not reported or identified	2,398	(35)	10,679	(17)
Total	6,775	(100)	61,874	(100)
Annual rate per 100,000 population		49.8		
Pediatric				
Exposure Category				
Hemophilia/coagulation disorder	—	(—)	35	(1)
Mother with/ at risk for HIV infection:	209	(88)	4,702	(95)
<i>Injection drug use</i>	47		1,825	
<i>Sex with IDU</i>	23		690	
<i>Sex with bisexual male</i>	3		60	
<i>Sex with person with hemophilia</i>	—		5	
<i>Sex with transfusion recipient with HIV infection</i>	—		8	
<i>Sex with HIV-infected person, risk not specified</i>	58		743	
<i>Receipt of blood transfusion, blood components, or tissue</i>	2		77	
<i>Has HIV infection, risk not specified</i>	76		1,294	
Receipt of blood transfusion, blood components, or tissue	—	(—)	89	(2)
Risk not reported or identified	28	(12)	109	(2)
Total	237	(100)	4,935	(100)
Annual rate per 100,000 population		3.2		

TOTAL and ANNUAL RATE PER 100,000 POPULATION	21,752	66.4	251,408
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Source: Centers for Disease Control and Prevention, 1999

Community Concerns

The following community concerns identified by NCOA in 1992 are still relevant today.

Conspiracy Theories. Many in the African American community contend that the virus was engineered with a vocal contingent believing that HIV was the product of biologic warfare efforts by the U.S. Army, the CIA, or some other government agency. Some in this contingent believe that the virus was deliberately introduced into African and African American communities as part of a genocide plan. Similarly, the epidemic of drug use in African American communities is seen as part of a conspiracy to destroy the community. People who believe these theories are inclined to distrust the government's efforts to combat the HIV epidemic and to ignore or mistrust government prevention and treatment messages.

Discrimination. Members of African American communities are greatly concerned over the added discrimination being HIV-positive may bring to the already substantial inequities linked to race, sex, class, and sexual orientation. This discrimination further limits the opportunities HIV-positive members of the African American community have for employment, education, housing, and health care.

Disproportionate impact. Unquestionably, HIV and AIDS have hit the African American community hard. Statistics show that if one speaks about women and AIDS, one is speaking about African American women; if one speaks about children and AIDS, one is speaking about African American children; and if one speaks about IDUs and AIDS, one is speaking about people in the African American community. Similarly, statistics also show that if one speaks about gay men and AIDS, one is speaking about African American men since roughly half of African American men who are infected are MSMs.

Drug Users. African Americans who are infected because of drug use or sexual contact with drug users often are alienated by of the health care system. They are often victims of a prejudice against substance users that permeates the health care system. Health care providers tend to hold

substance users to blame for their problems and treat them with something less than the dignity with which all would like to be treated when ill. In addition, drug users face considerable obstacles in obtaining community support. Many African American communities bear the brunt of the disastrous consequences of the drug epidemic and governmental efforts to mount a war on drugs (such as gang warfare, violence, crime, and addiction). In these communities, there is some ambivalence about using scarce resources to assist people who engage in drug use and commerce and who on the whole are viewed as a threat to the community.

History of Mistrust. Another tragic dimension of the HIV epidemic on this community is that it affects a population already alienated from the health care system and the government, a population that is cynical of the motives of those who come to help them. Alienation is, in part, a product of the historical relationship between African Americans and whites in the United States, the relationship of slavery. In 1990, we as a nation are still living out the legacy of that early relationship. Until and unless the consequences of that reality are taken into account, a full understanding of how to deal with AIDS as it affects African Americans will be impossible.

Homophobia. As in mainstream culture, many individuals, families, and formal leadership structures in the African American community (such as churches, fraternities, and professional organizations) have difficulty dealing with issues of sexual orientation. Thus, issues of concern to the African American gay, bisexual, and lesbian communities are often ignored, and African American gays, bisexuals, and lesbians are rendered invisible. Testing positive for HIV adds an extra burden to the lives of many gay and bisexual men of color who are already struggling to maintain a support base of family and friends. Indeed the stigma of homosexuality among African Americans has led many to misrepresent their mode of exposure to HIV.

Immigration. U.S. immigration policy, which currently excludes persons who are HIV positive from traveling to, immigrating to, or seeking refuge or asylum in this country, has had a disproportionately harsh impact on Haitian people who seek asylum and are HIV positive. Currently, more than 270 Haitians are confined by the U.S. government to a detention camp on Guantanamo Naval Base in Cuba, despite their having been found by the Immigration and

Naturalization Service to have credible fears concerning persecution should they be forcibly returned to Haiti.

Leadership. Although organizations and leaders in the African American communities are generally more active in the fight against AIDS than they were a few years ago, questions regarding the adequacy of leadership efforts continue to be raised. As the devastation in these communities becomes more and more evident, there is a growing resolve not to wait for leadership from the federal government. Additionally, while many in the community believe that engaging traditional African American leadership organizations such as the church in the fight against the epidemic is very important, it has become increasingly clear that it may be a mistake to rely solely on traditional mechanisms for this response. As the epidemic has progressed, new leaders who know what effects AIDS has had in African American communities have emerged and new organizations have developed. It is important to nurture and support these individuals and entities while also continuing to work to involve traditional leadership organizations more fully in efforts against HIV and AIDS.

Needle Exchange. It has been suggested that the controversy over needle exchange is in a way a metaphor for the deep skepticism in the African American community about the motivations of the AIDS establishment. There is a continuing uneasiness in many quarters about the focus on AIDS in the African American community while many other health problems of community seem to be receiving less and less public attention and funding. Many ask “Are they interested in the spread of AIDS because they are concerned about us, or are they interested in us because they are concerned about the spread of AIDS?” In addition, many people in the African American community are convinced that needle exchange programs will only lead to greater availability of needles, which in turn will result in an increase in injection drug use.

Origins of HIV. The question of the origin of HIV has commanded a great deal of attention in the African American community because of scientific research suggesting that the virus first appeared in central Africa. Many people in the African American community resent this speculation, fearing it is an attempt to blame them for the epidemic.

Orphans and Abandoned Children. Thousands of African American children are being orphaned as their parents die from AIDS. This reality has spawned concern over the future of these children, the burden placed on other family members (particularly grandparents), and the ability of an already overloaded foster care system to effectively care for them. In addition, abandoned children who have been drug exposed, who are HIV infected, or both are a part of the boarder baby problem in many inner-city hospitals.

Other Health Concerns. In the African American community, as in other communities of color, one must contend with the reality that other health and social problems preceded the epidemic: AIDS is but one of many health concerns affecting African American communities. Currently, African Americans suffer disproportionately from a number of health problems including high rates of infant mortality, heart disease, diabetes, certain cancers, and homicide. Furthermore, the epidemics of HIV and AIDS are increasingly becoming intertwined with problems of poverty, poor education, drug dependence, homelessness, and inadequate health care.

Research. The African American community's mistrust of medical research has a historical basis that sometimes outweighs the integrity and commitment of individual investigators or institutions conducting AIDS or other biomedical research. A large number of African American witnesses told NCOA that the Tuskegee Syphilis Study was one reason for their fear of experimentation and their further distrust of research initiatives.

Stigmatization. Many people fear that emphasizing the different effects that the HIV epidemic has had on the African American community only serves to reinforce stereotypes and foster increased discrimination. The community's fear of stigmatization is, in many ways, formed by the discrimination it sees being directed toward the Haitian community, which suffered severe stigmatization early in the epidemic when it was designated a risk group for AIDS.

Women. African American women who are infected with HIV have reported numerous barriers to their access of health care services. Some women fail to seek care for themselves because they are preoccupied by caring for their mates or children. Others face discrimination when they attempt to secure care because they are IDUs, are the sexual partners of IDUs, or are of

childbearing age. Many women, however, face moral scrutiny regarding their reproductive choices when they seek health care services. For example, a number of reports have been made of clinics that serve poor women of color refusing to perform abortions for women known to be HIV positive. In contrast, women have also reported being forcibly or unknowingly sterilized because of their HIV status or drug use.

The Hispanic/Latino Community

Community Description

The U.S. Bureau of the Census defines members of Latino communities as persons of “Mexican, Puerto Rican, Cuban, Central or South American, or other Spanish culture or origin regardless of race” [U.S. Bureau of the Census, 1978]. During the past 20 years, the Latino population has emerged as one of the fastest growing segments of the population in the United States.

The ethnic community recognized by the census group categories and the federal government as Hispanic is extremely diverse. It includes any person whose ancestry can be traced to Spanish-speaking countries in Central America, South America, the Caribbean, and Spain. Although this diversity of backgrounds provides a variety of social traditions and regional and demographic characteristics, people in this ethnic grouping are linked by similar cultural values. The states with the largest Latino populations are California, Texas, and Florida but large populations of Latinos also live in Arizona, New Mexico, Colorado, New York, New Jersey, and Illinois. Although faced with problems of unemployment, inadequate housing, and poor access to health care, many Latinos living in the United States also must seek access to programs that support their native language of Spanish.

Knowledge, Attitude, Beliefs, and Behavior

Level of education and cultural factors, such as the strong influence of the church and prevalent homophobia, influence the Latino communities’ response to the epidemic. In many cases, educational outreach efforts are not accessible to Latino communities because of language and cultural differences. A high proportion of adults can identify major modes of HIV transmission but have misconceptions about other facts. In 1997, the Kaiser Family Foundation conducted a national survey of Latinos and the HIV and AIDS epidemic and found that 20 percent of the respondents incorrectly believed that a vaccine for HIV exists (compared with only 5 percent of the general population who believed this). Another 20 percent of Latino respondents believed that there is a cure for AIDS (nearly twice the 11 percent found among the general population). The results also indicated that language is a strong barrier to knowledge of this epidemic; Latinos

who were interviewed in Spanish were more likely to voice misperceptions concerning HIV and AIDS than were Latinos who were interviewed in English [Kaiser Family Foundation, 1998c].

The recent national survey of the Latino community showed that its members had a higher rate of concern about HIV infection than did members of other ethnic groups. Forty-six percent of Latinos were personally concerned about contracting HIV compared with 24 percent of the general population. Seventy percent of Latino parents expressed fear that their children will become infected compared with 52 percent of parents in the general population. The desire for further information on HIV was also evident in the responses. Latinos were 3 times more likely than people in the general population to express a need for more information on how to use condoms (41 percent versus 13 percent). Likewise, a greater percentage of Latinos expressed the need for information on HIV testing (58 percent versus 32 percent among the general population) [Kaiser Family Foundation, 1998c]. One recent study found that condom with regular, casual, and commercial sex partners was lowest among Latinos [Aversa et al., 1998]. A study of college students in Puerto Rico found the prevailing attitude to be that condom use is a contraceptive method only, not a means to prevent STD and HIV infection [Ortiz-Torres et al., 1998]

In this survey, knowledge levels were lower among Latinos with few or no English skills. Sixty-three percent of those interviewed in Spanish for the Kaiser Family Foundation survey did not have a high school diploma. Individuals interviewed in Spanish reported obtaining the majority of their HIV information from television, radio, and the church. This is in contrast to the English-speaking Latinos surveyed who reported receiving most of their information on HIV from print sources, such as newspapers and magazines, and from television [Kaiser Family Foundation, 1998c].

Similar to the rest of the population, Latinos indicate little discussion on AIDS occurs between adolescents and adults. The CDC's 1997 Youth Risk Behavior Survey showed that 60.5 percent of Latino students had talked to an adult or family member about AIDS compared with 62 percent of white and 72.7 percent of African American students [Centers for Disease Control and Prevention, 1998e]. Among high school students, Latinos had rates of sexual activity that were higher than the national average with 57.7 percent of male students and 45.7 percent of female

students reporting having had sexual intercourse [Centers for Disease Control and Prevention, 1998c].

While Latino family bonds are traditionally supportive, the closeness of these bonds can make it difficult for an individual to be open about his or her personal life. Homophobia constitutes a considerable barrier in Latino communities. Emphasis on gender roles and machismo inhibits an open discussion of HIV and AIDS. One consequence of such silence is that many Latinas may not know or acknowledge that their husbands or boyfriends are or have been bisexual. These women are therefore unable to accurately assess their risk of exposure to HIV [Bardach, 1995].

In epidemiologic studies, determining exposure category for Latino AIDS cases is complicated by homophobia. Because of the social stigma associated with being gay or bisexual, infected individuals are less to disclose their risk category. Such fears also lead to the denial of susceptibility to HIV. As in African American communities, such denial can inhibit the Latino communities' ability to respond effectively to the epidemic.

Demographics

As of July 1, 1998, the Latino population in the United States numbered more than 30.4 million. This accounted for 11.3 percent of the total population, up from 9.1 percent in 1990 [U.S. Bureau of the Census, 1998]. Among the reasons for this increase in the Latino population is an increased birth rate and an increase in the level of immigration—about 2 million immigrants entered the United States between 1990 and 1994 [U.S. Bureau of the Census, 1995]. The U.S. Bureau of the Census projects a population of more than 36 million Latinos (or 12.6 percent of the total U.S. population) by the year 2005. By 2030, it is projected that nearly 1 in 5 Americans will be Latino [U.S. Bureau of the Census, 1996].

The socioeconomic status of Latinos is lower than that found within any of the other major census groups in the United States. More than one-quarter of all Latinos (27.1 percent) were living below poverty level in 1997 [Dalaker and Naifeh, 1998]. Low-income levels are further reflected in Latinos' rate of health insurance coverage. Only 66 percent of Latinos, compared

with 85 percent of whites, had such coverage in 1997 [Bennefield, 1998]. At all levels of income, Latino men and women were more likely to have no health insurance coverage than either their African American or white peers [National Center for Health Statistics, 1998].

Single women head 19 percent of Latino households, while 46 percent of African American households have this characteristic. However, the percentage of Latino households headed by a single woman in poverty (50.9) was greater than that found for African Americans (42.8) or whites (30.7) [Dalaker and Naifeh, 1998].

Overall mortality statistics for Latinos tend to be underreported nationwide. In 1996, Oklahoma did not report “Hispanic origin” on death certificates. Thus, while the age-adjusted death rate for Latinos declined 5.4 percent from 1995 to 1996, the 1996 figures are understated. In 1996, the mortality rate per 100,000 Latinos (365.9) continued to be lower than the mortality rate for non-Hispanic populations (496.2). Latino subgroups showed stark differences in mortality rates per 100,000 population with Puerto Ricans at 509 and Central/South Americans at 332.2 [Peters, Kochanek, Murphy, 1998].

In 1998, the Latino population had the youngest median age of any non-Hispanic racial groups—26 years [U.S. Bureau of the Census, 1998]. Thus, the leading causes of death among Latinos tend to reflect causes that are more prevalent among younger people. For Latinos between the ages of 25 and 44, HIV and homicide ranked higher as a leading cause of death than they did for members of this age range among the general population [Peters, Kochanek, Murphy, 1998].

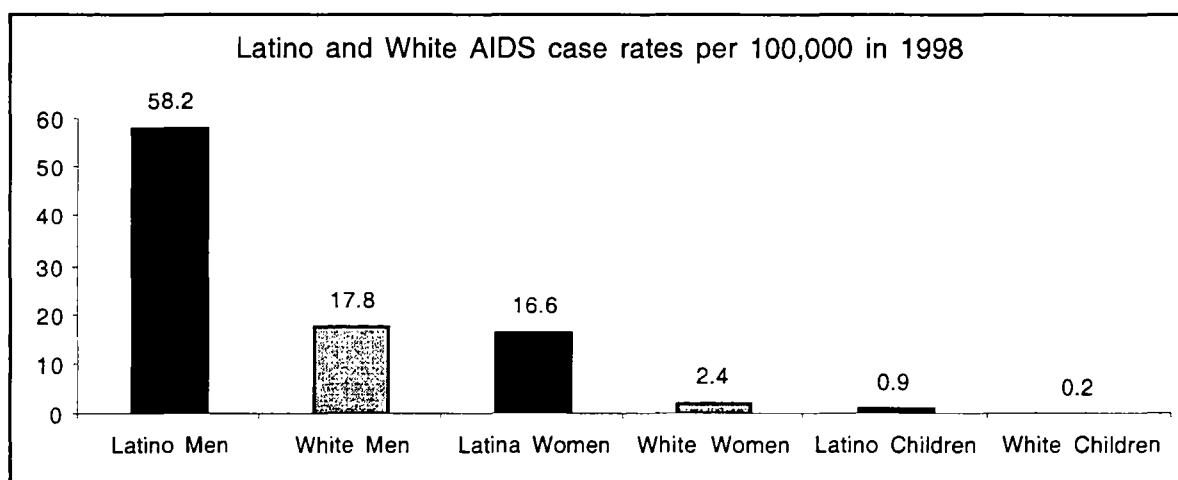
Epidemiology

Annual and Cumulative AIDS Incidence

Though Latinos represent 11.3 percent of the U.S. population, this ethnic group accounted for 18.1 percent (124,841) of the cumulative AIDS cases (688,200) through December 1998. In 1998, the adult/adolescent AIDS incidence rate per 100,000 Latinos was 37.8, almost 4 times

higher than that for whites (9.9), and Latinos represented 20 percent of all AIDS cases in this country [Centers for Disease Control and Prevention, 1999].

Of the 124,841 cumulative Latino AIDS cases reported through December 1998, 80.9 percent were among adult/adolescent males, 17.6 percent among adult/adolescent females, and 1.6 percent among children under age 13. Among Latinos, annual AIDS rates per 100,000 in 1998 were 58.2 for men, 16.6 for women, and 0.9 for pediatric cases. Of the 9,650 cases reported for Latinos in 1998 alone, 77.8 percent were among men, 21.3 percent among women, and 0.9 percent among children [Centers for Disease Control and Prevention, 1999].



Source: Centers for Disease Control and Prevention, 1999

Latino Men

Latino men accounted for 17.7 percent of all cumulative AIDS cases among adult/adolescent males in the United States through December 1998. In 1998, Latino men represented 20.4 percent (7,511) of the 36,886 total adult/adolescent male cases. The most frequently cited exposure category among the cumulative Latino male cases was sex between men at 43 percent, and injection drug use was second at 36 percent. Seven percent of Latino men identified both risk factors as their exposure category [Centers for Disease Control and Prevention, 1999].

Latina Women

As of December 1998, Latina women accounted for 20.1 percent of the cumulative AIDS cases in adult/adolescent females. Of new AIDS cases among adult/adolescent women in 1998, Latinas represented 18.7 percent (2,055) of the 10,998 reported. Mode of exposure was divided primarily between injection drug use (41 percent) and heterosexual contact (47 percent) with nearly one-half of the heterosexual AIDS cases attributed to a sex partner who had injected drugs [Centers for Disease Control and Prevention, 1999].

Latino Children

Latino children made up 23.1 percent of all cumulative pediatric AIDS cases in the United States reported through December 1998. They accounted for 22 percent of new pediatric AIDS cases reported in 1998. Perinatal transmission from an HIV-infected mother was the predominant exposure category at 92 percent of the 1,954 cumulative cases. Five percent of Latino pediatric cases were the result of receiving contaminated blood or blood components and another 2 percent were the result of hemophilia or other coagulation disorders [Centers for Disease Control and Prevention, 1999].

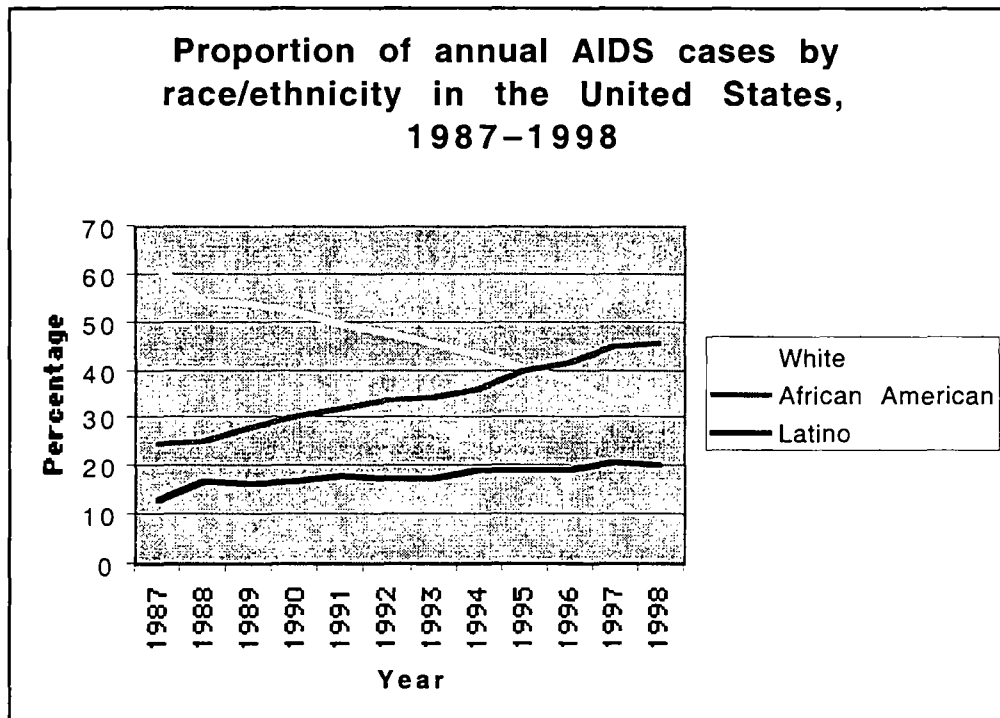
Latino Subgroups

Studies have noted that the profile of the AIDS epidemic varies considerably between the different ethnic subgroups within the Latino community. For adults/adolescents born in Central and South America, Cuba, and Mexico, the most frequently reported exposure category in 1998 was MSM (36, 34, and 48 percent of AIDS cases, respectively). For adults/adolescents with HIV who were born in Puerto Rico, injection drug use was the most common exposure category in 1998, accounting for 46 percent of cases. In that same year among persons born in Puerto Rico, 25 percent of adults/adolescents with AIDS reported heterosexual contact as their mode of exposure. This percentage is more than twice the 12 percent of U.S.-born Latinos with AIDS who identified heterosexual contact as their primary means of exposure. A large percentage of AIDS cases among U.S.-born Latinos were also attributed to MSM (37 percent) and to injection drug use (28 percent) [Centers for Disease Control and Prevention, 1999].

AIDS surveillance results have shown that in groups in which the predominant exposure category was MSM, many women had either undetermined modes of exposure or had had

heterosexual contact with a man with an unstated mode of exposure [Diaz et al., 1993]. According to a 1998 HIV and AIDS surveillance report, among AIDS cases, the mode of exposure had not been reported or could not be identified for 40 percent of adults born in Central or South America, for 47 percent of adults born in Cuba, and for 29 percent of adults born in Mexico [Centers for Disease Control and Prevention, 1999].

The AIDS epidemic in Latino communities continues to escalate. As the number of annual AIDS cases falls for whites, the number of AIDS cases among Latinos steadily rises. If this trend continues, AIDS cases among Latinos are expected to surpass AIDS cases among whites within



the next few years.

Source: Centers for Disease Control and Prevention

AIDS Mortality

Across all age groups in the Latino community, a total of 2,945 males and 785 females died of AIDS in 1997. By the end of 1998, the cumulative deaths for Latinos with AIDS numbered 59,033 males and 11,901 females. Latinos accounted for 17.3 percent of all cumulative AIDS

deaths through December 1998 and 18.7 percent of AIDS deaths in 1997 alone [Centers for Disease Control and Prevention, 1999].

AIDS mortality for Latinos dropped to the fifth leading cause of deaths in this community in 1996. However, HIV continues to rank higher as a cause of death for Latinos between the ages of 25 and 44 than it does for members of this age group among the general population in the United States [Peters, Kochanek, Murphy, 1998].

Latino AIDS Cases Reported in 1998 and Cumulative Totals through December 1998, United States

	<u>1998</u>		<u>Cumulative Total</u>	
	#	%	#	%
Adult/Adolescent Male				
Exposure Category				
Men who have sex with men (MSM)	2,720	(36)	43,180	(43)
Injection drug use	2,164	(29)	36,353	(36)
MSM and inject drugs	334	(4)	6,790	(7)
Hemophilia/coagulation disorder	19	(0)	414	(0)
Heterosexual contact:	638	(8)	5,329	(5)
<i>Sex with injection drug user (IDU)</i>	140		1,571	
<i>Sex with person with hemophilia</i>	2		8	
<i>Sex with transfusion recipient with HIV infection</i>	10		85	
<i>Sex with HIV-infected person, risk not specified</i>	486		3,663	
Receipt of blood transfusion, blood components, or tissue	25	(0)	561	(1)
Risk not reported or identified	1,611	(24)	8,323	(8)
Total	7,511	(100)	100,950	(100)
Annual rate per 100,000 population		58.2		
Adult/Adolescent Female				
Exposure Category				
Injection drug use	577	(28)	9,016	(41)
Hemophilia/coagulation disorder	—	(—)	45	(0)
Heterosexual contact:	906	(44)	10,220	(47)
<i>Sex with IDU</i>	275		4,866	
<i>Sex with bisexual male</i>	33		480	
<i>Sex with person with hemophilia</i>	4		34	
<i>Sex with transfusion recipient with HIV infection</i>	1		94	
<i>Sex with HIV-infected person, risk not specified</i>	593		4,746	
Receipt of blood transfusion, blood components, or tissue	21	(1)	535	(2)
Risk not reported or identified	551	(27)	2,121	(10)
Total	2,055	(100)	21,937	(100)
Annual rate per 100,000 population		16.6		
Pediatric				
Exposure Category				
Hemophilia/coagulation disorder	—	(—)	37	(2)
Mother with/ at risk for HIV infection:	75	(89)	1,798	(92)
<i>Injection drug use</i>	17		718	
<i>Sex with IDU</i>	12		482	
<i>Sex with bisexual male</i>	1		38	
<i>Sex with person with hemophilia</i>	1		7	
<i>Sex with transfusion recipient with HIV infection</i>	1		9	
<i>Sex with HIV-infected person, risk not specified</i>	18		245	
<i>Receipt of blood transfusion, blood components, or tissue</i>	1		33	
<i>Has HIV infection, risk not specified</i>	24		266	
Receipt of blood transfusion, blood components, or tissue	1	(2)	92	(5)
Risk not reported or identified	8	(10)	27	(1)
Total	84	(100)	1,954	(100)
Annual rate per 100,000 population		0.9		
TOTAL and ANNUAL RATE PER 100,000 POPULATION	9,650	28.1	124,841	

Source: Centers for Disease Control and Prevention, 1999

Community Concerns

The following community concerns that were identified by NCOA in 1992 that are still relevant today.

Community Diversity. Many have expressed their frustration with the lack of available data on Latino subgroups. The use of a broad-based “Hispanic/Latino” category does not allow for a true picture of the effects of the epidemic among the different groups that make up this category.

Community empowerment. Latinos have been underrepresented in policy positions at the local, state, and federal levels. The majority of Latinos affected by the AIDS epidemic live under conditions of poverty. Consequently, for this community there is a need to address the issues of HIV and AIDS as they are affected by conditions of poverty.

Drug users. For the Latino population, drug use is quickly becoming the primary means of Transmission and is already the principal transmission factor in the Latino population in the Northeast, the Midwest, and the Commonwealth of Puerto Rico. This population is also very difficult to reach owing to its often transient nature. Existing programs have been hampered by the failure to ensure treatment on demand or access to harm-reduction programs such as methadone maintenance or needle exchange.

Education. School-based education programs have been the primary focus of AIDS education programs for children and adolescents. However, because Latino children and adolescents the highest dropout rate in the nation, many do not benefit from these programs. It is estimated that only 50 percent of Latinos over the age of 24 have completed high school compared with 80 percent of those in this age range in the general population.

Families. There is concern that present HIV programs do not target the family as a whole. Whether it strikes a gay man or a substance user, HIV is a family and community issue for Latinos; when a member of the family becomes ill, the family tends to respond as a unit.

Latino Gay Men. There is concern among Latino gay men that homophobia is pervasive in their community. Gay men in the Latino community are concerned with the perceived inappropriateness of funding and lack of responsiveness and support for the development of programs to target exclusively the needs of gay Latino males.

Immigration. The current immigration policy excluding HIV-infected people from entering and living in the United States has had a disproportionately negative impact among the large numbers of undocumented and migrant workers in the Latino community. The *Immigration Reform and Control Act* granted legal status to a large number of undocumented aliens. However, people who tested positive for HIV are forced to apply for waivers, few of which are granted. Others who would qualify for legal status under the Act have not come forward to apply for amnesty or to seek care for HIV-related conditions because of their fear of deportation. The commission was also told about incidents of migrant workers becoming infected with HIV while in the United States but being refused reentry into the country by U.S.-based companies because of their serostatus.

Language. Language and culture present additional obstacles in providing prevention and service programs for Latinos. For those who are monolingual Spanish speakers, health care providers often do not have the resources for effective translation, a situation that impairs service delivery and forces inappropriate situations, such as when minor children must translate for parents in situations where confidentiality may be an issue.

Leadership. Although some community leaders and elected officials have shown outstanding support for AIDS prevention and service organizations, there is currently a need to further educate and encourage the involvement of Latino community leaders and elected officials on the issue. As in other communities of color, HIV and AIDS have not been popular causes with the leadership of the Latino community. Among these leaders, AIDS is seen as something that will damage the image of the community.

Migrant Workers. The migration patterns of migrant farm workers force many people to live in camps and move from state to state, never establishing the permanent residence needed to qualify for services from local communities. Many must live in remote communities where sanitation and close living quarters produce special health problems. Health care for people in these communities, particularly those needing HIV-related services, is limited or nonexistent.

Orphans. The Latino community is extremely concerned about the surviving children of HIV-infected families. As HIV disease continues to expand among IDUs and their partners, the need for a plan to care for the future of the children of infected couples or single parents is growing. In order to avoid having these children become part of an already overburdened foster care system, parents must be assisted in making arrangements for the care of their children after their death.

Prevention. There is concern that national HIV and AIDS information and prevention efforts have not reached the Latino community because of the inadequate number of programs that target the community from a linguistic as well as a cultural perspective.

Research. Latinos are concerned that cultural elements will affect the results of studies conducted to determine the knowledge, attitudes, beliefs, and behavior of people in their community. Inappropriate research methodologies have resulted in significant variations in results, with variables such as where interviews are conducted and whether the subject is alone or with his or her partner strongly influencing the types of responses received.

Women. There is concern in the Latino community that women's issues have not been adequately addressed in the context of HIV prevention and care. In the Latino community, women play an important role in educating families about health and in securing health care for immediate and extended family members. Too often, Latinas who are infected with HIV do not receive the support they need to both care for their families and address their own health needs. In addition, for a large number of Latinas, issues of reproductive rights have become increasingly critical. Many women feel pressured to terminate their pregnancy in the face of moral scrutiny

regarding their reproductive choices. Latinas infected with HIV have also reported a high incidence of violence in the home, apparently as a result of their serostatus.

The Asian American and Pacific Islander Communities (API)

Community Description

The U.S. Bureau of the Census describes members of the Asian American and Pacific Islander (API) communities as persons “having origins in any of the original peoples of the Far East, Southeast Asia, the Indian subcontinent, or the Pacific Islands” [U.S. Bureau of the Census, 1978]. Like African Americans and Latinos, the API population is by no means a homogeneous group. According to census data, there are more than 40 API subgroups within the API community. The population differs widely in the languages, cultures, and times of immigration of its members.

Asian American and Pacific Islanders are two separate and culturally distinct groups, whose broadly inclusive category descriptions serve to highlight some of the differences between the two. “Asian American” is a term applied to persons in the United States “having origins in any of the original people of the Far East.” Asian Americans are often defined according to subpopulations: Cambodian, Chinese, Filipino, Indian, Japanese, Korean, Malaysian, Pakistani, Thai, and Vietnamese.

“Pacific Islander” is term that includes persons who are American citizens whose ancestors came from islands in the South Pacific or who live in a group of predominantly small island nations that have a loose relationship with the United States (specifically, Guam, American Samoa, the Republic of Palau, the Republic of the Marshall Islands, the Commonwealth of Northern Mariana Islands and the Federated States of Micronesia), or who are native Hawaiians. Asian Americans and Pacific Islanders represent the third largest minority group in this country. Members of the Pacific Islander communities may identify with peoples from any of a group of islands that have a relationship with the United States—Guam, American Samoa, the Republic of Palau, the Republic of the Marshall Islands, the Commonwealth of the Northern Marina Islands, and the Federated States of Micronesia—or may have ancestors from Hawaii or other islands in the South Pacific.

Knowledge, Attitude, Beliefs ,and Behavior

National surveys of knowledge, attitudes, and behaviors do not currently report data for Asian American and Pacific Islander communities as a separate group. Although state and local studies have been done, they cannot be generalized to the whole Asian American and Pacific Islander community because of the diversity of the community and the differences in their geographic distribution.

The API communities have been slow to address AIDS in part because the effect of the disease on API communities has been small compared to the statistically more predominant epidemic in the African American and Latino communities. Indeed, API communities have the lowest AIDS case rate of the four racial and ethnic groups [Centers for Disease Control and Prevention, 1997a]. In a study of Asian Americans in San Francisco, Chinese Americans were more knowledgeable about AIDS than Filipino Americans and Vietnamese Americans but did not believe themselves to be at risk of HIV infection [Nemoto et al, 1998].

The Asian and Pacific Islander Caucus estimated in a 1994 report that the API community is about 5 years behind in HIV education and prevention efforts compared with the efforts of the gay white male community [Asian and Pacific Islander Health Caucus, 1994]. Strong cultural resistance has limited AIDS knowledge within the community. In a 1992 survey of women of color, Asian women were the most likely to believe only homosexual men and IDUs are at risk for HIV infection [Ueda, 1995]. In addition to this denial of the epidemic's threat to their communities, APIs are strapped by "sexuality taboos, familial expectations, and perceptions of API success in this country" [Kaczorowski, 1996]. Paul Kawata, executive director of the National Minority AIDS Council, notes that silence is often the norm on issues related to AIDS. This silence often means less knowledge about AIDS. A survey of Asians living in San Francisco found that Asian drug users who were interdependent also had less AIDS knowledge and were less likely to use condoms during sexual activity than those who were not drug users and not interdependent [Nemoto et al., 1998]. Sex and drugs are traditionally difficult subjects for members of the API communities to discuss [Kaczorowski, 1996; Asian and Pacific Islander Caucus, 1994; Chun, 1994; Lee and Fong, 1990]. Compared with Asians born in the United

States, Asian immigrants are even less likely to be knowledgeable about AIDS and less likely to use condoms [Nemoto et al., 1998].

The difficulty in disseminating AIDS information to such a diverse group of people is noteworthy with language differences presenting the greatest barrier [Kaczorowski, 1996]. In 1990, the U.S. Bureau of the Census estimated that two-thirds of the foreign-born API population spoke a language other than English as their primary language, and NOCA reports there are nearly 100 language dialects within the community [Asian and Pacific Islander Caucus, 1994; National Commission on AIDS, 1992a]. Translations of educational materials, surveys, and other information may be so inadequate that they are incomprehensible. Literal translations lose the crucial and more meaningful nuances that are essential to useful interpretations of the messages [National Commission on AIDS, 1992a]. For example, in the Tagalog language, clinical terms for penis, vagina, or intercourse do not exist, so health workers must resort to street terms that offend many people or to English terms that may be incomprehensible. In a more extreme cases, the Mien and Hmong communities have no written languages, making translations an impossibility [Lee and Fong, 1990].

Effective and culturally appropriate HIV-prevention efforts, as well as studies of the epidemic in API communities, need to be developed. Current surveillance practices are inadequate, bringing into question the reliability of conclusions drawn from the data [Asian American Health Forum, 1991; Lee and Fong, 1990]. Efforts are needed to overcome language barriers and norms regarding sexuality and to break the existing silence about the HIV epidemic in API communities [Kaczorowski, 1996].

Demographics

Asian Americans and Pacific Islanders, numbering over 9.7 million, represented 3.6 percent of the nation's population as of July 1998 [U.S. Bureau of the Census, 1998]. Like other communities of color, the API population is younger, on average, than the white population (median age: 38 years), with a median age of 31.5 years [U.S. Bureau of the Census, 1998].

While the percentage of APIs living under the poverty line is not as pronounced as that of African Americans or Latinos, API communities still have nearly 2 times the number of living below poverty (14 percent) than do whites (8.6 percent) [Dalaker and Naifeh, 1998]. In terms of family structure, API communities have the lowest percentage of families headed by a single woman (10.7 percent) of any major census group. Of those API families that are headed by a single woman, 28.9 percent live below the poverty line [Baugher and Lamison-White, 1996]. In 1997, 20.7 percent of APIs did not have any form of health insurance coverage [Bennefield, 1998].

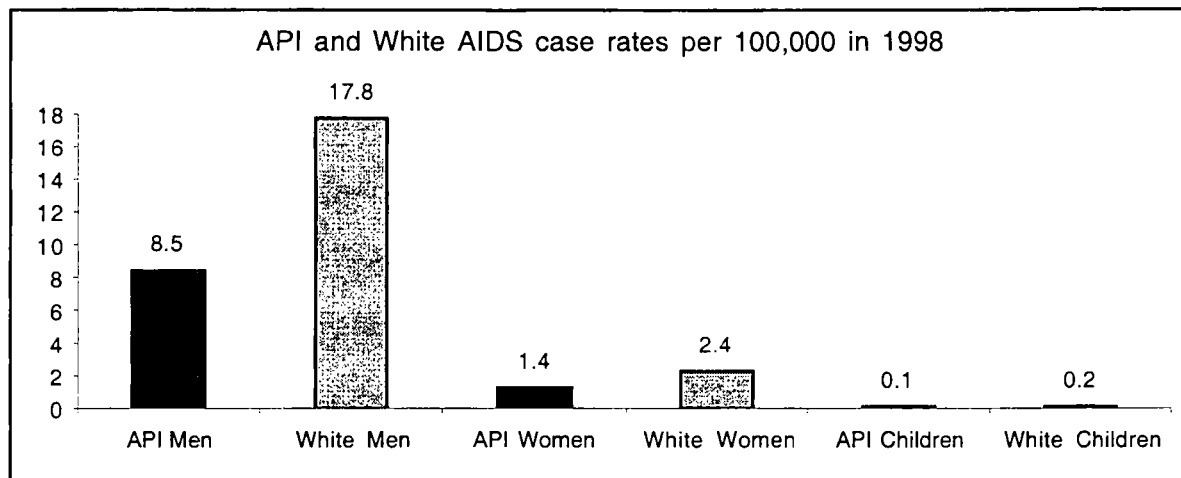
APIs have lower death rates across all age groups than white Americans do. In 1995, for example, mortality rates in this community were 37 percent lower than mortality rates among whites. Heart disease and cancer continue to rank as the leading causes of death for this population. In 1995, AIDS was the 10th leading cause of death for APIs [National Center for Health Statistics, 1997b].

Epidemiology

Annual and Cumulative AIDS Incidence

As of December 1998, APIs represented only 0.72 percent of cumulative AIDS cases in the United States, although they represented more than 3 percent of the country's population. The 1998 adult/adolescent AIDS case rate of 4.8 per 100,000 APIs was the lowest of all racial and ethnic groups. The API communities accounted for 0.81 percent of AIDS cases reported in 1998 alone [Centers for Disease Control and Prevention, 1999].

Of the 4,974 cumulative cases of AIDS in the API population reported through December 1998, 87.7 percent were among adult/adolescent males, 11.3 percent among adult/adolescent females, and 0.9 percent among children under the age of 13. In 1998, the annual rate of AIDS cases per 100,000 was 8.5 for men, 1.4 for women, and 0.1 for children under the age of 13 [Centers for Disease Control and Prevention, 1999].



Source: Centers for Disease Control and Prevention, 1999

Asian American and Pacific Islander Men

API men accounted for 0.8 percent of cumulative adult/adolescent AIDS cases reported among men in the United States through December 1998 and 0.9 percent of adult/adolescent male cases reported among men in 1998 alone. Among API men, the most common exposure category reported among cumulative AIDS cases was MSM (74 percent). Compared with men in other racial and ethnic groups, API men had the lowest percentage of cases attributed to injection drug use (5 percent). Three percent of API men reported both risk factors, and 2 percent identified receipt of blood, blood components, or tissue as their exposure category [Centers for Disease Control and Prevention, 1999].

Asian American and Pacific Islander Women

API women in the United States accounted for 0.5 percent of both cumulative adult/adolescent female AIDS cases reported among women through December 1998 and adult/adolescent cases reported among women in 1998 alone. API women represent the highest percentage of cumulative AIDS cases among women within any racial or ethnic group for which risk is not reported or identified (18 percent) as well as the highest percentage of cases attributed to contaminated blood or blood components (16 percent). In addition, API women, like API men, show the lowest rate for injection drug use exposure at 17 percent, a rate that is less than one-half found among any other racial and ethnic group. Forty-seven percent of cumulative cases among

API women report heterosexual contact as their mode of exposure [Centers for Disease Control and Prevention, 1999].

Asian American and Pacific Islander Children

API children in the United States accounted for 0.5 percent of both cumulative AIDS cases among children through December 1998 and pediatric cases reported in 1998 alone. Like API women, API children have the highest percentage of cumulative AIDS cases with exposure attributed to receipt of blood or blood components (22 percent). Compared with other children, they have the lowest percentage of cases attributed to perinatal infection (67 percent). Seven percent of cumulative API pediatric cases reported hemophilia or other coagulation disorders as their exposure category [Centers for Disease Control and Prevention, 1999].

The epidemiologic profile of APIs with AIDS resembles the patterns that were seen among African American and Latino communities early in the epidemic. For APIs, the ratio of AIDS incidence rates per 100,00 in 1998 was heavily skewed along sex lines with men at 8.5 and women at 1.4 [Centers for Disease Control and Prevention, 1999]. These statistics suggest that the epidemic is in its early stages in this population and may increase among API women and children.

AIDS Mortality

Of APIs with AIDS, 114 males and 22 females died in 1997. By December 1998, the cumulative deaths from AIDS among APIs numbered 2,504 for males and 286 for females. The API communities accounted for 0.7 percent of both cumulative AIDS deaths through December 1998 and AIDS deaths reported in 1997 alone [Centers for Disease Control and Prevention, 1999].

Owing to the current low AIDS incidence rates among APIs, HIV mortality continues to rank low among the top 10 causes of death for different API age cohorts as compared with the rates of HIV-related deaths among corresponding cohorts in other racial and ethnic groups. Still, HIV mortality rates have not improved among APIs as much as they have for whites. In the first half of 1996, the HIV mortality rate declined 6 percent among APIs compared with a 21 percent decline among whites [Centers for Disease Control and Prevention, 1997c].

Asian American and Pacific Islander AIDS Cases Reported in 1998, and Cumulative Totals through December 1998, United States

	<u>1998</u>		<u>Cumulative Total</u>	
	#	%	#	%
Adult/Adolescent Male				
Exposure Category				
Men who have sex with men (MSM)	185	(56)	3,212	(74)
Injection drug use	17	(5)	233	(5)
MSM and inject drugs	9	(3)	154	(4)
Hemophilia/coagulation disorder	2	(1)	64	(1)
Heterosexual contact:	22	(7)	139	(3)
<i>Sex with injection drug user (IDU)</i>	6		36	
<i>Sex with person with hemophilia</i>	—		—	
<i>Sex with transfusion recipient with HIV infection</i>	—		7	
<i>Sex with HIV-infected person, risk not specified</i>	16		96	
Receipt of blood transfusion, blood components, or tissue	9	(3)	108	(2)
Risk not reported or identified	85	(26)	454	(10)
Total	329	(100)	4,364	(100)
Annual rate per 100,000 population		8.5		
Adult/Adolescent Female				
Exposure Category				
Injection drug use	7	(12)	97	(17)
Hemophilia/coagulation disorder	—	(—)	5	(1)
Heterosexual contact:	24	(41)	267	(47)
<i>Sex with IDU</i>	5		75	
<i>Sex with bisexual male</i>	3		63	
<i>Sex with person with hemophilia</i>	1		5	
<i>Sex with transfusion recipient with HIV infection</i>	1		18	
<i>Sex with HIV-infected person, risk not specified</i>	14		106	
Receipt of blood transfusion, blood components, or tissue	3	(5)	91	(16)
Risk not reported or identified	25	(42)	104	(18)
Total	59	(100)	564	(100)
Annual rate per 100,000 population		1.4		
Pediatric				
Exposure Category				
Hemophilia/coagulation disorder	—	(—)	3	(7)
Mother with/ at risk for HIV infection:	1	(50)	31	(67)
<i>Injection drug use</i>	—		4	
<i>Sex with IDU</i>	1		5	
<i>Sex with bisexual male</i>	—		2	
<i>Sex with person with hemophilia</i>	—		—	
<i>Sex with transfusion recipient with HIV infection</i>	—		—	
<i>Sex with HIV-infected person, risk not specified</i>	—		9	
<i>Receipt of blood transfusion, blood components, or tissue</i>	—		1	
<i>Has HIV infection, risk not specified</i>	—		10	
Receipt of blood transfusion, blood components, or tissue	—	(—)	10	(22)
Risk not reported or identified	1	(50)	2	(4)
Total	2	(100)	46	(100)
Annual rate per 100,000 population		0.1		

TOTAL and ANNUAL RATE PER 100,000 POPULATION	390	3.8	4,974
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Source: Centers for Disease Control and Prevention, 1999

Community Concerns

The following community concerns that were identified in 1992 by the NCOA that are still relevant today.

Alienation. A person in the API community who is living with HIV may face tremendous alienation within his or her own ethnic and cultural community. Their stigma can be compounded by the revelation that the person is gay or is an IDU.

Clinical Trials. For clinical trials and other research opportunities, specific and affirmative guidelines need to be developed for multilingual and multicultural access to such trials by members of API communities and for the recruitment of participants for these trials from the API communities.

Community diversity. A number of witnesses presenting testimony before NCOA emphasized the need for recognition of the diversity among APIs so that AIDS programs can target specific racial or ethnic minority populations. By aggregating API statistics in surveillance reports, it is impossible for communities to know exactly where to focus their attention. Asian American AIDS service providers expressed a need to know the extent of the HIV and AIDS problem in their communities.

Community Empowerment. There is a great need to foster coalition building among API organizations throughout the nation so that these groups may get together and exchange information on a regular basis. Such exchange is valuable for the training of health professionals and for efforts to sensitize service providers on important epidemic-related issues concerning APIs.

Community Input. As with other communities, APIs told NCOA of the need to include community members in HIV program planning and policy development. Specifically, witnesses

pointed out the need to establish mechanisms that provide a forum for input from APIs, such as establishing advisory committees and hiring of racial and ethnic minorities to staff federal, state, and local health agencies.

Education. Witnesses at NCOA hearings voiced concern that money was being wasted on the translation of pamphlets and brochures originally developed for other audiences and they warned that the messages were therefore often inappropriate for the API audiences. (An example was given of a pamphlet that mentioned AIDS in African American and Latino populations but made no mention of AIDS among APIs.) Moreover, translations may be so inadequate that they render information incomprehensible while efforts at literal translations lose crucial and meaningful nuances that transmit the intent of the messages.

Funding. Frustration over their inability to compete effectively for funding for HIV and AIDS programs was brought up by API witnesses to NCOA. Anecdotal accounts of AIDS cases and HIV infections were often not considered specific enough to submit and support funding proposals. In addition, members of the API community were concerned that the low number of AIDS cases among APIs might mean that HIV and AIDS proposals developed for APIs would be given lower funding priorities.

Immigration. As with other communities, APIs who spoke with the commission strongly favored elimination of HIV-positive status as a basis for immigration exclusion and an end to mandatory HIV testing for immigrants and refugees.

Language. Language is a significant barrier to accessing HIV education and health care in API communities. For service providers, reaching significant numbers of APIs requires that services be provided in a variety of languages and dialects. For many APIs, the already complex and burdensome task of securing appropriate HIV services is compounded by their inability to speak English.

Model Minority Myth. The stereotype that Asian Americans are high achievers who excel academically and economically and who suffer from relatively few health concerns obscures

serious problems in the API community, including poverty, substance use, and significant health difficulties.

Outreach. A major component of the delivery of services to those affected by HIV and AIDS involves outreach to publicize services and to create trust between clients and service providers. Without these outreach efforts comprehensive HIV services cannot be delivered. In particular, outreach efforts are essential when attempting to reach newly arrived immigrants and refugees who do not speak any English.

Concerns raised to NCOA members by persons from trust territories in the Pacific included the following issues.

Community empowerment. Existing community-based organizations can be empowered to involve the community. Although HIV is not regarded as a major health problem by most Pacific Islanders, other health concerns do surface. Eventually the issues of HIV and AIDS can be addressed within the context of addressing these other health concerns.

Confidentiality. On any given Pacific island, it is typical for one public health nurse to care for the health needs of all the people on that island. Because they know everything and everybody, all public health nurses must be educated on the importance of confidentiality. Typical small communities on these islands have or will have major problems with confidentiality aspects of risk assessments (that is, HIV testing, AIDS reporting, counseling, and partner notification). For example, on some islands HIV testing is routinely conducted at one time on one day of each week. This means that anyone showing up at the clinic on that day at that time is suspected of, and stigmatized as, being HIV positive.

Cultural Competence. Individuals who do not come from or are not known in the API community are generally not trusted or believed. In these islands, academic degrees do not confer credibility and respect—familiarity within the community does. Position qualifications for health educators and outreach workers should be adjusted so that paraprofessionals can be hired to educate the community about HIV and AIDS.

Denial. Many people within these island communities believe that AIDS is a disease that affects only white men. Island governments face the difficult dilemma of creating laws to protect people from diseases that may be brought to the islands by tourism, while also working to maintain the economic stability that that tourism brings.

Funding. Funding criteria for support of prevention efforts for these communities should extend beyond the number of AIDS cases reported. Island communities can be decimated if HIV infection becomes established; prevention must take place before, not after, cases of AIDS are reported. One funding strategy could be to recognize areas that report sharp rises in STDs and teen pregnancies and to automatically target such areas for increased HIV-prevention funding.

Transportation. Many islands have only one site for HIV testing, often located in the island's main city, a location that may tens of miles away from residents who have no means of transportation. Island-based organizations need considerable support for large travel budgets, a circumstance often not understood by funding agencies. When apparently inflated travel budgets are cut substantially by funding sources, the effectiveness of the projects diminish.

The Native American Communities

Community Description

Prior to colonization, it is estimated that there were between 12 and 15 million aboriginal inhabitants in what is now the contiguous 48 states. By the end of the nineteenth century, the Native American population had been reduced to about 250,000. This collapse was largely the result of high death rates among native “New World” populations who were exposed to infectious diseases such as smallpox, tuberculosis, typhoid, cholera and typhus; diseases caused by “Old World” pathogens carried by colonizers from Europe.

Native North Americans were not and are not now one people but are members of many communities of many nations, each with its own language, traditions, and history. There more than 500 Native American tribes and Alaskan Native villages in the United States, each of which has a largely autonomous relationship with the United States government and each of which, as a sovereign nation, determines its own citizenship requirements.

Oklahoma has the largest Native American population in the United States and California has the second largest. Regardless of location, Native American communities still suffer from the damage caused by disruption that disease, war, population removal, and targeted government campaigns brought to their traditional economies and cultures.

Knowledge, Attitude, Beliefs ,and Behavior

Like APIs and other insular communities, Native American communities are expected to experience a rapid increase in their rate of AIDS incidence [National Commission on AIDS, 1992a; Sullivan, 1991; Conway et al., 1990]. Unfortunately, studies of Native American communities have been hampered by dramatic underreporting and misclassification [Brewer, 1996; Lieb et al., 1992]. National surveys of beliefs, attitudes, and practices do not currently report data on Native Americans as a separate group [National Commission on AIDS, 1992a; Centers for Disease Control, 1995c].

A 1990 report that examined the level of HIV knowledge in northwestern Native American communities showed that communities in Oregon and Idaho uniformly reported a good understanding of the three primary modes of HIV transmission (needles, mother-to-infant transmission, and unprotected sex). Misperceptions about the transmission of HIV, however, were prevalent in these communities: Although 96 percent of those surveyed correctly believed that the virus is transmitted through sexual intercourse, between 52 and 55 percent believed that HIV could be contracted by eating food prepared by someone infected with the virus and between 57 and 63 percent believed that HIV could be spread through a cough or sneeze [Hall et al., 1990].

High-risk sexual practices among Native Americans expose individuals to STDs and HIV. Surveys of STD incidence consistently show higher rates of gonorrhea, syphilis, chlamydia, and herpes among members of Native American communities compared with rates of these STDs among the general U.S. population [U.S. Department of Health and Human Services, 1995; Grossman et al., 1994; Sullivan, 1991; Attico, 1987; Johannes, 1987]. A high incidence of STDs suggests a frequency of sexual encounters without consistent condom use and could indicate an for increased susceptibility by members of the community to HIV infection [Sullivan, 1991].

Between 1988 and 1990, the Indian Health Service, in conjunction with the Adolescent Health Program at the University of Minnesota, conducted a survey of Native American adolescents attending reservation or Bureau of Indian Affairs schools. Among adolescents in grades 7 through 12, 35 percent of young men and 27 percent of young women had engaged in sex. Among the sexually active teens who used contraceptives, only 48 percent of the young men and 24 percent of the young women used condoms [Blum et al., 1992].

In Native American communities, traditional beliefs can be both an impediment to and a tool for confronting the epidemic. In the Navajo tradition, for instance, it is considered inappropriate to “talk about disease because if you do, you are wishing it on people,” according to Melvin Harrison, executive director of Navajo Nation AIDS Network [Brewer, 1996]. Additionally, within some tribal groups, such as the Navajo Nation, homosexuality is not officially recognized, making it difficult for the tribes to mount education campaigns addressing the risks of such

behavior [Sullivan, 1991]. However, Ronald Rowell, executive director of the National Native American AIDS Prevention Center, suggests that there are ways to use traditions to help in the fight against AIDS. He notes that one avenue for fighting homophobia is to try to educate people regarding traditional roles that gays have played in Native American cultural history. Traditionally, gays, who were considered part male and part female, served as marriage counselors. [Brewer, 1996]. Native Americans who are gay, lesbian, bisexual, or transgender (identified as “two-spirited”) have established annual conferences to promote their empowerment and to reclaim their traditional sex, gender, and spiritual roles so that they might address HIV and other health issues [McLeod, 1998]. Health education can also be presented by spiritual elders and healers who use traditional storytelling methods to teach members of their communities [Brewer, 1996].

Demographics

The Bureau of the Census defines a member of a Native American community as a person “having origins in the original peoples of North America, who maintains cultural identification through tribal affiliation or community recognition” [U.S. Bureau of the Census, 1978]. The Native American population comprises more than 500 American Indian tribes and Native Alaskan villages.

The Native American population numbered nearly 2 million as of July 1998 or 0.7 percent of the total population of the United States. The median age of this population in 1998 was 28 years, 10 years lower than the median age of the nation’s white population [U.S. Bureau of the Census, 1998]. In 1997, 27 percent of Native American families were headed by a single woman [Collins, L.V., 1997]. Native Americans have a higher rate of poverty than the rate found among the general U.S. population [U.S. Bureau of the Census, 1990].

There are startling differences in the incidence of certain diseases among Native Americans compared with whites. Among Native Americans over the age of 15, 1 in 3 reports having a disability and 1 in 7 reports having a severe disability [Collins, L.V., 1997]. Historically, this population has been disproportionately affected by infectious disease epidemics that have, in some cases, caused substantial decreases in the population’s numbers [Conway et al., 1992].

Urban Native Americans, for example, have higher incidences of communicable diseases such as hepatitis A and B, tuberculosis, and certain sexually transmitted diseases (chlamydia, gonorrhea, and syphilis) than urban whites have [Grossman et al., 1994]. People with communicable diseases such as these have been shown to have higher rates of contracting HIV than do people without these conditions [U.S. Department of Health and Human Services, 1990]. Thus, the higher incidence of these diseases in Native Americans is a significant marker for possible increased incidence of HIV infection in these communities [Sullivan, 1991].

Epidemiology

The Native American population under age 64 has mortality rates per 100,000 that are considerably higher than those of white Americans of the same age. For Native American males between the ages of 25 and 44, the mortality rate is 83 percent higher than that for corresponding white males. The mortality rate is 84 percent higher for Native American females between the ages of 25 and 44 than for their white counterparts [National Center for Health Statistics, 1997b].

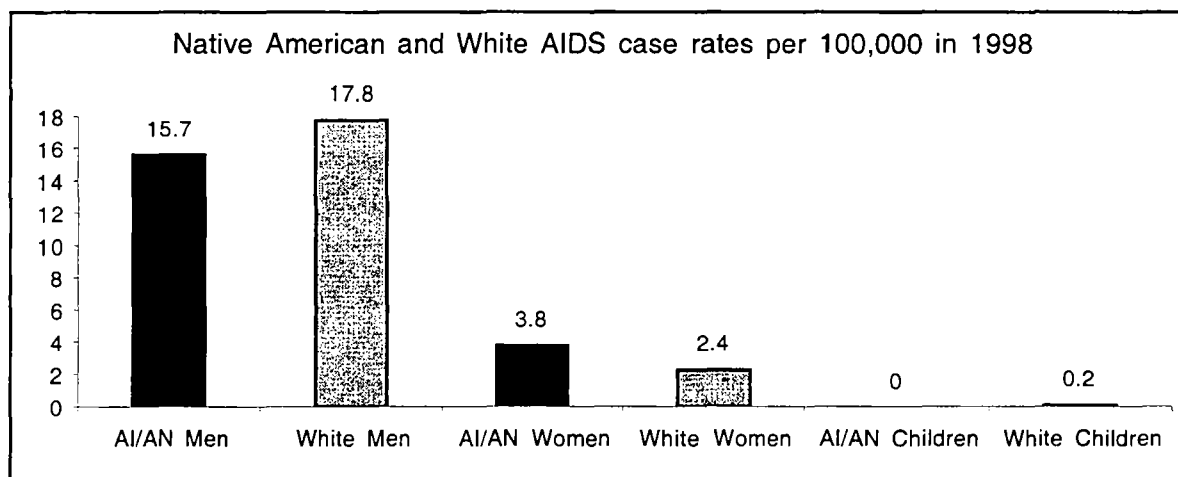
Racial misclassification is a significant obstacle in determining the extent of the epidemic in Native American populations. One study found that only 11 of 37 Native American AIDS clients of community-based AIDS organizations in Los Angeles were actually registered as Native Americans in the county's AIDS registry. The remaining 26 were classified as members of other races. The lack of agreement between case reports and death certificates suggests that Native Americans are commonly misclassified as either white or Latino [Smyser, Helgerson, and Hess, 1992; Lieb et al., 1989]. One possible explanation for misclassification is that some Native Americans have Hispanic surnames. Another reason stems from the ambiguity of the term "Native American," which some individuals interpret as meaning "born in the United States" [Lieb et al., 1992]. The result of all the misclassifications is that any statistics on AIDS in this community does not fully represent the extent of the epidemic among Native Americans.

Annual and Cumulative AIDS Incidence

Like APIs, Native Americans are underrepresented in the number of AIDS cases in the United States. Though they represent 0.7 percent of the nation's population, they accounted for under 0.3 percent (1,940) of the cumulative (688,200) AIDS cases reported through December 1998. In

1998 alone, the adult/adolescent AIDS case rate per 100,000 (9.7) was less than one-half the rate among the general population [Centers for Disease Control and Prevention, 1999].

Of the 1,940 cumulative AIDS cases diagnosed among Native Americans through December 1998, cases among adult/adolescent males represented 82.5 percent, cases among adult/adolescent females represented 16 percent, and cases among children under the age of 13 represented for 1.4 percent. In 1998, the annual AIDS case rate was 15.7 for men, 3.8 for women, and null for children. Of the 148 AIDS cases reported in 1998, 79.1 percent were among men and 20.3 percent among women. There were no cases reported among children [Centers for Disease Control and Prevention, 1999].



Source: Centers for Disease Control and Prevention, 1999

Native American Men

Native American men accounted for less than 0.3 percent of cumulative adult/adolescent male AIDS cases reported in the United States through December 1998 and for just over 0.3 percent (117) of new adult/adolescent male cases reported in 1998. MSM was the most frequently cited mode of exposure (57 percent), while men who use injection drugs or who identify MSM and IDU as risk factors accounted for 16 percent and 17 percent of cumulative cases, respectively [Centers for Disease Control and Prevention, 1999].

Native American Women

Similar to the men, Native American women accounted for less than 0.3 percent of both cumulative adult/adolescent female AIDS cases reported through December 1998 and new adult/adolescent female AIDS cases reported in 1998 alone. Forty-seven percent of women among the cumulative cases reported injection drug use as their primary mode of exposure. Heterosexual contact with an IDU accounted for 18.1 percent of the cases among these women [Centers for Disease Control and Prevention, 1999].

Native American Children

Native American children represented more than 0.3 percent of cumulative pediatric AIDS cases in the United States through December 1998. Although there were no reported Native American pediatric AIDS cases in 1998, two Native American pediatric AIDS cases were reported in 1997 [Centers for Disease Control and Prevention, 1998b and 1999]. Twenty-seven of the 28 cumulative cases reported through December 1998 were attributed to perinatal infection. One case was attributed to hemophilia or another coagulation disorder [Centers for Disease Control and Prevention, 1999].

AIDS Mortality

Of Native Americans reported with AIDS, 52 males and 16 females died in 1997. Cumulative deaths for Native Americans with AIDS numbered 877 males and 158 females through December 1998 [Centers for Disease Control and Prevention, 1999].

In 1995, HIV was not among the 10 leading causes of death for Native Americans even though HIV mortality for the population rose consistently between 1987 and 1995 [National Center for Health Statistics, 1997b]. In the first half of 1996, Native Americans had a greater decline in AIDS deaths, 32 percent, than did any other racial or ethnic group [Centers for Disease Control and Prevention, 1997c].

Native American AIDS Cases Reported in 1998, and Cumulative Totals through December 1998, United States

	<u>1998</u>		<u>Cumulative Total</u>	
	#	%	#	%
Adult/Adolescent Male				
Exposure Category				
Men who have sex with men (MSM)	53	(45)	919	(57)
Injection drug use	24	(21)	252	(16)
MSM and inject drugs	16	(14)	268	(17)
Hemophilia/coagulation disorder	2	(2)	28	(2)
Heterosexual contact:	3	(3)	39	(2)
<i>Sex with injection drug user (IDU)</i>	—		13	
<i>Sex with person with hemophilia</i>	—		—	
<i>Sex with transfusion recipient with HIV infection</i>	—		1	
<i>Sex with HIV-infected person, risk not specified</i>	3		25	
Receipt of blood transfusion, blood components, or tissue	—	(—)	8	(0)
Risk not reported or identified	19	(16)	87	(5)
Total	117	(100)	1,601	(100)
Annual rate per 100,000 population		15.7		
Adult/Adolescent Female				
Exposure Category				
Injection drug use	16	(53)	146	(47)
Hemophilia/coagulation disorder	—	(—)	1	(0)
Heterosexual contact:	4	(13)	111	(36)
<i>Sex with IDU</i>	3		56	
<i>Sex with bisexual male</i>	—		15	
<i>Sex with person with hemophilia</i>	—		2	
<i>Sex with transfusion recipient with HIV infection</i>	—		—	
<i>Sex with HIV-infected person, risk not specified</i>	1		38	
Receipt of blood transfusion, blood components, or tissue	—	(—)	13	(4)
Risk not reported or identified	10	(33)	39	(13)
Total	30	(100)	310	(100)
Annual rate per 100,000 population		3.8		
Pediatric				
Exposure Category				
Hemophilia/coagulation disorder	—	(—)	1	(4)
Mother with/ at risk for HIV infection:	—	(—)	27	(96)
<i>Injection drug use</i>	—		12	
<i>Sex with IDU</i>	—		7	
<i>Sex with bisexual male</i>	—		—	
<i>Sex with person with hemophilia</i>	—		—	
<i>Sex with transfusion recipient with HIV infection</i>	—		—	
<i>Sex with HIV-infected person, risk not specified</i>	—		3	
<i>Receipt of blood transfusion, blood components, or tissue</i>	—		—	
<i>Has HIV infection, risk not specified</i>	—		5	
Receipt of blood transfusion, blood components, or tissue	—		—	
Other/Undetermined	—		—	
Total	—	(—)	28	(100)
Annual rate per 100,000 population		0		

TOTAL and ANNUAL RATE PER 100,000 POPULATION	148	7.4	1,940
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Source: Centers for Disease Control and Prevention 1999

Community Concerns

The following community concerns were identified by NCOA in 1992 that are still relevant today.

Burnout. In the absence of community-wide awareness, a few dedicated individuals are providing the prevention education, direct service delivery, advocacy, support, and education that tribal leaders and governmental bodies need to address the emerging epidemic among Native Americans. The efforts of these individuals have been critical to raising awareness of the HIV epidemic among Native Americans.

Community Diversity. Group-specific and culturally competent AIDS education activities are sorely needed. No single approach to education and prevention will work for all Native Americans communities. Each nation or community has culturally specific attitudes and beliefs, particularly with regard to sex and sexuality. This diversity in beliefs requires that prevention programs be designed and delivered with input from each nation or community. Native American AIDS service providers told commission members that in their experience, AIDS education messages and materials are effective for Native Americans only when they are introduced by other members of their community. Recognition must also be given to the different needs of Native Americans living in isolated rural areas, such as in Alaska, and those people living in urban settings.

Confidentiality. A consistent theme throughout the commission's site visits was the issue of confidentiality. Individuals and tribal leaders voiced concern over the inability of the Indian Health Service to protect the confidentiality of patients. Evidence of breaches of confidentiality served to reinforce already prevalent fears of discovery and discrimination, fears that may prevent people from seeking HIV education, care, and treatment. Similar concerns were raised regarding the lack of sites for anonymous testing in states such as Minnesota and South Dakota.

Demographic Collapse. The poor health status of Native Americans as a whole and their vulnerability to HIV makes the virus a threat to this population. Many Native Americans see this epidemic as a threat that could produce another demographic collapse in their populations, especially if measures are not taken rapidly at all levels to prevent the spread of the virus.

Denial. Recognition that the HIV epidemic is an issue for Native Americans is inhibited by denial within Native American communities over the prevalence of MSM and of drug use.

Funding. During several visits, the commission heard of the need to have CDC fund tribal programs directly instead of distributing funds through layers of bureaucracy within state governments and within the Indian Health Service. The need for longer-term funding of programs was also made evident.

Health Care Providers. Many people who spoke to the commission expressed concern over the availability of health care providers who were knowledgeable about caring for people with HIV disease.

Invisibility. Perhaps the single greatest barrier to HIV prevention and care among Native Americans is their invisibility as a people. This invisibility is a result of two factors: the low numbers of Native Americans in the overall U.S. population and the multiple stereotypes that obscure a clear recognition of Native Americans. This invisibility places Native American people at a disadvantage when fighting AIDS because public resources often are distributed through a system that recognizes numbers or rewards the visibility engendered through effective organizing. Unfortunately, Native Americans are few in number and have been unable to capture public attention.

Services. Throughout the commission's visits in Native American communities, individuals and service providers complained of a lack of coordination among federal, state, and tribal governments in their efforts to deal with the HIV epidemic in Native American communities. Historically complicated relationships between the federal and state governments and the Native American nations have made effective HIV service delivery and health care financing difficult.

Individuals described situations in which they were shuffled between agencies or, even worse, turned away because there was no clear definition of which agency was responsible.

Programs in Place

AIDS Education and Training Center (AETC)

The National HIV/AIDS Education and Training Center Program, funded under the Ryan White CARE Act, is designed to educate and train health care providers in preparation for the care of HIV-positive patients. Begun in 1987 with four centers, the program has expanded to a network of 15 regional centers with more than 75 local performance sites, providing coverage for all 50 states, the Virgin Islands, and Puerto Rico. "The mission of these centers is to increase the number of health care providers who are effectively educated and motivated to counsel, diagnose, treat, and manage individuals with HIV infection and to assist in the prevention of high risk behaviors which may lead to infection" [American Medical Association, 1996]. A 1993 study demonstrated that providers trained by the AETC are both more competent and more willing to care for HIV patients than the general population of primary care providers. The progress made in training health care providers can be measured by the more than 700,000 providers who have participated in the program since 1991 [Health Resources and Services Administration, 1998].

National Health Service Corps

In 1992, NCOA made the following recommendation.

How has the President and Congress supported the National Health Service Corps in encouraging health professionals to work in underserved areas? What steps has the federal government and federal agencies taken to develop additional incentives similar to that of the National Health Service Corps?

A program that has been helping to fill the health care needs of people in underserved areas has been the National Health Services Corps. For more than two decades, the National Health Service Corps, founded by the United States Public Health Service in 1970, has recruited talented and committed health professionals to serve those areas of the country with the most critical needs. The corps offers scholarships and loan repayment options to medical students and health professionals who agree to serve for a minimum of two years in a designated underserved area in return for financial assistance with their medical education [Health Resources and Services Administration, 1996].

The proposed Disadvantaged Minority Health Improvement Act of 1990 directed the Secretary of Health to “make grants to schools for health professions for scholarships to full-time students from disadvantaged backgrounds” and to appropriate funds to schools for health professions with individuals from disadvantaged backgrounds constituting at least 25 percent of the enrollment [101st Congress, 1989]. Congress did not pass the proposed legislation.

Office of Minority Health

The Health Resources and Services Administration’s Office of Minority Health supports a variety of programs aimed at increasing the number of minority health professionals in the United States. The Office of Minority Health also works with the private and public sectors to oversee the design, implementation, and technical assistance of minority training programs as well as a Minority Management Development Program. Together these programs focus on advancing underrepresented people of color and disadvantaged individuals into health professions and management or administrative positions within the managed care industry [Office of Minority Health, 1997].

The Office of Minority Health also initiated the founding of the nonprofit National Association of Hispanic-Serving Health Professions Schools in 1996. This “partnership between the Federal government, health professions institutions/academic health centers, and the private sector” was incorporated to address the underrepresentation of Latinos in the health professions. By building from grade school programs through professional schools and institutions, the National Association of Hispanic-Serving Health Professions Schools works to ensure “the availability of sufficient Hispanics in the health care workforce” to meet the needs of the rapidly growing Latino communities [Office of Minority Health, 1997].

Association of American Medical Colleges

The Association of American Medical Colleges (AAMC) has established a number of programs targeted at improving minority enrollment in medical schools. Begun in 1991, Project 3000 by 2000 has helped reverse the trend toward decreased enrollments of underrepresented minorities with efforts that have spurred a 27 percent increase in matriculates and a 40 percent increase in applicants over a three-year period [Association of American Medical Colleges, 1996]. In addition to Project 3000 by 2000, the Robert Wood Johnson Foundation has helped the association establish a grant program to fund their Health Professions Partnership Initiative, the purpose of which is to increase representation of minorities in health professions by improving their access to high quality, precollege education.

The goal of AAMC and the Robert Wood Johnson Foundation is to encourage schools for health professionals to work with public schools and colleges in their communities to help prepare the minority health profession students of the future. Timothy Ready, director of the AAMC's Project 3000 by 2000, says:

The scarcity of Black, Latino, and American Indian applicants to health professional schools does not stem from a lack of interest in health careers. It is the result of pervasive and systemic educational disadvantages in many minority communities across the country. . . . Although the causes for these disparities are complex, it is no coincidence that they disproportionately affect the same minority communities that have borne the brunt of prejudicial treatment throughout most of American history. [Association of American Medical Colleges, 1996]

Ultimately, the advancement of persons of color into the health professions will play a major role in improving the accessibility that members of minority communities have to health care.

Equally important will be training physicians and service providers to be knowledgeable on HIV; this will greatly improve community prevention efforts and the care of people infected with the virus.

Presidential Advisory Council on HIV/AIDS

The past seven years have seen mostly weak responses to the challenges laid down by NCOA. As evidenced by the CBC's call in 1998 for the declaration of a public health emergency in minority communities, there is clearly a need for national efforts to be more focused and responsive to the most vulnerable populations. While the Presidential Advisory Council on HIV/AIDS and NCOA differ in genesis (the commission was created and appointed by Congress while the council was created and appointed by President Clinton), their missions are similar. The council serves as an adviser, watchdog, and conduit to and from communities affected by the epidemic. Since the council was created in 1995, it has clearly affected Administration policies including the several recommendations it has made to strengthen the federal response to the epidemic in communities of color. Of course, not all of what the council has recommended has been accepted by the President and his Administration. In particular, its call for a lifting of the ban on federal funds to support NEPs—programs that could significantly reduce the high transmission rates among IDUs and within minority communities—was rebuffed by the President in 1998.

The council has been one of the many voices across the United States that have continually advocated for people infected with HIV. By virtue of its mission, the council is in a key position to help shape federal HIV and AIDS policy.

The authority of the council is well established as evidenced by several facts: 1) the President has recognized that members of the council are key players in the AIDS arena; 2) the President has publicly stated that the council has an important role to play in shaping national AIDS policy; 3) the President, working through Sandra Thurman, a former member of the council and now the director of the Office of National AIDS Policy, has a close working relationship with the council; and 4) the council provides advice directly to the President in the form of recommendations, letters, and written reports and works in tandem with the national and international AIDS community and with the various federal agencies and departments that implement federal AIDS policy.

The council is a remarkably diverse group comprising men and women of various cultural backgrounds, sexual orientation, HIV status, and professional backgrounds including health care, research, religion, community-based organizations, and AIDS service organizations. Members must serve on at least one of the council's three main subcommittees that focus on prevention, services, or research, and they are free to serve on one or more of the council's five subcommittees that focus on issues of discrimination, racial and ethnic populations, international issues, prisons, or appropriations.

Although all activities of the council benefit racial and ethnic populations directly or indirectly, it is evident that there are several area of activity that have an overwhelming effect on these populations including those addressing access to treatment, prevention, women, youth, housing, and discrimination. In June 1998, the council declared that its priority during the following year would be to focus on the specific needs of racial and ethnic populations. The council agreed that racial and ethnic issues would be woven into all aspects of its efforts and that each of its subcommittees would specifically address how any new recommendations would affect racial

and ethnic populations. This was the first formal agreement that racial and ethnic issues would be a priority for the council.

Addressing Racial and Ethnic Issues at the Highest Levels

Since its creation, the council has passed numerous resolutions, requested status reports, met with key federal and private-sector policymakers, and expressed its concern over the pace of progress on issues that most affect racial minorities. Although some of the council's resolutions have been acted upon either completely or partially by the Administration, several issues remain of great concern.

The council continues to weigh in on a number of other issues such as the debate over an enhanced HIV-surveillance reporting system, return-to-work issues, international AIDS efforts, microbicide development; incarcerated populations, Medicaid expansion and waivers, Medicaid entitlement and appropriations, ADAP and private insurance coverage, HOPWA, discrimination, the appropriations process, Congress and federal legislation, youth (with a focus on gay and bisexual youth), and women, especially women of color.

Of particular importance to the council is the lack of adequate funding for HIV-prevention programs, especially programs targeting populations hardest hit by the epidemic. During its March 1998 meeting, the council expressed "no confidence" in the Administration's prevention efforts because it felt the Administration had both failed to fund needle exchange programs despite solid scientific evidence that such programs, when part of a comprehensive prevention strategy, decreased HIV infection rates and did not lead to increased drug use and failed to increase funding for prevention efforts despite the President's declared intention "to reduce new HIV infections until there are none." The council expressed strong concern that prevention goals will not be met without additional funding, especially funding targeted, specifically for minority populations, including youth and women.

The council, acting on the President's May 1997 statement that a vaccine to prevent HIV must be developed within the next decade, called for a coordination of federal efforts with those of the private sector and the international community to ensure that this goal be met. The council also

recommended the development of a national plan to find a vaccine as well as for the establishment of a position to oversee the implementation of such a plan.

The council recognizes that its efforts at direct and indirect coordination with the AIDS community, federal agencies, and the private sector have been successful in many areas and that its efforts, coupled with those of the multitude of national organizations and supporters within the Administration have meant that a lot more can be accomplished. Although funding for prevention efforts has not increased as quickly as it has for other areas, the council and other groups have been instrumental in ensuring that funding continues to be allocated at the local level through the Prevention Planning Councils and through direct funding of community-based organizations.

The council is in a key position to move the AIDS agenda forward, especially as that agenda addresses the concerns of communities of color. Recent discussions by the Administration and the Department of Health and Human Services have dealt with the President's Initiative on Race and with the need to eliminate disparities in health, providing the council with a great opportunity to focus the debate on HIV in racial and ethnic populations and to provide input at critical stages of the discussions. The council's goal is to ensure that this attention is not temporary but rather is a committed and sustained effort by the Administration, federal agencies, and national and international AIDS organizations to provide leadership and to adequately address the epidemic in minority communities.

The challenge of HIV and AIDS in minority communities is broad-reaching and varied and is one that is in desperate need of invigorated attention. A number of people and groups active against the epidemic were surveyed for this report including people who work daily within their communities and in organizations from around the country—from federal disease-prevention programs to local community-driven outreach organizations. All were asked to describe the innovative program or project they felt represented an effective approach to the challenge of HIV and AIDS in their community. The following section of this report presents this information as suggestions for adopting and adapting existing programs, as federal programs developed by the CDC, and as HIV-related programs showcased by nongovernmental organizations.

Centers for Disease Control and Prevention (CDC)

As the HIV epidemic devastates our communities of color, it challenges the infrastructure and priorities of our nation. The CDC is the main federal body that both monitors the epidemic and seeks to prevent its spread in the United States. Since 1988, the CDC has implemented the following programs to support local and national efforts to reduce the spread of HIV in communities of color.

- **Cooperative agreements with state and local health departments.** Through these agreements, \$253 million in current funding is provided state and local health departments to work with HIV Prevention Community Planning Groups to develop interventions to meet prevention needs. Specific HIV-prevention activities and services that focus on preventing or reducing high-risk behavior in racial and ethnic minority populations are currently funded with 57 percent (\$143 million) of the total funds.
- **Direct funding to minority community-based organizations.** Programs are funded to provide HIV-prevention case management, street and community outreach, educational workshops, and peer training-of-trainer programs. The CDC currently provides \$18 million to 94 of these organizations, 71 of which direct their programs toward African Americans.
- **Funding to national and regional minority organizations.** Nine million dollars in funding is provided to organizations that strengthen and increase the effectiveness of HIV-prevention efforts for racial and ethnic minority populations at high risk of HIV infection. Additional funds are provided to support assessments of the technical assistance needs of organizations serving minority populations.
- **Faith initiative.** Programs are designed to foster collaboration and participation of faith communities in HIV-prevention efforts in African American communities. In 1997, the CDC provided technical assistance and \$900,000 in funding to support multisectoral programs for HIV prevention. Approximately one-half of the funded programs target faith communities among African Americans.
- **Social marketing funding.** Funds are awarded to develop partnerships among national organizations to extend HIV-prevention strategies into communities and to strengthen social norms that contribute to the prevention of HIV.
- **Business responds to AIDS/Labor responds to AIDS (BRTA/LRTA).** The BRTA/LRTA programs recruit and support minority corporate leaders to serve as technical experts and/or advisors for HIV-prevention activities in African American communities. Participants in these groups include African American chief executive

officers of major national corporations; minority leaders in religion, politics, education, and sports; minority entertainment celebrities; and BRTA/LRTA partners, consultants, and business and labor experts [Centers for Disease Control and Prevention, 1998a; Gayle, 1997].

From 1989 through 1994, the CDC, along with researchers from five different sites, began an investigation of community-level prevention programs. Known as AIDS Community Demonstration Projects (ACDPs) these programs sought to “determine the efficacy of a specific community-level intervention for groups considered hard to reach and, if effective, to apply the strategies used in the intervention to subsequent HIV prevention programs” [Centers for Disease Control and Prevention, 1996a]. The ACDP study focused on behavior changes among people at risk of sexually transmitted or needle-borne infections. The findings from the study indicated that community-level interventions could favorably influence people who were at risk to adopt consistent risk-reducing behaviors if they were allowed sufficient time and given adequate exposure to the intervention.

Owing to the rapid pace of evolving technologies for HIV testing and treatment as well as changes in behavioral interventions, the CDC is working to address the following new needs: 1) increasing capacities to provide technical assistance, 2) evaluating programs and services to improve prevention effectiveness, 3) using new research findings, therapies, and technologies to develop innovative tools and interventions for prevention, and 4) strengthening the scientific basis for HIV-prevention programs [Gayle, 1997].

To strengthen HIV-prevention efforts, the CDC also plans to allocate additional funds to enhance HIV-related research and evaluation projects and technical assistance activities. The largest portion of CDC funding for HIV prevention is intended to support unmet prevention needs identified through the HIV-prevention community planning process [Gayle, 1997].

Programs by Nongovernmental Organizations

The challenge remains to develop strategies to combat new HIV infections in communities where they are most likely to occur and to provide culturally relevant services to people from all social and ethnic backgrounds. People living with HIV may require varying levels of social service supports depending on a host of factors including their health status, availability of family and other personal supports, socioeconomic status, and their history of medical or social

complication. Communities must work to maintain the stability, dignity, and independence of individuals at every stage of the disease.

The most important foundation for any kind of initiative is the support from the community to which it is targeted. This concept was recognized by NCOA in 1992 and has been consistently used by community-based organizations in their development of culturally sensitive programs. People from all backgrounds must be given the incentive to build communities that value HIV-risk reduction and encourage protective behaviors. “Actively developing and implementing HIV prevention programs appropriate to the needs of ethnic, cultural, and linguistic minorities, while integrating HIV education and awareness programs into existing services used by members of these communities, allows for completed validation of the existence of the community’s history and most importantly, it’s future” [Philadelphia Community Planning Group, 1994].

The following program descriptions have been recommended by various nongovernmental HIV- and AIDS-related organizations from across the county. They are included to raise discussion about what has worked in different communities and to serve as suggestions for other communities struggling to answer similar needs. The areas addressed by the following programs include:

- | | |
|-----------------------|--------------------------------|
| • Access to Treatment | • Migrant Farmworker Education |
| • Case Management | • Orphan Care |
| • Church Leadership | • Peer Education |
| • Client Services | • Physician Education |
| • Community Outreach | • Prevention |
| • Hospice Care | • Program Support |
| • Housing Services | |

Access to Treatment and Peer Education

Philadelphia Fight showcases **Project TEACH (Treatment Education Activists Combating HIV)**. Project TEACH, founded in 1996, presents the basics of secondary prevention to low-income, HIV-positive people and especially to African American who are recovering drug users. The program also teaches methods of communicating the information to others living with HIV. The program seeks to empower these individuals by disseminating current and accurate treatment information that is culturally and linguistically appropriate. Topics include staying healthy through assertive use of health care, pharmaceutical and complementary therapies, prevention and early treatment of infections, nutrition, clinical trials, stress reduction and peer support, and communication and advocacy skills.

Graduates of Project TEACH participate in the peer education program, speaking to groups and individuals in health clinics, drug treatment centers, and mental health drop-in facilities, or they work for other regional peer educational programs. In the first year of the program, 120 graduates went on to have formal and informal peer education interactions with hundreds of people. Project TEACH members learn skills and receive support to continue to mobilize against the epidemic, to fight to maintain the health of HIV-positive people, and to become knowledgeable and effective community representatives wherever they are needed.

Project TEACH added training for active drug users at a syringe-exchange drop-in center and a women-only discussion group focusing on issues of women's health, perinatal transmission, and pediatric HIV and AIDS. Project TEACH works to recognize the importance of peer educators as health educators and to support recognition of the needs of professionals involved in Project TEACH and other peer education projects.

Philadelphia Fight

Philadelphia, Pennsylvania

Phone: (215) 985-4HIV(4448), Fax: (215) 985-4952

Case Management

The **National Native American AIDS Prevention Center** showcases the network known as **Native Care: HIV/AIDS Integrated Services Network for American Indians, Alaskan Natives, and Native Hawaiians**. The network implements the Ahalaya Case Management model to provide culturally responsive case management services and HIV education to local

Native American communities. Case managers are able to seek assistance for their clients from whatever provider is able to help. The program focuses on access to existing services and is relatively inexpensive to operate. It has the additional attraction of being a bridge between Native American and mainstream systems of care by integrating services on behalf of clients. These programs have achieved more overall cooperation and collaboration between service providers in areas where the programs have operated. Programs have been run in sites in Arizona, Hawaii, Minnesota, New York, and Oklahoma.

The case management model contains a vital Native American cultural component. This is expressed in two ways. First, programs work with traditional healers to allow clients access to their services. Second, programs focus on maintaining relationships or reconnecting individuals with their families and cultural communities. This helps maintain the mental as well as physical health of the clients.

The success of this case management program has led to the expansion of research opportunities for the Native American population. The center currently is examining further refinements of case management and service access models as well as the relationships among substance abuse, STDs, and HIV infection.

Since the founding of the National Native American AIDS Prevention Center in 1987, the center has found that the majority of clients served at every location report less stress and improved health. Clients around the country have overwhelmingly reported that they feel they are better served when their provider is Native American.

National Native American AIDS Prevention Center

Oakland, California

Phone: (510) 444-2051, Fax: (510) 444-1593

Church Leadership

The Balm In Gilead showcases their **Black Church Week of Prayer for the Healing of AIDS**. This national program, modeled after the organization's successful local program, The Harlem Week of Prayer for the Healing of AIDS, is an AIDS education campaign designed especially for the black church community. Formerly a one-day event, the now weeklong observance begins every first Sunday in March and continues throughout the week. Today, thousands of African American churches and communities across the nation are using the power of prayer and

education to prevent further HIV transmission and to care for individuals and families whose lives are touched by AIDS. To help National Week participants create effective programs, The Balm In Gilead offers training and support services for individual churches, community-wide collaborations, and statewide initiatives.

The Balm In Gilead is a not-for-profit, national organization dedicated to stopping the spread of HIV through educating and mobilizing African American churches to become community centers for HIV-prevention education and compassionate care. The Balm In Gilead created The Black Church Week of Prayer for the Healing of AIDS in 1992 to bring attention to the role African American churches must play in the AIDS crisis. The church has always been a pivotal voice and consciousness of the African American community. However, The Balm In Gilead believes that the overwhelming silence among African American churches must be counted as a factor along with inadequate prevention messages, poverty, substance abuse, homelessness, and poor health care for the soaring rate of HIV infection among African Americans. In order to end the AIDS epidemic in the African American community, African American churches must be mobilized to become strong voices of advocacy, education, and prayer for the healing of AIDS.

The Balm In Gilead

New York, New York

Phone: (212) 730-7381, Fax: (212) 730-2551

Client Services

The **Asian Pacific AIDS Intervention Team (APAIT)** showcases their “**family room**” **day drop-in program**. This program recognizes the strong familial ties of many APIs and uses socialization and activities to support HIV-positive clients. Western-style support groups are foreign concepts that even some American-born APIs are not accustomed to. “We were not taught by our parents to ask for help and disclose personal information to strangers” is an example of comments by APAIT clients. On the other hand, playing mah-jong (Chinese tile game), eating Asian dishes, and informal gatherings like “talking story” (Hawaiian influences) are familiar to APIs and allow them to socialize in nonthreatening and culturally appropriate ways.

Breaking through isolation is accomplished in the day program. A client of the team can obtain emotional support from his or her peers. Once a sense of comfort and trust has been established, other services, such as individual counseling and case management services, are introduced.

Treatment education roundtables are conducted within the day program and are aimed at increasing clients' knowledge of Western and complementary therapies. Clients ultimately learn about community resources and are able to choose the services that meet their needs.

APAIT began its HIV and AIDS work in 1987 so as to address the diversity of the API gay, lesbian, bisexual, and transgender populations. The "family room" is one of a number of programs which works with the diverse API cultures to break barriers and develop self-efficacy and empowerment. The success of the client services program is evident in the number of clients who are proactive in their care, interested in improving their quality of life, and willing to help others like themselves. This is demonstrated in the biannual retreats organized by and for HIV-positive APAIT clients so that they may share the knowledge they have gained, learn new ways to cope and take care of themselves, or simply get away from the city for a weekend with their peers.

Asian Pacific AIDS Intervention Team
Los Angeles, California
Phone: (213) 553-1830, Fax: (213) 553-1833

Community Outreach

The **Minnesota American Indian AIDS Task Force** showcases their **educational outreach** programs. Using a cultural approach the task force's Native American instructor/outreach worker applies spiritual and cultural teachings to the issues, presenting information on HIV-prevention responsibilities to families, clans, communities, and the Native American nation. This information is conveyed through a variety of methods including lectures from HIV-positive speakers who are Native Americans, elders, and videos; presentations of basic facts and statistics about HIV and sessions on skills-building approaches. Information presented covers sexuality, substance abuse, risk reduction, and psychosocial factors related to risk and protection. The skills-building sessions focus on negotiating condom use, on sexual histories, and on being able to make choices about needs, wants, and desires related to sex.

The purpose of this educational outreach is to encourage participants to look at the history of oppression that has resulted in prevalent substance abuse, destructive relationships, sexual abuse, violence, and the intergenerational manifestations of these problems. The effects of these phenomena must be understood before resistance skills can be built and healing can begin. This form of culturally based education promotes participants' examination of the barriers and social

divisions within Native American communities that are created by homophobia, racism, tribalism, ageism, sexism, and AIDS-phobia. These divisions prevent community members from addressing HIV and helping and supporting those affected.

Since its founding in 1987, the Minnesota American Indian AIDS Task Force has been identifying community needs surrounding HIV and AIDS and creating culturally driven strategies to address those needs. All programs are culturally based and are developed with considerable input from client groups. They include: Ganawenima (“To Take Care Of”) Case Management Program, Ogitchidag Gikinoomaagad (“Warrior Teachers”) Peer Education Program, Community Education Program, Correctional Facility Outreach Program, Two Spirit Risk Reduction Project, Women’s Peer Education Program, and the Maynidoowahdak Odena (“A Place Where Ceremonies Happen”) Housing Project.

Minnesota American Indian AIDS Task Force
Minneapolis, Minnesota
Phone: (612) 870-1723, Fax: (612) 870-9532

Hospice Care

Omega House of Houston showcases their **residential hospice care program**. This program has a population that is representative of Houston’s HIV-infected population: slightly under 50 percent white, 22 percent Latino, 27 percent African American, and a small percentage from other ethnic communities. Many residents come from a county hospital facility that does not meet their needs as personally and efficiently as Omega House.

Various house staff and volunteers speak one or more of nine different languages enabling them to communicate with residents and their families from a wide range of ethnic backgrounds. Program brochures and other documents are available in both English and Spanish and a staff member fluent in these languages is on premises during business hours. Omega House staff attend 12 hours of cultural sensitivity training during their employment to ensure that all staff members are well equipped to meet the needs of residents.

Omega House was established in 1986 by Eleanor Munger, an early AIDS Foundation hospital visitation volunteer, who saw the need for a place, other than the wards of charity hospitals, where dying AIDS patients could receive care. To date, Omega House has cared for more than 370 people. Since its inception, Omega House has been the only facility in Houston offering

more than 30 days of residential, terminal-stage care to people with AIDS without regard for their ability to pay.

The intensive commitment of caring for end-stage patients often exhausts caregivers, who may be ill themselves. And with the epidemic spreading among women and children, it is virtually impossible for a caregiver to provide adequate attention to everyone in a household. Omega House believes that in such situations residential hospice care may be a valuable option. As HIV spreads and the number of persons with AIDS continues to increase, there will continue to be a need for hospice care for the medically indigent.

Omega House, Inc.,

Houston, Texas

Phone: (713) 523-7110, Fax: (713) 526-8144

Housing Services

The **AIDS Action Committee** of Massachusetts showcases their **residential and housing advocacy programs**. The programs were founded in 1992 through a collaboration with community development corporations in several Boston neighborhoods that were seriously affected by HIV. All programs serve low-income households representing a range of racial and ethnic backgrounds. The first residence to open was the SRO Collaborative, providing single housing units and support services to 30 persons with AIDS. In the next four years, the department opened two other residential programs, the Joseph McAllister House, with nine efficiency apartments, and the Joy Street Residence, which serves both individuals and families affected by AIDS. Additionally, the department has created two statewide, short-term rental assistance programs: The Homelessness Prevention Program, which helps prevent evictions by assisting with rent payments for five months; and the Rental Start-up Program, which provides households with their first month's rent and security deposit. The department also expanded its Housing Advocacy Program, which provides housing search and assistance to four sites, including the city hospital and a shelter for homeless people.

Housing advocacy clients come from diverse backgrounds and have a wide range of social and health issues. Approximately 60 percent of those served in the AIDS Action Committee's residential programs, especially the SRO Collaborative, are from communities of color. Residential clients bring with them a number of confounding issues that are unrelated to their HIV status but that have a great impact on their overall health and the health of the community.

Addiction and mental illness are difficulties confronted by a majority of clients. Residential services has developed a working model for addressing such difficulties. It is based on a harm-reduction philosophy and uses a flexible, nonjudgmental, and behavior-based approach to the disease of addiction. The Housing Advocacy Program has been very successful in reaching households from communities of color because it provides outreach services in community health care facilities, where most members of communities of color go to receive social services and primary health care, and it serves clients in their neighborhood health centers or the city hospital, where their confidentiality can be protected.

The changing face of the AIDS epidemic is affecting women and children from communities of color. A growing need is residential housing programs for families, since the majority of the programs existing today only serve individuals. As more women become infected, the AIDS Action Committee hopes to expand its services to provide housing and related services to women and their children.

AIDS Action Committee

Boston, Massachusetts

Phone: (617) 437-6200, Fax: (617) 437-6445

Migrant Farmworker Education

The **National Coalition of Advocates for Students** showcases their ***Viviremos* Project**. Sponsored by and in collaboration with state and local education and health agencies and community-based organization, *Viviremos* training sessions prepare selected people at major migrant sites to implement the coalition's bilingual (Spanish/English) curriculum, "Viviremos! On the Road to Healthy Living/El Camino Hacia La Salud." This curriculum, designed specifically for farmworker youth, is composed of five bilingual lessons that focus on essential HIV education, skills-building to assess risk behaviors, problem solving, development of self-worth, and communication skills to negotiate risky behaviors. The *Viviremos* Project also works with farmworker parents in a family-centered approach. Parents are provided with Spanish language tapes, produced by the Northwest Chicano Radio Network, that focus on improving communication between parents and their children on the topics of sex, HIV, and other STDs.

Since 1987, the *Viviremos* Project has helped build the capacity of education, health, and community-based farmworker organizations in more than 20 states to present effective prevention education to youths and families working as seasonal and migrant labor. *Viviremos*,

funded through a grant from the CDC, has played an important role in building linkages between migrant health and migrant education through advisory committees convened in key migrant states. Within the CDC's Division of Adolescent Student Health, *Viviremos* is the only project of its kind designed to prevent the spread of HIV among farmworker youths. *Viviremos*, committed to building school-community partnerships, has helped develop standards for the delivery of education and health services to prevent HIV infection among this population. The coalition also has developed a series of documents on farmworker education, school-based education, and student support services that are available to anyone who calls.

Most recently, the *Viviremos* Project, now in its 12th year, is focusing its efforts in the three states with large migrant labor populations: Florida, Texas, and California. In conjunction with this effort, the coalition is working with *Viviremos* trainers, state departments of Migrant Education and Health, and with community-based organizations to ensure geographic availability of certified *Viviremos* trainers who will continue to provide culturally competent HIV education to farmworkers well beyond the life of the project.

National Coalition of Advocates for Students
Boston, Massachusetts
Phone: (617) 357-8507, Fax: (617) 357-9549

Orphan Care

The Orphan Project showcases its program for **policy research on children orphaned by the AIDS epidemic**. As a result of the epidemic and its link to drug abuse, it is estimated that by the year 2000 more than 125,000 children and adolescents in the United States will have lost their mothers to AIDS. The majority of these youth are African American and Latino. A foundation-supported effort, The Orphan Project's goal is to stimulate research on and explore policy options for the entire spectrum of affected children—from dying infants to healthy adolescents. Of particular concern are issues concerning confidentiality and disclosure, custody and placement, bereavement, emotional and financial support for infected parents and new caregivers, and greater public awareness of the problem.

In carrying out its works, The Orphan Project convenes meetings, publishes articles and reports, and develops collaborative work with researchers, direct service providers, and family members. Although New York City is its primary focus of its activities, The Orphan Project also collaborates with concerned individuals and organizations in other regions and focuses on global issues relating to orphans of the HIV epidemic in the developing worlds. In collaboration with

the Family Center, a direct service organization, The Orphan Project has organized a Permanency Planning Network of more than 50 agencies that provide legal and social services, funders, and other interested individuals. The network convenes meetings with guest speakers who address a variety of topics concerning HIV-affected families and the providers who serve their needs. The network also has a separate legal subcommittee.

The Orphan Project was established in 1991 by Carol Levine, an AIDS policy researcher active in the field since 1982. Prior to her work with David Michaels, an epidemiologist, there were no reliable estimates of the number of children orphaned by AIDS. The Orphan Project's future issues include disseminating the results of experience to date, finding ways to support young caregivers, and developing a global community of researchers and practitioners.

The Orphan Project

New York, New York

Phone: (212) 494-0755, Fax: (212) 494-0823

Peer Education

Southwest Community Services in Philadelphia showcases their “**Don’t Believe the Hype**” radio program and **Teen Health Related Issues Video Education (THRIVE) Project**. Both projects are produced by and for area youth who are primarily African American with guidance provided by Misericordia Hospital W/SW AIDS Community Advisory Committee. The hour and a half, live, call-in AIDS radio program allows the audience, guest speakers, area youth, and professional staff to discuss AIDS concerns. The program, which is interspersed with contemporary music, reaches approximately 5,000 listeners weekly. The THRIVE Project involves more than 60 teens in the scripting, acting, and production of reproductive health videos on such issues as abstinence, condoms/safer sex, and peer power. These teens also serve AIDS peer educators within their schools, churches, and communities.

Southwest Community Services was founded in 1990 by area residents to identify community needs and to create community-driven strategies to address those needs, focusing on low-income and minority residents. The organization has been particularly active in responding to the alarming number of reported AIDS cases in their area of the city. All programs, services, activities and resources are introduced and staffed by minority residents from southwest Philadelphia.

Southwest Community Services, Inc.
Philadelphia, Pennsylvania
Phone: (215) 729-8911, Fax: (215) 729-8915

Physician Education

The **Harvard AIDS Institute** showcases the **Arthur Ashe Program in AIDS Care**. In response to the need for minority providers trained in AIDS care and to the severity of the epidemic in communities of color, the Harvard AIDS Institute, The Henry J. Kaiser Family Foundation, and National Medical Fellowships, Inc., have established the Arthur Ashe Program in AIDS Care, which seeks to foster the participation of medical students from traditionally underrepresented groups in HIV-related care and research. The program also aims to provide students with a means of obtaining essential AIDS-related clinical skills since such knowledge can often mean the difference between life and death for their patients.

The program consists of a four-week multidisciplinary training program in HIV care and AIDS-related issues for fourth-year medical students. Students spend their days in clinical rounds with physician mentors who are especially knowledgeable about HIV and AIDS. Intensive seminars, lecture series, and forums are scheduled throughout the program. These special events cover not only clinical medicine but also issues such as sexual orientation, women's concerns, and psychosocial dynamics.

Following medical school graduation and during residency training, Arthur Ashe students are matched with mentors in HIV care at their respective institutions. Both during and after the fellowship, students are encouraged to communicate with individuals in the larger AIDS community through a World Wide Web site, such communication helps to ensure the sharing of ideas crucial to the AIDS community. The Arthur Ashe Program in AIDS Care aims to train physicians who are attuned to AIDS care regardless of their specialty interests.

Students participating in the first two years of the program were members of African American, Puerto Rican, and Native American communities and represented such specialty interests as pediatrics, family care, surgery, and gynecologic oncology. Each student was selected for academic excellence, leadership, dedication to HIV and AIDS issues, and proven commitment to community involvement.

Harvard AIDS Institute
Boston, Massachusetts
Phone: (617) 432-4400, Fax: (617) 432-4545

Prevention

The **HIV Center for Clinical and Behavioral Studies** showcases the **Latinos Empowering Ourselves (LEO)** project. Project LEO is an HIV-prevention program that focuses on empowerment of Latino immigrant MSM. This aim is addressed in a 14-session program that follows a 3-step plan: reflection and critical thinking about one's life circumstances, acquisition of practical skills, and self-monitoring of sexual behavior. Under the guidance of a group facilitator, men reflect on their past and current experiences of oppression and stigmatization and on the impact that these experiences have had in their lives. They discuss how their behavior follows or fails to follow the existing rules, attitudes, and beliefs about sex, substance use, goal setting, pleasure-seeking behaviors, capacity to enact safer sex, and future plans. To assist the men in acquiring practical skills, a teacher of English as a second language implements a curriculum that introduces HIV-prevention goals within a process that develops critical consciousness. Finally, participants are provided with sexual diaries in which they note their weekly sexual activity with men and women and the level of protection they used. These diaries are anonymous.

Project LEO was developed as a result of a study conducted with Latin American MSM who attend the HIV Center for Clinical and Behavioral Studies/New York State Psychiatric Institute/Columbia University. Future efforts will include implementing Project LEO within other immigrant communities whose members are also non-English speakers.

The HIV Center for Clinical and Behavioral Studies
New York, New York
Phone: (212) 740-3203, Fax: (212) 740-3508

Prevention

People of Color AIDS Coalition, Inc. showcases their **Brothers Network**. This network was initiated in an effort to involve more men of African descent in work against HIV and to address the unmet prevention needs of men of African descent who have sex with other men. The purpose of the Brothers Network is to develop leadership capacity and community advocacy for HIV prevention, encourage men of African descent to participate in local and state HIV-

prevention community-planning initiatives, develop networks of support for men of African descent whose behaviors place them at high risk of HIV infection, encourage the development of organizations specifically targeting men of African descent, provide continuous training and technical assistance to local groups, provide local and state HIV-prevention planning information to this underserved population, improve community organizations' HIV-prevention activities by sponsoring nongender/ethnic-related activities, and develop chapters of Brother-to-Brother throughout the state of Florida.

The St. Petersburg chapter of Brother-to-Brother was formed in 1996. It is from this local model that the idea of a statewide initiative developed. The St. Petersburg chapter has grown from 10 members to more than 50 members and is expected to have more than 100 members by the end of 1998. The first annual Brothers Network Retreat/Summit (funded by the state Bureau of HIV/AIDS) was held in November 1997 and, from this gathering, five new chapters of Brother-to-Brother were started in the state. The summit helped men of African descent in their efforts to start networking and to become visible rather than remaining a population rendered invisible by public health officials. More men of African descent throughout the state of Florida are getting involved in HIV-prevention efforts and those who are involved are reporting that they are practicing safer sex because of the efforts of the Brothers Network.

People of Color AIDS Coalition, Inc., is the oldest minority AIDS service organization in Pinellas County, Florida. Founded in 1990 as a food bank to serve the needs of five people, the coalition's mission has expanded to include services, such as case management, counseling, street and community outreach, substance-abuse counseling, a clothing-exchange center, and a medical chest; prevention education/information; referrals; and advocacy for communities of color in Pinellas County. It now has a client base of 700 and is increasing that base monthly by an average of 18 people. Ryan White Title I is currently the only source of funding for the coalition. Its HIV-prevention programs target men of African descent who have sex with men.

People of Color AIDS Coalition, Inc.

St. Petersburg, Florida

Phone: (813) 822-2437; Fax: (813) 896-6122

Prevention

Prototypes, A Center for Innovation in Health, Mental Health and Social Services, showcases the **“Women Need to Know”** prevention media campaign. The core component of this campaign, which was implemented in collaboration with Healthier Solutions, Inc., is a series of televised public service announcements featuring female entertainment celebrities paired with HIV-positive women of color. The announcements, broadcast in English, Spanish, Chinese, Korean, Thai, Vietnamese, Tagalog, and Hindi, feature frank discussions by women about women and HIV. Other materials produced for the campaign include posters, billboards, and transit advertisements featuring the HIV-positive spokeswomen. All materials include a toll-free information/referral number for women.

In very concrete contributions toward the mission of community education and the overall success of the campaign, many individuals, organizations, and companies have donated their time, talent, and ingenuity to the development and delivery of the prevention messages. Participating celebrities include Cookie Johnson (Magic Johnson’s wife), Native American actress Elaine Miles (“Northern Exposure”), Asian American actress Elizabeth Sung (“The Joy Luck Club”), Latina television personality Maty Monfort (“Mike and Maty Show”), African American actress Kim Fields Freeman and actress/singer Queen Latifah (“Living Single”), and some with the on-air celebrities of the Telemundo Spanish-language television network.

The “Women Need to Know” media campaign operated during 1996 and was funded by the Los Angeles County Department of Health Services AIDS Program Office using CDC funds.

Because of the success of the “Women Need to Know” campaign in Los Angeles and its special response to an unmet need in the prevention arena, the 10 local and statewide projects funded under the Health Resources and Services Administration’s (HRSA) Women’s Initiative for HIV Care and Reduction of Perinatal HIV Transmission expressed interest in using the campaign’s materials. With support from HRSA’s Maternal and Child Health Bureau and Bureau of Health Resources Development, the expanded campaign will reach seven additional cities (Chicago, Dallas, Fort Lauderdale, New Orleans, New York, Philadelphia, and St. Louis) and three additional states (Maryland, Massachusetts, and New Jersey). All participating agencies believe the campaign successfully reached women who may not have been reached before and demonstrated how “true partnering” is integral to effective prevention efforts.

Prototypes

Culver City, California

Information/referral number: (800) 600-2232

Phone: (310) 641-7795, Fax: (310) 649-3096

Program Support

The **National Minority AIDS Council** showcases their **Technical Assistance and Training Program**. This program is a national initiative to provide technical assistance and training to minority community-based organizations. The goal of the program is to build the capacity and strengths of minority community-based organizations throughout the United States and Puerto Rico.

Through its Technical Assistance and Training Program, this council's technical assistance staff conducts on-site needs assessments to identify the strengths and areas for development for community-based organizations in the following areas: resource development and grant writing, fiscal management, networking and collaboration, media and public relations, staff and volunteer recruitment and training, program development, service delivery, and computer/management information systems. These technical assistance consultants also provide a framework for the development of an action plan to support the long-term health of organizations through capacity-building technical assistance and training. Organizations receiving action plans are further assisted by council staff in their review, implementation, and evaluation of the plan and the services of the technical assistant.

The council, in collaboration with the National Native American AIDS Prevention Center, executes regional training sessions target people of color who are interested or involved in the CDC's HIV Prevention Community Planning Groups. Community planning leadership and orientation training is designed to ensure that knowledge and key information pertaining to the history and goals of community planning are disseminated and to address issues of collaboration, group process and management, high minority turnover, and issues of parity, inclusion, and representation. A proactive form of technical assistance ensures that the CDC's vision for community planning is implemented throughout this comprehensive training. Preliminary findings of summary reports indicate the need to include training for minorities on such topics as roles and responsibilities of group members, mission, vision and goals of planning groups,

understanding of the process, methods to address burnout, development of an effective plan, methods of access resources, and support.

National Minority AIDS Council

Washington, DC

Phone: (202) 483-NMAC (6622), Fax: (202) 483-1145

CONCLUSION (Draft)

Individuals who have been working in the trenches of this epidemic of more than a decade know that the threat that HIV poses to communities of color is not new. Statistics continue to grow, minority communities continue to go without resources, and personal stories of struggle against the odds continue to emerge. To hear that programs and policies that meet the needs of racial and ethnic populations still need to be developed is not surprising. It is just disappointing. This country needs to move beyond saying and begin doing. It needs to focus its knowledge and understanding of the epidemic in ways that can bring change. It needs to act.

Harvard AIDS Institute

October 7, 1999

Dear Colleague,

This letter invites your thoughtful input and criticism of a document that the *Leading for Life* campaign and the Harvard AIDS Institute will publish January 2000. This document has been in development for number of years but with the generous support of Bristol Myers Squibb and other donors, a final draft has been developed.

The draft document, *A National Crisis Update: The Challenge of HIV and AIDS in Communities of Color*, is an update to the 1992 report issued by the National Commission On AIDS, entitled *The Challenge of HIV/AIDS in Communities of Color*. With the encouragement of Dr. June Osborne, the chair of the National Commission and numerous others involved then and since, we have re-examined the epidemic and the recommendations that were offered in 1992.

Enclosed you will find a draft copy of the *National Crisis Update*. We are asking experts such as you, to review the document to ensure that it will be accurate, complete, and useful to policymakers well into the next millennium. As you read the report, please keep the following questions in mind: First, is the document accurate and complete? And second what policy recommendations naturally flow from the data presented?

We have not developed any new policy recommendations to accompany this document. Instead, we prefer that any policy recommendations that are offered come from our peers during this review process. We extend an invitation to you and your organization to sign on as collaborators in the development of this report and to serve as advocates for the adoption of its policy recommendations.

In last section of *National Crisis Update*, programs sponsored by several organizations are highlighted in a "Programs in Place" section. If you have an exemplary program or service that you feel should be included in this section, you may fill out the brief questionnaire and we will try to include your program.

Max Essex, DVM, PhD
Chair

Richard Marlink, MD
Executive Director

Neil Rudenstine, PhD
Chair
Policy Board

Maurice Tempelsman
Chair
International Advisory Council

Mrs. William McCormick Blair, Jr.
Co-Chair
International Advisory Council



651 Huntington Avenue • Boston, Massachusetts 02115 USA • phone: 617-432-4400 • fax: 617-432-4545

Please review the enclosed document and provide us with any feedback by October 22, 1999. You can offer your opinion by fax or email. Feedback can be faxed to the attention of Patricia Carter at 617-432-2487. Or if you prefer, you may send email to pcarter@hsph.harvard.edu. We apologize for the short turn-around time but we thank you for your involvement and support.

Leading for Life is a campaign whose purpose is to serve as a conduit through which information about HIV and AIDS can be transferred from community and academic experts to policymakers and the mass media. Through the *National Crisis Update*, we hope to illuminate the challenges that HIV and AIDS pose to people of color and to prompt action among our leaders. We cannot meet this goal without your support. Your input is invaluable and we look forward to hearing from you.

If you have any questions about this publication or the peer review process, you may contact Patricia Carter, the coordinator for the *Leading for Life* campaign, at 617-432-2487.

Sincerely,

A handwritten signature in black ink, appearing to read "R. Marlink".

Richard Marlink, MD

A handwritten signature in black ink, appearing to read "Mario Cooper".

Mario Cooper, Esq.

Attachments: Programs in Place Form
National Crisis Update Draft

delivered 2/8/00

Harvard AIDS Institute

February 3, 2000

FAX TWELVE PAGES TO: 202-456-2438

Ms. Sandra Thurman
Director, Office of National AIDS Policy
736 Jackson Place
NW Washington, DC 20503

Dear Ms. Thurman:

Sandy!

I am pleased to invite you to participate in the *Second National Conference on HIV and AIDS in Botswana: Extending the Challenges and Benefits of Prevention and Care to All*, to be held in Gaborone, Botswana. This conference—sponsored by the Botswana Ministry of Health and the Harvard AIDS Institute—will be held from Tuesday, February 15 through Friday, February 18, 2000.

This conference will include substantial emphasis on mother-to-infant HIV transmission, as well as sessions on basic science, treatment for those living with HIV and AIDS, vaccine design, traditional medicine, and the epidemic's economic impact. The conference will offer Botswana researchers, clinicians, and public health officials an opportunity to learn more about the virus and to find new ways to work together to strengthen the country's response to the epidemic. We are planning for a maximum of 300 participants from Botswana and southern Africa, including health care workers, laboratory personnel, public health leaders, government officials, and researchers.

We would like to request that you serve as co-chair, along with our colleague, Professor Sheila Tlou, during a session on Perinatal HIV Transmission. This plenary session is scheduled for Thursday, February 17, from 8:00 to 10:00 a.m. We would appreciate it if you could give brief remarks—three to five minutes—to open the session. Your comments could be related to Perinatal HIV Transmission specifically, or to your personal experience in AIDS service organizations. I have attached a copy of the conference agenda for your review.

Max Essex, DVM, PhD
Chair

Richard Marlink, MD
Executive Director

Neil Rudenstine, PhD
Chair
Policy Board

Maurice Tempelsman
Chair
International Advisory Council

Mrs. William McCormick Blair, Jr.
Co-Chair
International Advisory Council



Second National Conference on HIV and AIDS in Botswana

February 3, 2000

Page Two

Conference Center

The meeting will be held at The Grand Palm Hotel, Molepolole Road, Private Bag BR105, Gaborone (phone: +267-312-999; fax: +267-312-989).

Laboratory Dedication

On Tuesday, February 15, 2000 at 8:00 a.m., the Botswana Ministry of Health and the Harvard AIDS Institute will host a ceremony to open our new laboratory—the Botswana-Harvard HIV Reference Laboratory. We hope you will be able to help us commemorate its dedication by attending this ceremony. The ceremony will take place at the laboratory, which is located at Princess Marina Hospital in Gaborone. Transportation will be available from the Grand Palm Hotel. An agenda is attached.

If you require any additional information, feel free to contact me or Kimberly Hensle, manager of conferences (phone: 617-432-4400; fax: 617-432-4545). Thank you for your consideration of this invitation. We look forward to your participation in this important event for Botswana.

Best regards,

A handwritten signature in black ink, appearing to read 'Ric', with a stylized flourish extending from the end.

Richard Marlink, MD
Executive Director

Dedication of Botswana-Harvard AIDS Institute HIV Reference Laboratory

Tuesday, February 15, 2000

08:00am to 12:00noon

Princess Marina Hospital, Gaborone, Botswana

Master of Ceremonies L.R.G. Manthe

08.00am	Members of the Public to be Seated
08.30am	Honourable Minister of Health Mrs. Joy Phumaphi Arrives
08.40am	Dignitaries Arrive
08.50am	His Excellency Ambassador John Lange Arrives
09.00am	National Anthems by Botswana Prisons Band
09.10am	Prayer: Pastor Johannes Kgwarapi
09.20am	Welcoming Remarks: The Permanent Secretary of Health
09.30am	Musical Item by National Health Laboratory Choir
09.40am	Remarks from His Excellency Ambassador John Lange
09.50am	Remarks from Harvard AIDS Institute: Professor Max Essex, Chair
10.00am	Remarks from Harvard AIDS Institute: Maurice Tempelsman, Chair, International Advisory Council
10:10am	Musical item by Botswana Prisons Band
10:20am	Remarks from Miss Universe 1999: Mpule Kwelagobe
10:30am	Traditional Dance by Itsoseng Private Senior Secondary School
10:40am	Musical item by National Health Laboratory Choir

10:50am	Opening Speech by Honourable Minister of Health Mrs. Joy Phumaphi
11:10	Poem by Sgt. M. Mokgosi
11:20	Musical Item by Botswana Prisons Band
11:30	Vote of Thanks by Director of Health Services: Dr. Patson Mazonde
11:40	Unveiling of Plaque by Honourable Minister of Health Mrs. Joy Phumaphi
11:50	Tour of the laboratory Led by: Ms. T.N. Bokete, Chief Laboratory Scientist; and Dr. Monty Montano, Research Fellow

Conference Agenda

Please note that this schedule is subject to change.

SECOND NATIONAL CONFERENCE ON HIV AND AIDS IN BOTSWANA

Extending the Challenges and Benefits of Prevention and Care to All

February 15-18, 2000
Grand Palm Hotel, Gaborone, Botswana

Tuesday, February 15:

Registration and Opening Ceremony

2:00 -5:00 p.m. Registration
6:00 p.m. Opening Ceremony
7:30 p.m Welcoming Reception

Wednesday, February 16:

8:30 a.m.-12:25 p.m.

Session A: Epidemiology and Public Health

Chair: Rose Mandevu

Rapporteurs: Roger Shapiro and Bright Bagwasi

8:30 -8:35 a.m. Chair Announcements

8:35 - 9:00 a.m. Plenary:
Overview of the Global AIDS Epidemic: Elhadj Sy

9:05 - 9:30 a.m. - Plenary:
The HIV/AIDS Epidemic in Botswana and Southern Africa: Can We Stem the Tide?: Edward Maganu

09:35 -10:00 a.m. - Plenary:
Molecular Epidemiology of HIV: Max Essex

10:00 -10:30 a.m. - Tea Break

10:30 -10:55 a.m. - Plenary:
HIV and AIDS in Botswana: Patson Mazonde

11:00 -11:25 a.m. - Plenary:
Living with HIV/AIDS in Botswana: Billy Mosedame

11:30 -11:55 a.m. – Plenary:
National MTCT Programme Overview: Gladys Mogapi

12:00-12:25 p.m. – Plenary:
Botswana-Harvard Partnership: Ibou Thior and Patson Mazonde

12:30-1:30 p.m. – Lunch

1:40-3:35 p.m.
Concurrent Session B1: Community Response to the HIV/AIDS Epidemic

Chair: Rupert Hambira

Rapporteurs: Magdeline Mathiba and Nthabiseng Phaladze

1:40 p.m.-1:45 p.m. - Chair Announcements

1:45 p.m -2:05 p.m. - Plenary
Traditional Medicine: John Rwomushana

2:10 p.m. – 2:30 p.m. - Plenary
Traditional Medicine and HIV in Botswana: Sophisto Nthobatsang

2:35 p.m. –3:20 p.m. - Panel Discussion:
NGO Partnership for HIV and AIDS: Patricia Daoust, AIDS Action Committee, USA; V.
Ngcongco, Consultant; Mark Ottenweller, HOPE Worldwide, South Africa; Koketso Rantona,
BONASO, Botswana

3:20 p.m. –3:35 p.m. - Questions for the panel

3:35 p.m. - 4:05 p.m. -Tea Break

4:10-6:30p.m.
Concurrent Session B2: Home Based Care

Chair: Goitsewang Fisher

Rapporteur: Ditsapelo McFarland

4:10-4:15 p.m. - Chair Announcements

4:15 – 4:30 p.m. – Abstract
The Many Faces of Care: A Programme for AIDS-Affected Children and their Families: G.
Jacques

4:35 – 4:50 p.m. – Abstract
Family Caregivers' Perception of the Quality of Home Based Care (HBC) to the Terminally Ill
AIDS Patients in Botswana: Joyce Tamocho

4:55 – 5:10 p.m. – Abstract

The Challenges of Home Based Care in Botswana: A Critical Analysis of the Concept: Christine Stegling

5:15 – 5:30 p.m. – Abstract

Collaborative Networking Towards Quality Care for the People with AIDS in the Homes:
Josephine Mazonde

5:35 – 5:50 p.m. – Abstract

Saving the Children Orphaned by AIDS: C.O. Abosi

5:55 – 6:10 p.m. – Abstract

Experience and Needs of Caregivers Regarding Community Home Based Care for AIDS Patients
in Francistown: U.P. Modongo-Mathebula

6:15 – 6:30 p.m. – Abstract

An Evaluation on the Effectiveness of the Gabane Community Home Based Care Project: Nthutang
Gaorekwe

1:40-6:30 p.m.

Concurrent Session B3: HIV Treatment and Care

Chairs: Theresa Bokete and Joseph Makhema

Rapporteurs: Koketso Rantona and Nora Motlhabane

1:40-1:45 p.m.- Chair Announcements

1:45: -2:05 p.m.- Plenary:

Care for People Living with HIV in Resource Poor Countries: Richard Marlink

2:10 – 2:30 p.m. - Plenary:

Advances in Antiretroviral Therapy: David Katzenstein

2:35-2:55 p.m. - Plenary:

Clinical Therapy in Botswana: Churchill Onen

3:00 – 3:20 p.m. - Plenary:

Pediatric AIDS: Treatment and Care: Catherine Wilfert

3:25-4:05 p.m. - Tea Break

4:10-4:30 p.m. - Plenary:

Low Cost Interventions for HIV Treatment: Robert Redfield

4:35 – 5:05 p.m. - Plenary:

Tawanda Gumbo

5:10-5:30 p.m. - Plenary:

Dynamics of Major African HIV Epidemics and Implications for Prevention and Care: Knut
Fylkesnes

5:35 to 6:15 p.m. - Panel Discussion

Clinical Therapy: Joseph Makhema, Kgosidialwa Mompoti, Richard Marlink, Howard Moffat, N.M Hone, and The Botswana Medical Aid Society

6:15 - 6:30 p.m. – Questions to Panel

7:00 – 8:30 p.m. – Reception sponsored by Boehringer Ingelheim

Thursday, February 17

8:00-9:55 a.m.

Session C: Perinatal HIV Transmission

Chairs: Sandra Thurman and Sheila Tlou

Rapporteur: Pricilla Woto/Lucy Maribe

8:00 - 8:05 a.m. - Chair Announcements

8:05 - 8:25 a.m. – Plenary:

Perinatal HIV Transmission: Sophie Le Coeur

8:30 - 8:50 a.m. – Plenary:

Mother to Child Transmission in Botswana: Loeto Mazhani

8:55 - 9:10 a.m. – Plenary:

Perinatal Transmission of HIV in Botswana: A Multi-Centre Study Among HIV Positive Nursing Mothers: Ibou Thior

9:15 - 9:30 a.m. – Plenary:

Breast Feeding and Vertical HIV Transmission: Shahin Lockman

9:35 - 9:55 a.m. - Plenary:

New Possibilities for Blocking Mother to Infant HIV Transmission: Roger Shapiro

10:00 - 10:30 a.m. - Tea Break

10:30 a.m.-12:40 p.m.

Concurrent Session D1: Perinatal Transmission and HIV Testing

Chair: Mable Magowe

Rapporteur: Dintle Mogobe

10:30 - 10:35 a.m. - Chair Announcements

10:35 – 10:50 a.m. - Abstract

Breastfeeding Practices in Botswana: Itai Madamombe

10:55 – 11:10 a.m. - Abstract:

Community Perspectives on Initiatives to Prevent Mother to Child Transmission of HIV in Botswana: Sheila Tlou

11:15 – 11:30 a.m. – Abstract:
Male Involvement in Mother to Child Transmission (MTCT) in Botswana: Poloko Kebaabetswe

11:35 – 11:50 a.m. – Abstract
Social and Demographic Factors Associated with Acceptance of HIV Testing: Tebatso Paul

11:55 a.m. – 12:10 p.m. – Abstract
HIV Testing Issues: John L. Saul and L. Abotseng

12:15 – 12:40 p.m. – Plenary
Diagnostic Testing: Rosemary Mubanga Musonda

10:30 a.m.-12:50p.m.
Concurrent Session D2: Gender/Policy/Psychological Impact
Chair: Caroline Davids
Rapporteur: Shahin Lockman

10:30-10:35 a.m. - Chair Announcements

10:35 – 10:50 a.m. – Abstract
Men's Perceptions of the Effects of HIV/AIDS on Childbearing in an Informal Settlement in Francistown (Botswana): T.S. Mmusi

10:55 – 11:10 a.m. – Abstract
Fostering Hope in People Living with AIDS (PLWA) in Africa: The Role of the Nurse: H.A. Akinsola

11:15 – 11:30 a.m. - Abstract
Mary Bassett

11:35 – 11:50 a.m. – Abstract
Grief of Being HIV/AIDS Positive and of AIDS: Implications for Family Members and the Community: Nomagugu Oagile

11:55 a.m.- 12:10 p.m. – Abstract
The Role of Nursing in Health Care Policy and Resource Allocation for HIV/AIDS in Botswana: N.A. Phaladze

12:15 – 12:30 p.m. – Abstract:
The Trauma of HIV/AIDS: A Monster in the Dark: P.L.P. Disele

12:35 – 12:50 p.m. – Abstract:
The Gender Aspects of HIV/AIDS and Policy Recommendations for Botswana: Magdeline Mathiba

10:30 a.m.-1:10 p.m.

Concurrent Session D3: Education and Youth

Chair: Felicity Leburu and Mpule Kwelagobe

Rapporteur: Ephraim Ncube

10:30-10:35 a.m. - Chair Announcements

10:35 – 10:50 a.m. – Abstract

Behavioural and Prevention issues on HIV/AIDS: A Case of the University of Botswana: Ester Seloilwe

10:55 – 11:10 a.m. – Abstract

Sexuality Communication Between Mother and Teenage Girls in Relation to HIV/AIDS (Molepolole, Botswana): M.M. Selelo

11:15 – 11:30 a.m. - Abstract

Christians Fight Against HIV/AIDS – Conduct versus Condom: Poloko Kebaabetswe

11:35 – 11:50 a.m. – Abstract

The Challenges Faced by Youth in HIV/AIDS and Other Sexuality Issues: L. Tlale

11:55 a.m.- 12:10 p.m. – Abstract

HIV/AIDS Education and Counseling to the School Community: L.T. Khathola

12:15 – 12:30 p.m. – Abstract:

HIV/AIDS Education and Counseling: A Challenge to the School Community: Elizabeth Busang

12:35 – 12:50 p.m. – Abstract:

Nutrition and the Ailing Immune System: A Challenge in the New Millennium: P.L.P. Disele

12:55 – 1:10 p.m. - Abstract

Nutrition and AIDS: A Challenge to All: Elizabeth Busang

12:45 – 2:15p.m. – Lunch

2:15-3:50p.m.

Session E: Botswana's Response

Chair: Sinah Chaba

Rapporteur: Boemo Sekgoma

2:15-2:20 p.m. - Chair Announcements

2:20 - 2:35 p.m. - Plenary:

HIV/AIDS Prevention and Health Education in Botswana/IEC – Lydia Seeletso

2:40 - 3:30 p.m. - Panel discussion:

Voluntary Confidential Counseling and Testing: The Achilles Heel for Prevention of HIV/AIDS Transmission from Mother to Child (MTCT) – M.K. Sherif with a panel

3:35 - 3:50 p.m. - Questions to Panel

3:55 - 4:25 p.m. -Tea Break

4:25-6:45p.m.

Concurrent Session F1: Clinical Research

Chair: Churchill Onen

Rapporteurs: Richard Marlink and Ibou Thior

4:25-4:30 p.m. - Chair Announcements

4:30-4:45 p.m. – Abstract

The Significance of Herpes Zoster in HIV/AIDS in Kweneng District August 1996:

F. Eohonu-Elyetu

4:50 – 5:05 p.m. – Abstract

The Implication of the Syndromic Case Management Approach for STD's in Southern Botswana's MCH/FP Programme: A Situation Analysis: L. Mokganya

5:10 – 5:25 p.m. – Abstract

The Aetiology of STD's and Risk Factors in Botswana – A National Survey: Mafizur Rahman

5:30 – 5:45 p.m. – Abstract

Clinical Manifestations of HIV Disease in Children: Three Years Experience at NRH: T.

Gebrekrastos

5:50 – 6:05 p.m. – Abstract

Tuberculosis Among Health Care Workers in Palapye: M.K. Sherif

6:10 – 6:25 p.m. – Abstract

Cryptococcal Meningitis in Patients Infected with Human Immunodeficiency virus (HIV) in

Thamaga: S.K.S. Mbwana

6:30 – 6:45 p.m. – Abstract

Early Psychomotor Development Deterioration in HIV Positive Children: Annette Stellinga

4:25-6:25 p.m.

Concurrent Session F2: HIV Community Education

Chair: Dineo Mogapi

Rapporteur: Prisca Tembo

4:25-4:30 p.m. - Chair Announcements

4:30 – 4:45 p.m. – Abstract

Peer Education and AIDS Prevention Among Botswana Women: Nurses as Partners: Sheila Tlou

4:50 – 5:05 p.m. – Abstract

The Business/Corporate Aspect of the Challenges Threatening the Workforce: Shadi

Makgekgenene

5:10 – 5:25 p.m. – Abstract

Health Education Project on HIV/AIDS: L.P. Oagile

5:30 – 5:45 p.m. – Abstract

Beyond Evaluation of HIV/AIDS Prevention Programmes in Botswana: O.A. Afemikhe

5:50 – 6:05 p.m. – Abstract

Information Dissemination: An Empowerment Tool in Dealing with the HIV/AIDS Problem: T. Masoloko

6:10 – 6:25 p.m. – Abstract

Theatre Against HIV/AIDS – Lessons from Botswana: Otukile Vuyisele

6:30 - 6:45 p.m. - Abstract

Linking Health and Human Rights to Advance the Well-being of Gays, Lesbians, and Bisexuals of Botswana: J.R. Zuyderduin

Friday February, 18

8:30 a.m.-12:30 p.m.

Session G: Basic Science

Chair: Max Essex

Rapporteurs: Isaac Mtoni and Dr. Kombe

8:30-8:35 a.m. - Chair Announcements

8:35 - 9:00 a.m. – Plenary:

HIV Protection: Phyllis Kanki

9:05-9:30 a.m. – Plenary:

HIV Vaccine Approaches: Yichen Lu

9:35-10:00 a.m. – Plenary:

Data Management and Trial Design for Vaccine and Drug Trials: Peter Gilbert

10:05–10:30 a.m. – Plenary

Analysis of HIV-1C Virus for Vaccine Design: Vladimir Novitsky

10:30 - 11:00 a.m. - Tea Break

11:05-11:30 a.m. - Plenary

Determinants of HIV – 1C Pathogenic Evolution: Monty Montano

11:35-12:20 p.m. - Panel:

Science of Subtype C: Leonard Manthe, Sarah Gaolekwe, Monty Montano, and Vladimir Novitsky

12:20-12:30 - Questions to the Panel

12:30 - 2:00p.m. - Lunch

Recommendations and Conclusions/Closing Ceremony

2:00–3:00 p.m.	Recommendations and Conclusions
3:00–4:00 p.m.	Closing Ceremony
4:00 p.m.	Reception and Entertainment