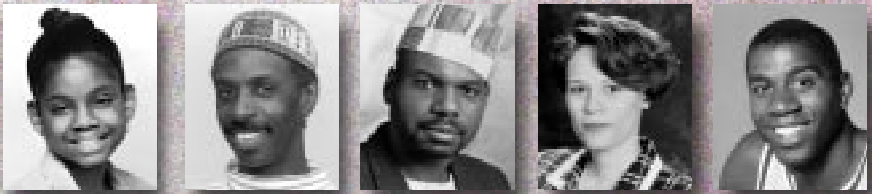
The NIA Plan

EXECUTIVE SUMMARY • FEBRUARY 24, 2000

A Comprehensive Plan of Action for African Americans to Help Reduce the Spread of HIV/AIDS in Our Communities



African American AIDS Policy and Training Institute

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Health Resources and Services Administration
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Black and white images pictured on cover (from left): Hydeia L. Broadbent, Reggie Williams, Marlon Riggs, Rae Lewis-Thornton and Ervin "Magic" Johnson. Full page images adapted from the NAACP video "House on Fire." Photographic images in this document are selected to illustrate the effects of HIV/AIDS on African American communities. The use of a photographic image does not connote endorsement of The NIA Plan.

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Forward

I laud the efforts of the African American AIDS Policy and Training Institute and their partners who developed The NIA Plan Executive Summary in order to identify recommendations on how to reduce the spread of HIV/AIDS in the African American community.

I want to encourage individuals and groups to use The NIA Plan Executive Summary and other tools that are appropriate for your community to help those living with HIV/AIDS. I believe that in working together we can create solutions that will prevent the future spread of HIV/AIDS in African American communities.

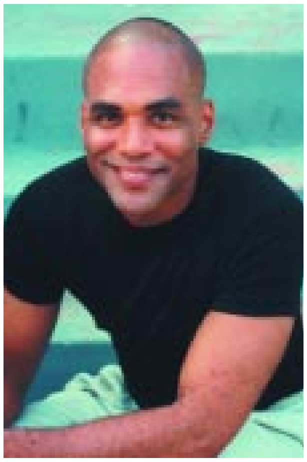
As the late Dr. Benjamin E. Mays, President Emeritus of Morehouse College, and my mentor said to me, "The tragedy in life doesn't lie in not reaching your goal. The tragedy lies in having no goal to reach." We have our goal and the time is now to educate, motivate and mobilize our community in the fight against HIV/AIDS.

David Satcher, M.D., Ph.D.
Assistant Secretary for Health and Surgeon General

DAVID SATCHER,
M.D., PH.D.

Transmittal Letter

February 23, 2000



PHILL WILSON

In 1998, the Congressional Black Caucus (CBC) with leadership from Maxine Waters and Donna Christian-Christensen asked the Secretary of Health and Human Services to call for a "State of Emergency" request regarding AIDS in African American communities.

In solidarity with that request, dozens of African American AIDS activists, educators, health professionals, community leaders, and people living with HIV/AIDS have joined forces to develop a strategic action plan to stop HIV/AIDS in our communities.

The NIA Plan is the fruit of their labor.

Although The NIA Plan builds on the work of previous HIV/AIDS initiatives, it offers a unique and comprehensive solution to the AIDS crisis that is—for the first time—indigenously based.

Thus, *we hope The Nia Plan will empower and encourage African American communities in their efforts to address the rising epidemic of HIV/AIDS in our neighborhoods and our homes.*

Although The NIA Plan was born out of the CBC initiative, it's growth has come from a process of listening—listening to people already infected and those not infected, listening to African American leaders and everyday people. We've attempted to document what we heard. This plan comes from us. It speaks our language and it attempts to deal with our realities.

The purpose of The NIA Plan is to develop definable tasks and measurable goals and objectives for community stakeholders. Not only does it identify discrete recommendations for action, we hope it will spark a national dialogue on how to increase the number of people properly treated and reduce the number of African Americans becoming infected.

This is a living document. It is not meant to be an exhaustive manifesto. Take from it what you will and contribute to the battle what you can. Those of us living with HIV/AIDS salute you for picking up the gauntlet by picking up this Plan.

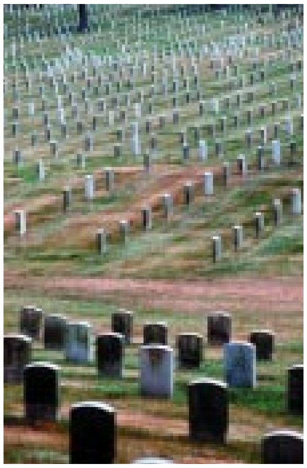
We owe a great deal to Congresswoman Maxine Waters, Congresswoman Donna M. Christian-Christensen and the entire Congressional Black Caucus for their leadership on this issue. They continue to do their part. Now it's up to us. Our community, quite simply, is running out of time. The agenda is full, the task is great and the time is short. But together we will prevail.

Yours in the struggle,

Phillip Wilson

Phill Wilson, Director
African American AIDS Policy and Training Institute

Summary



Twenty years after the AIDS epidemic began, AIDS continues to affect African Americans disproportionately.[1]

- AIDS is the leading cause of death for African American men between the ages of 25 and 44 and the second leading cause of death for African American women in the same age range.

- Though only 12 percent of the U.S. population, Blacks make up almost half of all new AIDS cases.

- More than half of all AIDS cases among children and women are African American.

There is a crisis in our midst, and twenty years into the epidemic, there is still no national comprehensive plan of action to combat AIDS in our communities.

Thus, The NIA Plan is a plan of action.

"Nia" is one of the seven principles of the African American holiday, Kwanzaa.[2] It is a Swahili word that means "purpose." The purpose of the plan is to help all of us answer the question, *"What can we do to help stop the spread of HIV/AIDS in our communities?"*

The plan addresses what faith communities, civil rights groups, fraternal and community-based organizations, media, professional associations, government agencies, and medical organizations can do in their own institutions to reduce the spread of HIV/AIDS in Black communities.

But first we must look inward. We must confront powerful emotions about sexuality, drug use and other behaviors and learn to respond with our hearts and our heads, with love and not with fear.

Overview

Chronology of Selected Events

In order to know where to go, we need to know where we have already been in responding to the AIDS crisis. This chronology[3] provides a list of key dates and events in the nearly 20-year history of the AIDS epidemic.

> *When the first AIDS cases were reported in 1981, the disease was believed to affect white gay men almost exclusively. The following year,* ***in 1982, we learned that African Americans were disproportionately affected by the epidemic. Yet the public perception, media attention, and funding continued to focus on white gay men.***

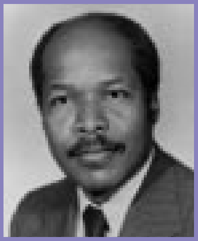
June 5, 1981	**The Centers for Disease Control (CDC) publishes news of a new disease in** *Morbidity* **and** *Mortality Weekly Report (MMWR).*
July 3, 1981	**First article in** *New York Times.*
July 13, 1981	**First article in** *New York Native.*
January 1982	**Disease is named gay-related immunodeficiency disease (GRID).**
March 4, 1982	**MMWR lists four risk groups for AIDS—homosexuals, hemophiliacs, Haitians, and injection drug users.**
June 15, 1982	**Twenty-three percent of initial AIDS cases reported to CDC are among African Americans, who represent only 12 percent of the population.**
July 27, 1982	**CDC adopts "Acquired Immune Deficiency Syndrome" (AIDS) as**

	the official name of the new disease. In September 1982, the term AIDS is used in a publication in MMWR.
December 1, 1982	Congress votes $2.6 million to CDC for AIDS research.
December 17, 1982	MMWR reports four cases of unexplained immune deficiency in infants.
January 7, 1983	CDC adds heterosexual partners of AIDS patients as the fifth risk group for AIDS.[4]
December 1983	National Association of People With AIDS (NAPWA) founded.
December 1983	The first stories on AIDS by Black newspapers appear but do not focus on racial disparities of the disease.
1984	AIDS identified as being caused by a human retrovirus, Human Immunodeficiency Virus (HIV).
May 1984	Rock Hudson diagnosed with AIDS.
1985	The FDA approved first ELISA test kit to screen for antibodies to HIV.
April 1985	CDC drops Haitians from high risk groups for AIDS.
October 2, 1985	Rock Hudson dies. Congress allots $70 million to AIDS research the following day.
December 1985	Ryan White, a 13-year-old hemophiliac with AIDS, is barred from school in Indiana.
1986	The Black Coalition on AIDS (BCA) is founded.
Janaury 1986	President Reagan mentions AIDS in public for the first time.
June 1986	U.S. Justice department "permits" employers to ban employees with AIDS from work.
December 1986	Surgeon General C. Everett Koop sends guidelines against AIDS transmission to every U.S. household.
1987	National Black Leadership Commission on AIDS (BLCA), National Minority AIDS Council (NMAC), and the National Task Force on AIDS Prevention (NTFAP) are founded.
March 1987	AIDS Coalition to Unleash Power (ACT-UP) founded.
March 19, 1987	FDA approved AZT, the first drug approved for treatment of AIDS.
April 1, 1987	President Reagan describes AIDS as "public health enemy number one."

In the mid to late 1980s, several national organizations were created specifically to address AIDS in African American communities.

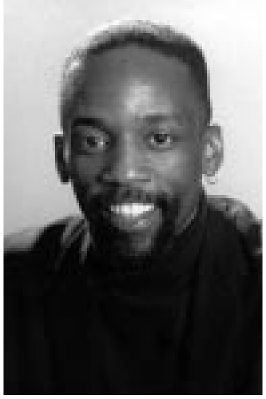
April 29, 1987	**FDA approved the first Western blot blood test kit, a more specific HIV test.**
October 1987	**The AIDS quilt memorializes those lost to AIDS nationwide.**
November 1987	**President Reagan, acting against the advice of the U.S. Public Health Service, announces mandatory AIDS testing of immigrants, prisoners, patients.**
1988	**HHS Secretary Louis Sullivan declares AIDS a "public health emergency."**
December 1988	**Pediatric AIDS Foundation founded.**
December 1, 1988	**The World Health Organization's Global Programme on AIDS launches the first "World AIDS Day."**
December 20, 1988	**ABC-TV News broadcaster Max Robinson dies of AIDS-related complications.**
1989	**"The Harlem Week of Prayer for the Healing of AIDS" is launched as an effort to involve Black clergy in AIDS ministries. The organization later becomes The Balm in Gilead.**
1989	*The Crisis,* **the official magazine of the NAACP, publishes its first article that discusses AIDS.**
December 1, 1989	**Dancer and choreographer Alvin Ailey dies of AIDS on the first anniversary of World AIDS Day.**
1990	**Non-white AIDS incidence rate surpasses the rate for whites.**
February 9, 1991	**Gospel recording artist James Cleveland dies of AIDS-related complications.**
November 7, 1991	**Los Angeles Lakers basketball star Magic Johnson announces that he is living with HIV.**
1992	**Malcolm Jamal-Warner, Magic Johnson, Arsenio Hall, Paula Abdul, Jasmine Guy, and others produce a program about preventing AIDS**

Ten years after the disease was first reported, national attention finally focused on AIDS in Black communities when professional basketball star Magic Johnson disclosed his HIV status. Since then, government policymakers and community leaders have slowly recognized and responded to the changing epidemiology of the disease. ***Today, AIDS is increasingly a Black disease.***



DR. LOUIS SULLIVAN (top), JAMES CLEVELAND (bottom)

	called "Time Out—The Truth About HIV, AIDS and You."
April 8, 1992	Tennis star Arthur Ashe announces at a press conference that he is living with AIDS.
February 6, 1993	Arthur Ashe dies of AIDS-related complications.
May 7, 1993	FDA approves the Reality Female Condom, "which offers women a barrier product to protect themselves without relying on the cooperation of their partner."
December 23, 1994	FDA approves the first non blood-based collection kit utilizing oral fluid for use in the detection of the antibody to HIV-1.
1995	African American National Clergy Summit on HIV/AIDS is convened at the White House.
1995	CDC's reports Black AIDS incidence rate surpasses rate for whites.
January 1, 1995	Friends for Friends founded.
March 1995	Rap artist Eric Wright (also known as "Eazy-E"), co-founder of the rap group NWA, dies of AIDS-related complications.
June 29, 1995	In Oakland, first of several forums co-sponsored by Joint Center for Political and Economic Studies and the CDC focuses on AIDS among African American adolescents. Other forums are later held in Detroit and Memphis in 1996.
November 4, 1995	Black gay poet and writer Essex Hemphill dies of AIDS-related complications.
December 6, 1995	First White House Conference on HIV and AIDS.
October 22, 1996	The Harvard AIDS Institute launches Leading for Life, "a campaign to mobilize African American leaders to stand up against the AIDS crisis that is devastating their communities."
March 5, 1998	African American HIV advocates issue statement with nine



ARTHUR ASHE (top), EAZY-E (middle) and ESSEX HEMPHILL (bottom)

	demands, including the declaration of a "state of emergency" in African American communities concerning AIDS.
May 11, 1998	Congressional Black Caucus calls for Secretary of Health and Human Services to declare a public health emergency.
July 12, 1998	NAACP leaders promise "a series of actions to raise awareness of HIV/AIDS."
August 5, 1998	The National Medical Association issues a statement declaring "war on HIV/AIDS" in Black communities.
August 1998	National Convention of Delta Sigma Theta approves a resolution to "reaffirm its commitment to AIDS prevention and education programs…"
October 28, 1998	President Clinton announces $156 million government initiative "to stem the AIDS crisis in minority communities."
February 25, 1999	National Conference on African Americans and AIDS convenes and develops list of action steps to address HIV/AIDS in African American communities.
September 1999	Del. Donna Christian-Christensen (D-VI), chair of the Congressional Black Caucus committee focused on health issues asks Congress to provide $349 million to fund an Emergency Public Health Initiative on HIV/AIDS targeting African Americans and other minorities. The HHS budget for federal AIDS funds is estimated at $7.8 billion.
December 1, 1999	African American AIDS Policy and Training Institute releases The NIA Plan on World AIDS Day.
January 13, 2000	For the first time ever, the Centers for Disease Control reports that more Black and Hispanic gay men than white gay men were diagnosed with AIDS in 1998. Minorities represented 52 percent of gay and bisexual men who were diagnosed with AIDS in 1998 compared to 31 percent in 1989.
February 2000	National Conference on African Americans and AIDS held in Washington.

Background

The AIDS epidemic has reached dramatic proportions among Black people, but many African Americans are still unaware of its impact on their communities. Stereotypes and mistaken assumptions about AIDS have led some Blacks to question the relevance of AIDS awareness to our communities. At the same time, recent media attention prematurely suggesting the "end of AIDS" has misled others into thinking that the problem is over.

In reality, AIDS is still a major health threat to African Americans. In fact, the perception that AIDS is not a problem or that it is "somebody else's problem" contributes to a lack of attention and energy directed at fighting this disease.

Principles

The two guiding principles behind The NIA Plan are:

1. Everyone counts.
2. Everyone can help.

First, everyone counts. In order to stop the spread of HIV and AIDS in our communities, we cannot allow ourselves to by divided by class, gender, sexual orientation, age, status or behavior. We must remember that all of us are important and none of us is expendable. After all, the assumption that Black people, as a group, are expendable may have contributed to the slowness by some policymakers in responding to the crisis of AIDS in our communities.

Second, everyone can help. Every church, every sorority, every fraternity, every reporter, every health professional, every educator, every activist, every elected official, every parent, and every individual can make a difference. Stopping AIDS is not just the government's business or the activists' business; it is everyone's business.

The NIA Plan is written primarily for community-based organizations and other stakeholders who want to know more about AIDS and what they can do to stop it. We've tried to use plain language and provided a chronology of important events, glossary of basic terms, and a bibliography of literature and other resources so that individuals and groups can continue to educate themselves.

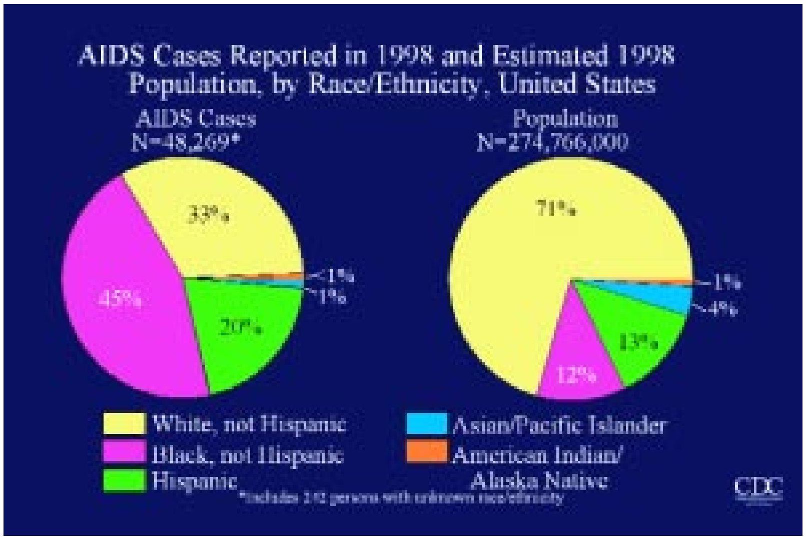
The Problem

1. African Americans, make up about 12 percent of the population, yet, as the following chart indicates, they account for nearly half (45 percent) of all new AIDS cases.[5]

2. The face of AIDS has become increasingly Black. Compared with other racial and ethnic groups, African Americans have the highest rate of HIV infection, the highest AIDS

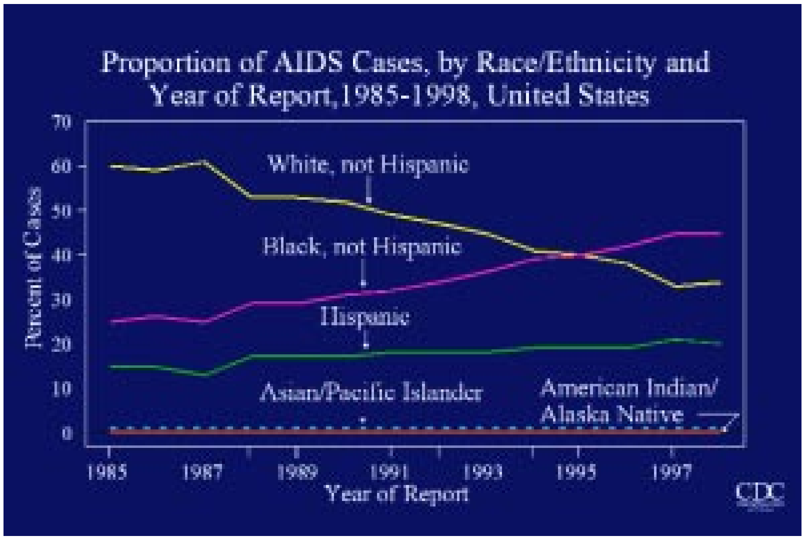
mortality rate, and the highest number of productive years lost.[6]

While the percentage of AIDS cases has declined among whites, it continues to rise among Blacks, as evidenced in the following chart.[7]



3. In addition to dealing with HIV and AIDS, many in our communities suffer from other social ills that make it difficult to respond and receive treatment—not the least of which is a lack of access to medical care.[8] One in five African Americans (21.5 percent) lacked health insurance compared to 15 percent of whites, according to a recent report from the U.S. Census Bureau.[9]

Even for those who do have access to health care, new drug therapies are expensive.[10] Sixty percent of Americans living with AIDS rely on Medicaid for some form of assistance, and Medicaid serves as the principal funder for primary care for 48 percent of African Americans living with HIV.[11]



4. Too few existing AIDS prevention, reduction, treatment, and research projects are created by or tailored toward African Americans. Studies show that prevention projects developed and implemented by African Americans are more likely to be successful than those created outside the community.

5. Early in the epidemic, media images focused primarily on gay white men who raised and targeted significant funding to serve the gay white male community. Consequently, many African Americans believed that AIDS was not a significant problem for our community.

6. As new AIDS cases have started to decline dramatically among the white population, public attention by the media, government agencies, funders, and concerned citizens has

diminished, at the very same time that AIDS is becoming more of a challenge for African Americans.[12]

7. In spite of the vacuum created by the disappearance of white involvement, indigenous Black institutions (media, faith-based institutions, and other groups) have been reluctant to become actively involved in the AIDS struggle. In part because we suffer from so many other problems and in part because of the stigma associated with the disease, a fully mobilized African American population has been missing in this struggle.

The Goals

Despite the numerous challenges in connection with African Americans and AIDS, there is hope. Programs for AIDS education, prevention, treatment, and research are being successfully implemented in Black communities. The NIA Plan can be used to spread the word about these programs to various community stakeholders.

The NIA Plan has six specific goals to achieve:

1. *Provide* **individually-tailored answers to the question: "What can I or my organization do to stop AIDS from spreading in our community?"**

2. *Encourage* **African American stakeholders to take action to help stop the spread of AIDS in their communities.**

3. *Identify* **the people most at risk for HIV based on their behavior.**

4. *Identify* **characteristics of effective AIDS prevention programs that can be replicated for African American communities.**

5. *Identify* **barriers to treatment and care in African American communities and present culturally appropriate remedies to these barriers.**

6. *Make recommendations* **to develop effective, comprehensive behavioral and clinical research strategies.**

People at Risk

Introduction

From the outset, we must be clear about the following points:

- Groups are not at risk for AIDS; people are.
- Increased risk for all people is based on their behavior.
- The focus on behavior should not be used to condemn people or groups.
- People most at risk are defined based on existing epidemiological data.

We must be careful when we use the term “at-risk group” because no group of people is inherently more at risk for AIDS than any other group of people. Instead, it is the behavior of people that makes them at risk, not their status or membership in a particular segment of the population.

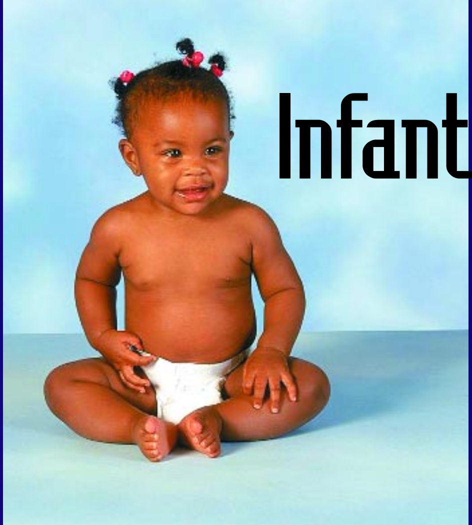
For example, homosexuals are no more at risk for HIV than are heterosexuals. Rather, it is the behavior of unprotected sex (heterosexual or homosexual) that may lead to the spread of HIV. Similarly, injection drug users are no more at risk than anyone else for HIV. By itself, the use of injected drugs does not spread HIV; the use of contaminated needles does.

When we condemn people because of homosexual activity or drug use, we miss the point that these behaviors do not spread the virus that causes AIDS.[13] We also miss the opportunity to educate and to advocate for policies that advocate for condom distribution and support the role that needle exchange can play when appropriately targeting behaviors at risk.

We must also be sensitive to issues of class. When designing strategies to respond to group needs, we must remember that some members of our communities do not have readily available access to capital, technology, health care, education, or other resources that may be useful for them. Nor should we assume that everyone in our communities will be easily persuaded to avoid risky behaviors, especially when such behaviors may secure an immediate need (e.g., trading sex for food or temporary shelter).[14]

AIDS is a disease about behavior, not status. Even for infants and children, the virus is initially transmitted by someone's behavior. But placing the emphasis on high-risk behavior, where it [the emphasis] should be, should not be used as an excuse to condemn or attack people in certain demographic groups most likely to engage in those behaviors. Nor should it be used as a device to exalt those who were infected with HIV without engaging in any high-risk behavior of their own.

We must avoid the temptation to label only some people with AIDS as "innocent," for to do so suggests that everyone else with AIDS is guilty and therefore less deserving of our concern and action. As we have said before, one of our guiding principles for The NIA Plan is that everyone counts.



Infants and Children

Hydeia L. Broadbent was just three years old when her parents learned that she was living with HIV. Adopted only weeks after her birth, Broadbent had been welcomed into a loving family. Fortunately, they not only accepted the responsibility of caring for a child living with HIV, they also agreed to use their experience to help educate others.

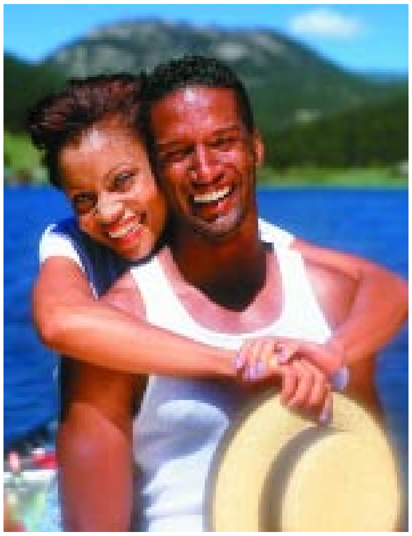
"My mom and dad never kept it a secret. They always kept it open, because my mom always told me, 'You're Black, a woman. Why hide having AIDS?' "

Some time after Hydeia's diagnosis, doctors told her parents that she would not live to be six years old, and by the time she was five her HIV had progressed into full-blown AIDS. But Hydeia continued to grow.

Today, at 14 years old, she has become one of the nation's leading spokespeople for children living with AIDS. "I am the future and I have AIDS," she told the *New York Daily News* recently. 'People with AIDS should not feel ashamed," she added.[15]

Thousands of children in our communities are living with this disease. Of the 4,358 AIDS cases reported among children younger than 12 in the United States through December 1998, nearly 57 percent were among African Americans.[16]

Adolescents and Young Adults[17]



Of the 7,200 HIV cases reported among 13- to 24-year-olds from January 1994 to June 1997, 63 percent were among African American youth.[18] When we focus on 13- to 19-year-olds, African American youth in this age range accounted for 15 percent of the population in 1996 but represented 58 percent of the adolescent AIDS cases in 1997.

Even among adolescents and young adults, some populations are more likely than others to be infected with the HIV virus. These include gay and lesbian youth, incarcerated youth, homeless and runaway youth, pregnant or parenting youth, and school dropouts. By developing programs that target these groups rather than ignoring them, we might help slow the spread of HIV and AIDS among young people.

How can people in these groups be reached? Black adolescents and young adults are often closely connected to popular culture, and this connection creates an opportunity to reach them on a mass marketing level.

When asked where they receive messages and information about HIV/AIDS, adolescents and young adults mentioned TV, radio, and the Internet.[19] At the same time, they seemed dissatisfied with the quality and quantity of information available for them. "TV commercials don't ever talk about HIV," one young person said, and noted that they sell "everything else." In fact, at least one major study shows that 89 percent of young African Americans support major TV networks accepting advertisements from condom manufacturers and including more condom references on certain TV shows.[20]

FACT:

In 1998, 61 percent of all women with AIDS were Black, according to the Centers for Disease Control.

Women

When Belynda Dunn tested positive for HIV, she felt isolated and alone. "I remember what a lonely place that was," she recalled recently. "There was no place for me to go. I mean, absolutely no place. No support groups."

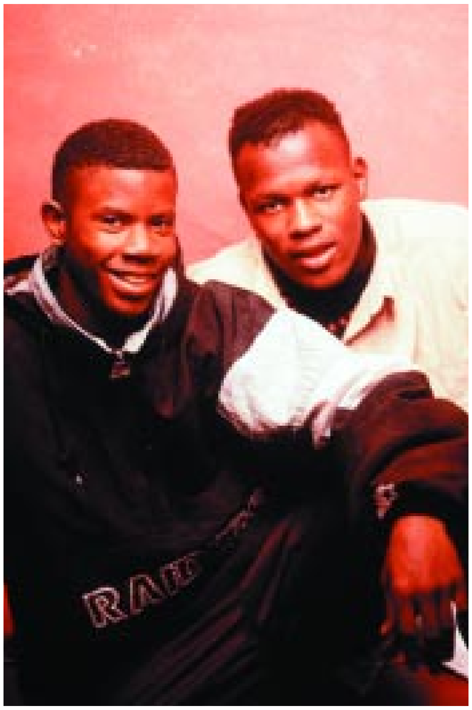
Her experience is not uncommon for women with HIV. Dunn, now a national AIDS activist, today seeks to solve the problem of the inadequacy of pre- and post-test counseling for women.

Dunn is well aware of the statistics that Black women make up 61 percent of all female AIDS cases, but she notes that many of the women choose to remain anonymous and therefore without care. "I have been out there so long not seeing any other faces, I wonder where they are, within my own city," she asks.

Rusti Miller-Hill has her own story as a person living with HIV. A few years ago, she was addicted to crack cocaine, treated, and then relapsed. Then her daughter saw her using drugs for the first time.

"I'd been out on the streets for three days," she told POZ magazine.[21] "I hadn't washed, changed clothes or combed my hair. I had on sneakers two sizes too big for me." That's when her daughter Brandi told her "don't come back until you bring my mother back." Those words actually gave Miller-Hill a reason to continue using drugs. "Why not? I had my excuse. My daughter didn't love me no more."[22]

Shortly thereafter, Miller-Hill was arrested for possession of crack with intent to sell and was sentenced to three years in jail. That's where she began her recovery. She educated herself, stopped using drugs, and gave birth to another child. Throughout her transformation, she has remained grounded. As she says, "I remind myself that I'm always just a step away from being a crackhead."[23]



Men Who Have Sex with Men[24]

Craig Washington was infected with HIV in 1985. In the same year that Rock Hudson died of AIDS, Craig began to notice his own symptoms. He remembers the climate at the time was "very different" in some ways, but in other ways today is much the same, he laments.

"I remember around that same time Eddie Murphy, who at that point was the most popular Black comedian, was telling jokes about AIDS," Washington recalls. In one joke, Murphy said he was afraid that he might get AIDS because his girlfriend had gay friends. "He told this joke, people laughed. And I think that that sent a message to me, as a very young Black gay man, that, you know, my life experience is really not that important."

That was in the mid 1980s, and today some comedians still do tell jokes about HIV and AIDS. However, one thing that has changed over time is Washington's perspective. He felt "fear" and "denial" when he first tested positive, and he declined to reach out to other gay men he knew for support. Now 39 years old, Washington has been living with HIV for 14 years and has been actively "working in the trenches" to fight the disease in his hometown of Atlanta and elsewhere.

MSM is a term used to describe men who engage in homosexual activity, although they may or may not identify as "gay," "homosexual" or "bisexual."

One of the primary challenges in providing education, prevention services, and treatment to this group is in identification. "MSM" is a technical term and most men who fit into this category are not likely to identify themselves as such. In addition, many MSMs do not openly disclose their sexual orientation or behavior.

MSMs make up a significant percentage of overall AIDS cases in African American communities.

Injection Drug Users

Kalio was diagnosed with AIDS while he was on a temporary work furlough from prison. When he returned to prison, he says he was in "denial" about his AIDS status. He and his wife had already known about his HIV before he went to prison, and two of his ex-girlfriends had died of AIDS.

Like many others infected with HIV, the words "isolation" and "denial" flow freely from Kalio's lips. Intravenous (or IV) drug users experience a special isolation not only because of the social stigma of drug use but because of the potential legal ramifications of disclosing their usage.

"There are many of us out there who want to live, who are infected with the virus. I'm one of them. I chose to live," he explains. "I got on methadone. And being on methadone maintenance has been a great help to me."

Although he has taken steps to turn his life around, he still feels a sense of ostracism from others in the community.

"I have undergone a lot of turmoil, isolation . . . despair, stigma, you know, just like the gay community, just like a lot of the women. But a lot of times doctors and people of your caliber from the media and such don't look at a drug user as a human being. You know, you look at us as animals," Kalio said.

Current and recovering drug users like Kalio speak of the need for holistic treatment that deals with their physical, emotional, mental, social, and spiritual concerns.

Kalio adds hopefully, "There should come a time when just as you accept people who are gay, women who have HIV, you should also accept, not be judgmental, of people who use drugs."

Focus groups with injection drug users support the anecdotal testimony. According to the focus groups, this group "felt no connection to civil rights organizations . . . showed the least affinity for the Black church . . . [and] felt the most abandoned by Black Leaders and traditional black organizations." Focus group research also bore at least one unexpected outcome in that injection drug users interviewed "did not feel that they had poor access to care."[25]

Injection drug use accounted for 9 percent of all AIDS cases among white men as of June 1996 but accounted for 36 percent of the cases among Black men.[26]

Community Stakeholders

Introduction

"Despite its impact on the African American community, AIDS is not typically perceived among African Americans as an issue requiring the same level of intervention and concern as other public health issues, such as violence and drug abuse."[27]—Robert E. Fullilove, Ph.D.

The NIA Plan is designed to illustrate why AIDS deserves our attention and why many of the social and public health issues affecting African Americans are interrelated. The complete version of The NIA Plan (available online at www.AAAinstitute.org) provides specific, concrete actions that any community-based organization can begin to take immediately.

The recommended actions were developed from a number of sources, including:

- **a steering committee of community stakeholders,**
- **interviews with leaders and members of community organizations,**
- **recommendations from previous African-American HIV/AIDS inititatives, and**
- **input from a series of town hall meetings conducted in the fall of 1999.**

This section of The NIA Plan focuses on what can be done by African American civil rights groups, faith communities, fraternal organizations, government agencies, media, and professional associations to address HIV/AIDS in their communities. It also discusses how African American AIDS service organizations can work together with these other organizations to build powerful coalitions that transcend single-issue politics.

Although we must recognize that many of our communities and organizations lack financial and other resources, money is not the only weapon needed in our arsenal.

We also need commitment, understanding, motivation, and action.

African American communities must adopt the philosophy of abundance to expand the pool of resources available for all our needs rather than the philosophy of scarcity that encourages us to fight among ourselves for limited resources to address only *some* of our community's needs.

This section of The NIA Plan focuses on what can be done by African American civil rights groups, faith communities, fraternal organizations, government agencies, media, and professional associations to address HIV/AIDS in their communities. It also discusses how African American AIDS service organizations can work together with these other organizations to build powerful coalitions that transcend single-issue politics.

One commonly repeated recommendation is that stakeholder groups become more involved in their local community planning councils, which assist and design planning of local prevention programs.

Civil Rights Groups

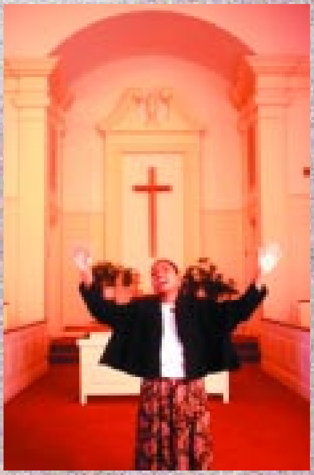
When many of us think of Black organizations, we think of civil rights organizations. These organizations include the National Association for the Advancement of Colored People (NAACP), the Southern Christian Leadership Conference (SCLC), the Martin Luther King Jr. Center for Nonviolent Social Change, Operation Push, the National Council of Negro Women, the Urban League, and numerous others.[28]

Since the NAACP was founded in 1909, it and sister civil rights organizations have played a major role in improving the lives of African Americans. These groups have waged a war on many fronts to fight discrimination and the effects of prejudice. In addition to their civil rights functions, some of these organizations serve other roles in our communities by promoting networking, economic empowerment, and professional development.

Civil rights groups have an important role to play in the fight against HIV and AIDS also. These organizations can make a significant difference in the battle because they bring to the table name recognition, institutional credibility, pre-existing infrastructure, connections to policymakers, and organizing power to mobilize African Americans. These attributes provide the civil rights organizations with the power to demand greater attention to AIDS issues from public and private interests.

Despite this power, many civil rights organizations face the barrier of limited resources and already overextended agendas. One useful approach to combating this lack of resources is by leveraging existing resources, recognizing the connections between various issues of prejudice, and drawing parallels where appropriate.

Faith Communities



Religion and faith play a central role in the lives of many African Americans.[29] Black faith communities and religious leaders led the fight against slavery in the nineteenth century and against segregation and discrimination in the twentieth century. But as AIDS continues to exact a toll on more and more churches and communities, how will people of faith respond to the challenge of AIDS in the next century?

For nearly 20 years, Black churches have been at ground zero in the AIDS crisis. Many of their members have passed away and many others are still living with the disease. Nevertheless, the response by the Black faith community has been mixed.

Some Black churches, such as Riverside Church in Harlem, New York, have lead the way in responding to AIDS. Other churches have lagged behind by ignoring the issue or simply preaching against it. The issue of AIDS is complicated by the mix of morality and politically-charged behavior commonly associated with HIV.

The task of involving faith communities in HIV/AIDS work is not a short-term project; we must be in it for the long term.

PERNESSA SEELE

Pernessa Seele, director of the Balm in Gilead, a national organization that mobilizes African American churches to respond to AIDS, explains that both the clergy and AIDS activists need to understand the connections between them. "We, the AIDS-activist community, must understand that the church is made up of people like you and I who are struggling how to live a better life," she says.

Seele suggests that AIDS activists use incentives and not just criticism to motivate churches to take action. "We need to highlight the success stories so that more churches can see and hear the success stories," she says.

Seele also emphasizes the importance of recognizing the differences, diversity, and nuances among churches so that activists will know the right approach for the right church.

Fraternal Organizations

"Fraternal organizations" is actually a catch-all phrase to include fraternities, sororities, social groups, and Masonic groups. These groups often play a multi-purpose role as social, professional, and charitable organizations of, by, and for Black communities.

These organizations play a major role in enhancing the quality of life for many African Americans and provide social, cultural, and charitable outlets them as well.

The NIA Plan research has identified a number of barriers to the participation of fraternal, social and Masonic organizations in HIV/AIDS education and advocacy. They include fears and concerns about homosexuality and the formation of other priorities including economic, social justice, and non-health related agenda issues.

When gay male participants in focus groups were asked to address the role of fraternal groups in fighting AIDS, some responded critically. "Fraternities are not open to homosexuality," one said. "You are okay as long as you don't say anything," said another. "You gotta represent that image, and being gay does not represent masculinity," a third responded.[30]

To combat these barriers, activists will need to make the case that HIV/AIDS is not only an economic and social justice issue, but that it is also an important public health issue in its own right.

Some suggestions for fraternal activities include the development of public media campaigns that employ the participation of leading African American celebrities and high-ranking officials such as Surgeon General David Satcher.

To address the problem of resource allocation, some fraternal organization members have considered developing partnerships with local and national businesses to help support or fund AIDS-related work.

Fraternal, social and Masonic organizations should also be approached by their own members who are infected or affected by HIV/AIDS.

Congressional Black Caucus Position:

"There is a state of emergency regarding the AIDS crisis in the Black community, therefore the U.S. government should declare the AIDS epidemic in the Black community a public health emergency. This declaration would enable the government to redefine, focus, mobilize and target AIDS resources to those communities that are most afflicted by the disease."

Government Agencies

Most government agencies have been slow to respond to the AIDS crisis among African Americans. Government officials "have known since the mid-80s that the epidemic was marching with blitzkrieg efficiency into minority communities," writes activist Mario

CONGRESSIONAL BLACK CAUCUS

Cooper, "but they have yet to produce a comprehensive program that even begins to address it."[31]

Donna Shalala, the secretary of Health and Human Services (HHS), notes that we must continue to strengthen and expand HIV/AIDS prevention and care programs. According to Mrs. Shalala, since President Clinton took office, overall funding for AIDS and related programs within HHS has increased by 131 percent.

A broad disparity exists among government agencies. While some government agencies are pro-active and well-funded, others are complacent and inert or overburdened and resource-poor.

Some activists have complained that as AIDS becomes "Blacker and browner" it becomes more difficult to secure funding from government agencies. Another issue identified was the need for greater organization and coordination between and among government agencies.

In light of these barriers, activists will need to become more organized, build coalitions, and develop broad-based political messages to help motivate government agencies to respond. Publicly-elected officials are likely to respond to demonstrated political benefits or consequences of their actions.
Some activists emphasized that AIDS is not over and that African American communities need a "bigger, Blacker response" in order to motivate government decision-makers.

Media

African Americans rely on many different sources of information for news, including Black-owned publications, radio stations, and television outlets, but they also follow the so-called "mainstream" media.[32] While we want to encourage all media to cover the crisis of AIDS in our communities, <u>The NIA Plan</u> focuses on Black-owned media organizations.

A number of barriers prevent the media from addressing issues of AIDS among African Americans. Among these barriers are the perceptions that HIV/AIDS is only "soft news," that it is not news at all, or that coverage of these issues will cost the media money in lost sales, ratings, or audience share. Some fear that HIV/AIDS is a politically dangerous topic for the media to address, while others feel it is not their role to educate the public about this issue.

Legal liability concerns, space and time constraints, privacy issues, and lack of resources are other reasons cited for the lack of coverage about HIV in Black communities.

In response to these barriers, media are likely to be motivated by increased popularity of the issue, exclusive stories, new angles, or financial incentives that help generate resources to cover their costs.

AIDS educators and activists would be advised to help the media learn to cover the story in a number of ways, including creating an authoritative website with information about AIDS in Black communities, generating financial assistance to help subsidize the cost of regular reporting on these issues, providing technical assistance to news rooms, establishing quantitative coverage goals, educating the media and reporters, developing a resource and inventory list, sending press kits, writing letters to the editor, and creating a media watchdog arm to analyze coverage of issues involving African Americans and HIV.

Professional Associations

Professional associations include a wide range of groups such as the National Bar Association, the National Society of Black Engineers, and the Association of Black Psychologists.[33] It could also include groups such as the National Association of Black Journalists and the National Medical Association, which are discussed in other sections of this report.

Professional organizations exist, in part, to educate their members about new developments in their fields and to provide valuable opportunities for networking.

DIANA WILLIAMSON, M.D.

WALTER SHERVINGTON, M.D.

Medical Organizations

The NIA Plan also examines the unique and important role of medical organizations. For example, the National Medical Association is the nation's leading African American medical organization. In addition to their work-related priorities in joining these associations, medical professionals may also be motivated by financial incentives and prestige, including the financial rewards and prestige associated with research and training.

Concerns raised by medical professionals include lack of training, territorialism, and specialization. Territorialism occurs when specific individuals attempt to dominate an issue and refuse to allow others to be involved in the discussion, whereas specialization becomes a concern when someone becomes so involved in the issue that she or he is pigeonholed into only one line of work.

Self-interest, pressure from the outside, and leadership on the inside were three factors identified to motivate these organizations and their members to become more involved in issues of HIV and AIDS among African Americans. Still, some health professionals raised questions about how serving HIV patients might affect their clientele and patient load and about payment and reimbursements rates for services provided.

In response to these concerns, Dr. Walter Shervington, incoming president of the National Medical Association, and Dr. Diana Williamson, medical director for the African American AIDS Policy and Training Institute, suggest that treating people living with HIV/AIDS patients can be cost-effective. They emphasized multi-disciplinary practices and moving from hospital stays to outpatient care as two techniques to be considered.

General Recommendations

What makes The NIA Plan especially important is that it is targeted toward community-based organizations as well as professional AIDS service providers and policymakers. The recommendations included throughout The Plan build on the work of meetings, conferences, research data, focus groups, and survey results.[34]

What is needed now is commitment and urgent action.

Many of the recommendations included in The NIA Plan can be applied to individuals as well as organizations. In particular, parents, teachers, and other role models can make an enormously positive impact on those around them.

The lesson from focus groups is that more work needs to be done by traditionally Black organizations (TBOs) to address issues of HIV and AIDS. In response to the question, "Where do you get messages and information about HIV/AIDS and substance abuse?" members of all focus groups agreed that messages and information "come almost exclusively from AIDS service organizations." When asked whether they received any messages or information from traditionally Black organizations, one respondent answered:

"Traditionally black organizations came to HIV pretty late. The presumption was that HIV/AIDS is a gay disease and affected whites only. That's why there's so much HIV and AIDS in our community, because they thought it was just a gay disease."

The absence of connection between focus group participants and TBOs indicates an opportunity for TBOs to increase their membership and strengthen their message. As one focus group participant responded, "I ignore Black agencies because they ignore Black gay men." A nearly identical response was given by a participant in a focus group of Black drug users. "I ignore Black agencies 'cause they ignore us," the participant said. Another comment made in the focus group of drug users suggested that Black organizations run the risk of losing support from some Black people by ignoring HIV/AIDS issues.

By addressing HIV/AIDS and other issues of interest to people affected by HIV/AIDS, many Black organizations might be able to increase the participation of those affected by HIV in their organizations. An infusion of new members might help strengthen or revitalize many of these organizations.

Similarly, in a focus group of black women, at least one acknowledged, "Most of the good information I get comes from white organizations. I'm ashamed to admit it," she admitted. This disclosure reveals another opportunity for TBOs to make themselves more relevant and useful to their constituencies.

Black adolescents and young adults interviewed in focus groups felt that TBOs dealt primarily with "safe things." Respondents recommended a number of activities to get TBOs more involved, including holding town hall meetings, Black film festivals, and educational perfomances.

Many of the recommendations included in this report can be applied to individuals as well as organizations. In particular, parents, teachers, and other role models can make an enormously positive impact on those around them.

> "This is a national crisis . . . We will not rest until it is understood as one, until it is considered as one and worked on as one."
> —U.S. Rep. Maxine Waters (D-California)

Parents, for example, need to be reminded of what they can do with their children. Perhaps the best advice for parents comes from 14-year-old Hydeia Broadbent: “I know some of you may have kids, you should be able to sit down, talk to them, because they do listen to music, they do watch TV, they do go to the movies, and they know—they know about AIDS, but I don't think they know all the facts about AIDS. . . . kids should be able to have a place where they can go and get the facts about AIDS, so they can, hopefully, protect themselves against it.”

After a year of meetings, conferences, focus groups, and town hall meetings, several general observations and recommendations have emerged and are listed below.

Observations:
- AIDS is not over
- AIDS is becoming increasingly serious in Black communities
- Effective leadership will make the difference

Recommendations

- Network with other individuals and organizations
- Emphasize and advertise model programs such as the pager adherence program to assure medication compliance
- Address AIDS as a social justice issue
- Approach the problem from the perspective of empowering people who are living with or affected by HIV
- Provide mentorship for new activists and those who are not yet activists
- Establish legislative goals including the reauthorization of the Ryan White CARE Act.
- Increase training for health professionals
- Provide technical assistance to those dealing with HIV/AIDS
- Seek special assistance from related industries
- Demonstrate the connection between AIDS and other issues
- Involve historically-Black colleges and universities in AIDS prevention, treatment, and research
- Develop a comprehensive website on AIDS in Black communities
- Disseminate information beyond the activists
- Insist that pharmaceutical companies provide resources, funding, support
- Connect AIDS to other health issues facing our communities
- Develop new angles for elected officials to understand, discuss
- Push medical schools to teach HIV behavior prevention, not just HIV science
- Work with physicians at the community level
- Include spirituality as a component of HIV/AIDS reduction
- Use a multi-disciplinary approach to prevention, treatment, and research
- Develop an AIDS resource inventory
- Create specific time-defined goals to underscore the sense of urgency
- Make it easy for people to be engaged

Developing the NIA Plan

Background

What would happen if African Americans committed themselves to stopping the spread of HIV/AIDS in Black communities? Working together, we could put an end to AIDS in our communities.

The NIA Plan is designed to help African Americans make this commitment. The Plan seeks to tap into the energy of many different Black communities and helps to make it easier for individuals and organizations to do their part to stop the spread of HIV and AIDS.

Following World War II, President Truman's Secretary of State George Marshall proposed an extensive $13 billion plan to re-build Europe. The "Marshall Plan" was more than foreign aid; it was a coordinated self-help plan that took into account two realities: (1) A plan to save Europe must be European, and (2) available public and private resources needed to be leveraged for maximum impact.

The NIA Plan recognizes the same realities understood with the Marshall Plan and applies them to our communities. These realities are:

1. Any plan to save African Americans from AIDS must be generated by African Americans.

2. All available public and private resources need to be leveraged for maximum impact.

These two realities have informed the development of this plan. The African American AIDS Policy and Training Institute (AAAPTI) has been working collaboratively with numerous other Black organizations and institutions to create this plan. The Institute firmly believes that successful AIDS reduction efforts must involve the commitment and resources of public institutions, government agencies, community organizations, businesses, activists, and concerned individuals.

The NIA Plan takes its name from the Kwanzaa principle of purpose, and its purpose is to stop AIDS in African American communities. But we are also led by other principles of Kwanzaa, including Umoja (unity) and Kujichagulia (self-determination).

We seek to increase unity in our communities, but the unity we seek is in diversity, not in homogeneity. This unity must be based on mutual understanding, trust and respect.

Finally, we need to be mindful of the Kwanzaa principle of self-determination, which includes empowering people to define themselves, name themselves, help themselves, and create their own identities rather than being defined, named, helped, and identified by others.

When African Americans do commit themselves to stopping the spread of HIV/AIDS in Black communities, then we will finally find a solution to the challenges posed by this disease.

Steering Committee Meeting

On July 5, 1999, African American AIDS activists began a series of coordinated discussions with other African American community leaders to talk about what could be done to stop the spread of HIV and AIDS in our communities.

The July meeting brought together decisionmakers from some of the nation's leading Black community organizations for a two-day meeting in Los Angeles.[35] The meeting was convened by Phill Wilson, the director of the African American AIDS Policy and Training Institute and facilitated by Diana Williamson, M.D., M.Sc., the Institute's medical director.

This Los Angeles group, informally described as a "Steering Committee," reviewed the latest in AIDS epidemiological data, medical research, prevention and treatment efforts, and model programs.[36] Just as importantly, the participants listened to the testimony of people living with AIDS representing women, youth, gay men, and drug users.

Dr. Martin Shapiro from the Rand Corporation presented research information about HIV-related patients who received medical care in 1996. Dr. John Peterson of Georgia State University presented data on prevention research.

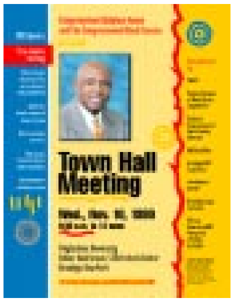
Importantly, the meeting was specifically designed to target those who are not HIV service providers or activists as a means of bringing them into the discussion and eliciting their thoughts and ideas. As a "working group," the participants broke into smaller groups for targeted, facilitated sessions to discuss what actions can and should be taken by faith communities, civil rights groups, fraternal and community-based organizations, media, professional associations, and government to deal with AIDS in Black communities.[37]

The breakout groups examined five questions related to the specific group they were targeting: (1) what are the current attitudes and beliefs of the group about HIV/AIDS; (2) what barriers prevent these groups from engaging in HIV/AIDS work; (3) what would motivate these groups and their leaders/members to be more involved; (4) what concrete steps can or should these groups take to help reduce the spread of HIV/AIDS in Black communities; and (5) what specific action can the Steering Committee members take to get the target group to take the steps identified.

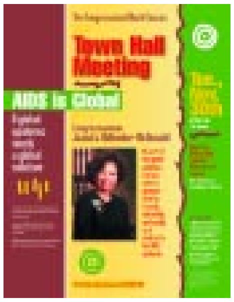
Regional Meetings

A series of regional meetings in various locations throughout the United States was the critical information gathering resource for <u>The NIA Plan</u>. The meetings took place in the fall of 1999 in Los Angeles, New York, Baltimore and Atlanta.

Town Hall Meeting



Town Hall Meeting



Town Hall Meeting

AIDS is Global

Town Hall Meeting

AIDS in the Black Community

Town Hall Meetings

As an ongoing project, <u>The NIA Plan</u> will also be informed by a series of town hall meetings. The town hall meetings are scheduled to take place in fall 1999 and winter 2000 and are sponsored jointly by AAAPTI and members of the Congressional Black Caucus.

Implementing the NIA Plan

Plan of Action

The NIA Plan is not just a strategic plan; it is a plan of action. It lists specific action steps that individuals and institutions can and should take to help stop the spread of HIV/AIDS in our communities.

The NIA Plan is informed by several pieces of research. These include:

1. focus groups to determine the needs and opportunities of infected and non-infected at-risk group members,[38]

2. feedback solicited from community organizers and leaders before and after the creation of this first plan,

3. community responses to the recommendations of the Steering Committee meeting, and

4. other research conducted by the AAAPTI staff.

The Plan is also a work in progress. The information gathered from the Steering Committee meeting, regional meetings, and town hall meetings has been assembled, analyzed, and condensed for inclusion in this Executive Summary for release on the occasion of the last World AIDS Day of the millennium.

To review the complete version of The NIA Plan, contact the African American AIDS Policy and Training Institute:

AAAPTI
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Los Angeles, California 90027-1409
323-663-4194 phone
323-666-8846 fax
www.aaainstitute.org

Programs in Place

The Characteristics of Reputationally Strong Programs Project has visited 18 such programs with the intent of finding commonalties that contribute to their success. Analysis of the collected information indicates several common characteristics of these programs. Some are related to the agency, such as the existence of strong agency and administrative support for the intervention, the intervention's fit with the agency's mission, and linkage to other services and programs within and outside of the agency.

Other common characteristics are related to the intervention design, such as clearly identified audience, goals, and objectives; use of behavioral and social science theory; multiple approaches used in implementation, and cultural sensitivity and community input.

Still others are related to the staff conducting the intervention. They are adequately trained, highly committed, nonjudgmental, culturally sensitive, and willing to work with limited resources. These traits are essential to high quality intervention delivery and are independent of the staff's educational attainment.

Below is just a small portion of the collection of sample programs now in place.

- Albert Einstein Hospital Immunology Program For Women With HIV, Bronx, New York
- AMD Pharmacy's Pager Adherence Program
- Historically Black Colleges And Universities Program
- HIV/AIDS Strategic Plan for the Chicago Area: 1999-2001, Chicago, Illinois
- National Football League Players Association Advertising Campaign
- New York Daily News Newspaper Supplement Program
- Project Azuka, Savannah, Georgia
- Women Initiating New Directions, AIDS Action Committee, Boston, Massachusetts

Prevention Plan

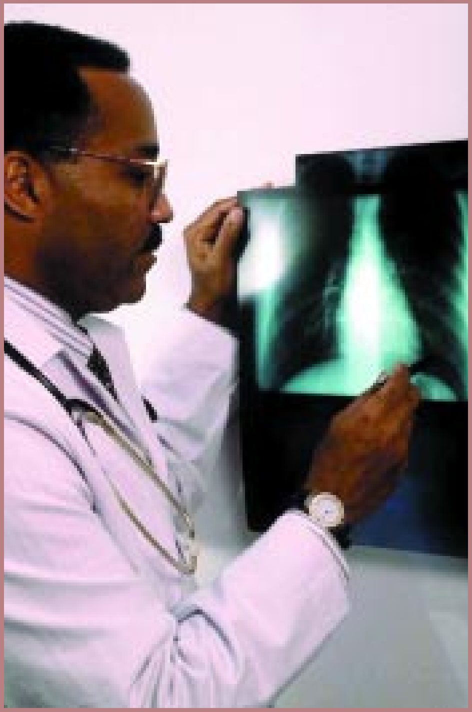
The prevention component of The NIA Plan is being developed by reviewing the existing research, literature, focus groups, and other evidence of successful HIV prevention work. This component highlights HIV prevention barriers, objectives, and other issues for the various subpopulations in Black communities.

Like the treatment and research plans, the prevention component of The NIA Plan is an ongoing effort that begins with these recommendations but will be continually developed by reviewing the existing research, literature, and other evidence of successful HIV research work. Ultimately, our goal with the prevention plan is to identify characteristics of effective AIDS prevention programs that can be replicated for African American communities.

Several psychosocial theories have helped to guide existing HIV/AIDS prevention programs. These theories include the health belief model, the theory of reasoned action, and the social learning theory.[39] In recent years, some behavioral researchers have observed the limitations of the existing models of sexual risk behavior. Dr. Hortensia Amaro has noted that existing models "are based on individualistic conceptualization of behavior and fail to consider the broader cultural and social context of sexuality." Also important, she notes that the current models "are based on the assumption that sexual behaviors and encounters are controlled totally by the individual and that these encounters are always initiated under the individual's control."

The assumptions behind existing models may discount the role of gender or age or other factors in determining or influencing behavior. For example, Amaro found that in most studies sexual risk behaviors in women and men are seen as the same even though some behaviors (e.g., wearing a condom) are different. 'For men, the behavior is wearing the condom; for women, the behavior is persuading the male partner to wear a condom or, in some cases, deciding not to have sex when the male partner refuses to wear a condom."

Treatment Plan



The treatment component of The NIA Plan is being developed by reviewing the existing research, literature, and other evidence of successful HIV treatment initiatives. This component highlights HIV treatment barriers, objectives, and other issues for the various sub-populations in Black communities.

Like the prevention and research plans, the treatment component of The NIA Plan is an ongoing effort that begins with these recommendations but will be continually developed by reviewing the existing research, literature, clinical trials, and other evidence of successful HIV treatment work. Ultimately, our goal with the treatment plan is to identify barriers to treatment and care in African American communities and present culturally appropriate remedies to these barriers.

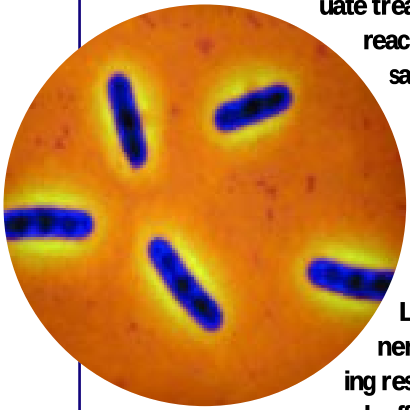
One of the more dramatic changes in the perspective of AIDS has been the development of protease inhibitors—drugs that thwart viral replication of the protease enzyme by blocking the synthesis of the enzyme.

Significant numbers of patients undergoing protease inhibitor treatment regimens are reporting undetectable levels of HIV in their blood. Despite these encouraging signs, such patients still carry the virus and they do have the capacity to infect others.[40]

In developing a treatment plan, we must be mindful of existing support for AIDS treatment and care services. Currently, the Ryan White CARE (Comprehensive AIDS Resources Emergency) Act, administered by the Health Resources and Services Administration (HRSA), is the only federal public program specifically to provide medical and related services for people living with HIV/AIDS.[41]

Treatment and research are necessarily connected, and some parts of this section overlap with parts of the Research Plan to follow. We begin with the assumption that we must increase the number of African Americans who are taking part in clinical trials. A clinical trial is a human experiment designed to study the effectiveness of treatments by comparing two treatments or comparing a potential treatment with a placebo.

The staggering racial disparities for HIV infection and mortality highlight the need to evaluate treatment and adherence programs and their effectiveness in reaching populations that have not responded to previous messages.



Research Plan

Like the prevention and treatment plans, the research component of The NIA Plan is being developed by reviewing the existing research, literature, and other evidence of successful HIV research efforts. This component highlights HIV research barriers, objectives, and other issues for the various sub-populations in Black communities.

The research component of The NIA Plan is an ongoing effort that begins with these recommendations but will be continually developed by reviewing the existing research, literature, clinical trials, and other evidence of successful HIV research work. Ultimately, our goal with the research plan is to make recommendations to develop effective, comprehensive behavioral and biomedical research strategies.[42]

According to the Office of AIDS Research at the National Institutes of Health, $342 million (38 percent) of its $900 million AIDS clinical research budget is “minority directed.”[43] These figures do not distinguish the percentage directed at African Americans, who make up nearly half of all new AIDS cases.

As the need for antiviral agents and vaccines became clear early in the epidemic, clinical trials became the means for treatment of those infected for this was one of the only ways to receive treatment. Women and people of color were underrepresented in these trials, thus underscoring the disconnect between these populations and treatment providers. African Americans also revealed suspicion of treatment providers and treatments.[44]

To respond to these suspicions, treatment providers and researchers are encouraged to follow principles that create confidence in their practices. Three principles outlined in a 1988 report include:

1. respect for persons—recognition of the right of persons to exercise autonomy

2. beneficence—the minimization of risk incurred by research participants and the maximization of benefits to them and to others, and

3. justice—the principle that therapeutic investigations should not unduly involve persons from groups unlikely to benefit from subsequent application of the research.[45]

As a starting point, goals of effective research work should include the following:

■ To conduct Phase IV and Phase V studies that look at the effects of proven HIV drugs on African Americans with a focus on how these drugs affect persons with a predisposition to diabetes, hypertension, and asthma or other risks for co-morbidity. To specifically look at the drug interactions for HIV treatments and treatments for other chronic conditions at high incidence among African Americans.

■ To conduct behavior studies in parallel to the biomedical and behavioral prevention studies that look at community-based practice and documents principles of effective strategies for African Americans. A primary function would be to give the scientific validity to what we know works for our people.

■ To design and conduct research that addresses the importance of social networks in HIV transmission. Some of these networks that have already identified ways of reducing HIV infection but may need additional interventions are gay or bisexual men, non-monogamous married men, commercial sex workers, the transgendered, women, adolescents, the homeless, persons at risk for multiple incarcerations, the chronically mental ill and drug users.

■ To conduct research that addresses the barriers to minority participation in clinical trials. This would include issues of study enrollment, as well as community, provider and individual perceptions of human clinical studies.

■ To conduct research that looks at the impact of social forces on HIV service and treatment access with a clear goal of identifying ways to address the effect of poverty, racism, violence, religion, social stigma, and homophobia.

■ To identify resources to increase the number of African American researchers and the resources to conduct and publish their research.

Conclusion

To stop the spread of HIV and AIDS in our communities, all of us have to play a role. Inaction is not an option. The lives of hundreds of thousands of African Americans are at stake and depend on us.

In creating The NIA Plan, we have been guided by the principles that everyone counts and everyone can help. We must confront our fears and issues that would persuade us otherwise.

Stopping AIDS need not be the only priority, but it must be a high priority for all of our organizations, institutions, and leaders.

In fact, leaders must recognize the synergistic relationship between various issues affecting the African American communities. Poverty, lack of education and insurance, and other social challenges are co-factors for HIV infection.[46] Only a comprehensive approach to the problems facing African American communities that recognizes the intersection between these issues is likely to succeed.

When the next generation asks what we did about AIDS, how will we be able to respond? Will we be able to say that we came together, maximized our resources and talents? That we refused to let homophobia, racism, sexism, or classism stop us from ending the epidemic?

Will we be able to say that we tore down the walls separating us from one another? Or will we have to say that HIV won the battle because we built walls that divided us? That our hearts were not big enough to embrace all of what we were and what we are?[47]

The challenge belongs to you and to all of us. Working together, we can win the fight against AIDS and build a brighter future for all of us.

Glossary of Terms and Acronyms

AAAPTI	African American AIDS Policy and Training Institute
ADAP	AIDS Drug Assistance Program, funded under Title II of the Ryan White Care Act
AIDS	Acquired immune deficiency syndrome
ASO	AIDS service organization
AZT	Drug designed to help treat HIV infection in combination with other drugs and to prevent passage of the virus from pregnant women to their babies; also known as "Zidovudine"
CBC	Congressional Black Caucus
CBO	Community-based organization
CDC	U.S. Centers for Disease Control and Prevention
HBCU	Historically-Black colleges and universities
HCFA	Health Care Financing Administration; administers Medicaid and Medicare programs
HHS	U.S. Department of Health & Human Services; also referred to as DHHS
HIV	Human immunodeficiency virus

HRSA	**Health Resources and Services Administration; administers Ryan White CARE Act**
HUD	**U.S. Department of Housing and Urban Development**
Medicaid	**Federal-State health insurance program for some low-income and needy people**
MMWR	**CDC's** *Morbidity and Mortality Weekly Report*
Nia	**Swahili word that means "purpose"**
NIH	**National Institutes of Health**
Protease inhibitor	**Drug that thwarts viral replication of the protease enzyme by blocking the synthesis of the enzyme**
Ryan White CARE Act	**Comprehensive AIDS Resources Emergency Act administered by HRSA**
SAMHSA	**Substance Abuse and Mental Health Services Administration**
STD	**Sexually-transmitted disease**
TBO	**Traditionally Black organization**

About the Institute

The African American AIDS Policy and Training Institute (AAAPTI) is a non-profit educational organization that conducts activities designed to (i) reduce new HIV infections in African American communities, and (ii) increase access to treatment resources and/or (iii) improve quality of life for African Americans living with HIV/AIDS, including:

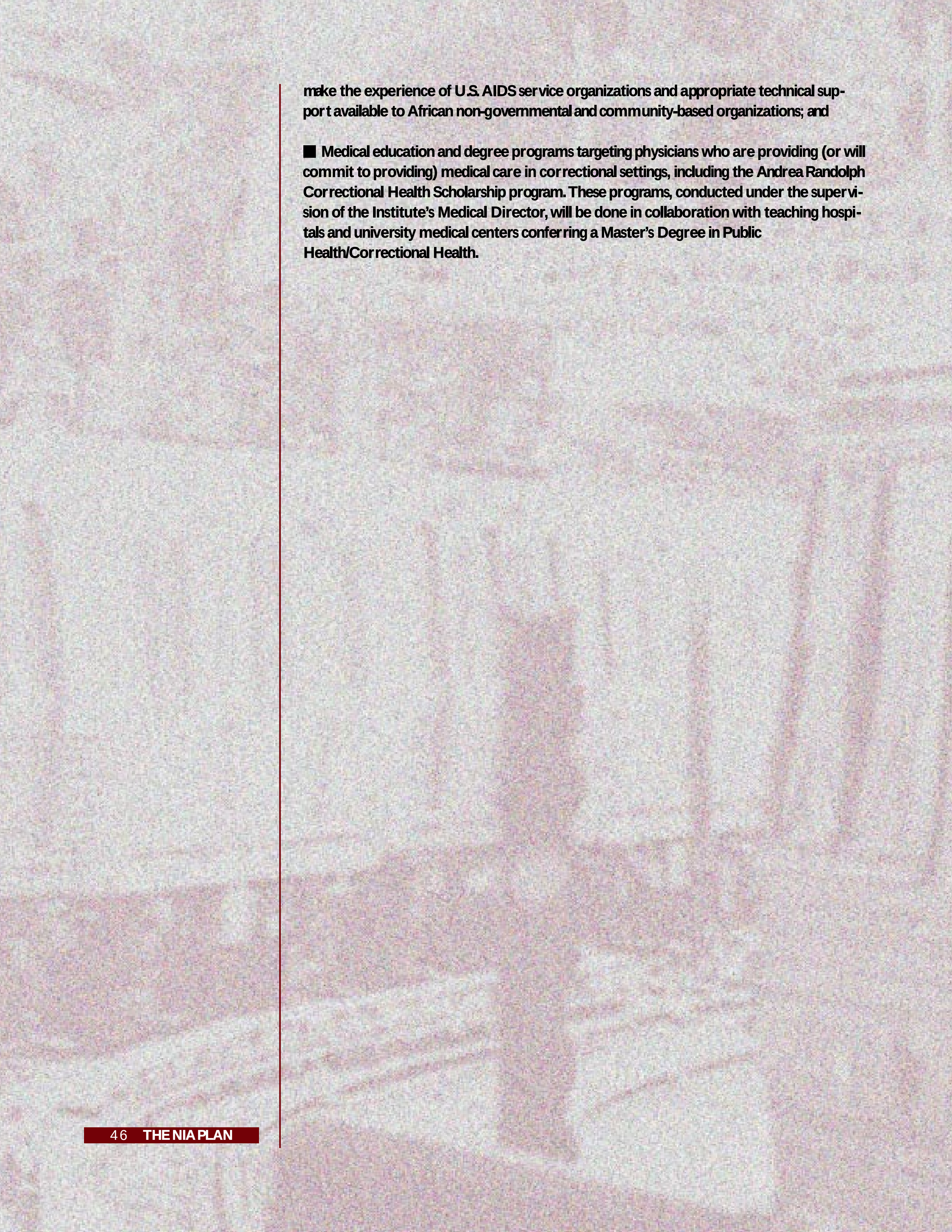
- Training modules for African American peer treatment and prevention advocates enabling them to directly serve African Americans living with HIV or at risk for HIV infection according to intervention models proven (or to be proven) effective;

- Policy development and planning, including The NIA Plan, a comprehensive plan of action for African Americans to help reduce the spread of HIV/AIDS in our communities, conducted in collaboration with federal, state and local government agencies, universities, community-based AIDS service organizations, health care providers, opinion leaders and "gatekeepers," to formulate and disseminate policy proposals;

- Research in support of the Institute's training and policy-making activities, including (i) background research in already available statistics and data on HIV and African American populations, and (ii) cutting-edge research on models for prevention and treatment interventions;

- Publishing policy recommendations, training manuals and articles in support of its training and policy-making activities, using print and electronic media. Specifically, the Institute will publish The NIA Plan and other policy proposals, various research papers and culturally appropriate information about HIV to African American audiences in the form of newsletters and a website;

- International initiatives, including the Simon Nkoli Exchange program, designed to



make the experience of U.S. AIDS service organizations and appropriate technical support available to African non-governmental and community-based organizations; and

- Medical education and degree programs targeting physicians who are providing (or will commit to providing) medical care in correctional settings, including the Andrea Randolph Correctional Health Scholarship program. These programs, conducted under the supervision of the Institute's Medical Director, will be done in collaboration with teaching hospitals and university medical centers conferring a Master's Degree in Public Health/Correctional Health.

Attachments

Attachment A

STEERING COMMITTEE

Abdelaziz Abdelaziz, M.S., M.S.E., National Muslim AIDS Initiative
Dr. Randall Bailey, Interdenominational Theological Center
A. Cornelius Baker, National Association of People with AIDS
Bill Barnes, Office of Mayor Willie Brown
Keith Boykin, Author, Consultant
Hydeia L. Broadbent, Hydeia Broadbent Foundation
Deloris Bullard, Hydeia Broadbent Foundation
Dianne Bush, National Council of Black State Legislators
Patricia Carter, Leading for Life, Harvard AIDS Institute
Roscoe Cooper, Mayor's AIDS Task Force
Elaine Daniels, M.D., Ph.D., DuPont Pharmaceuticals
Chris DeMarzo, AMD Pharmacy
Wayne Duncan, PHA, Centers for Disease Control and Prevention
Belynda Dunn, Touch Me Ministries
Ferd Eggan, City AIDS Coordinator
Michael Elazier, Congressional Black Caucus
Eric Flowers, Ramsell Corporation & Associates
Maurice Franklin, Gay Men of African Descent
Gil Gerald, Gil Gerald & Associates
Eric Goosby, M.D., Office of HIV/AIDS Policy at HHS
Warren Hewett, Center of Substance Abuse Treatment at SAMHSA
Joe Hicks, City of Los Angeles Human Relations Commission
Ernest Hopkins, San Francisco AIDS Foundation and C AEAR Coalition

Michael Johnson, M.D., Health Resources and Service Administration
Wilbert Jordan, M.D., MPH, The King Drew Medical Center
Marguerita Lightfoot, Ph.D., UCLA Center of CHIPTS
Michelle Lopez, *New York Daily News*
Marsha Martin, Ph.D., Special Assistant to Secretary of Health & Human Services, Donna Shalala
James Milner, Interscience
Rasheeda Mohammed, National Council of Negro Women
John Peterson, Associate Professor of Psychology, Georgia State University
Michael Poulson, Center for Urban Epidemiological Studies
Beny Prim, M.D., National Minority AIDS Council
Gregory Roberts, Magic Johnson Foundation
Angela Saffo-Daniels, Bristol-Myers Squibb
Edwin Sanders, Metropolitan Interdenominational Church
Pernessa C. Seele, The Balm in Gilead
Martin Shapiro, Rand Corporation
Walter Shervington, National Medical Association
Charles Stewart, California HealthCare Foundation
Steve Wakefield, Night Ministries
Craig Washington, AID Atlanta
LeRoy Whitfield, Journalist
Ramona Wiley, AMD Pharmacy

Attachment B

CONGRESSIONAL BLACK CAUCUS MEMBERS

African American Members of the 106th United States Congress

The Honorable Sanford D. Bishop
Georgia, 2nd District
U.S. House of Representatives
1433 Longworth House Office Building
Washington, DC 20515
202-225-3631

The Honorable Corrine Brown
Florida, 3rd District
U.S. House of Representatives
1610 Longworth House Office Building
Washington, DC 20515
202-225-0123

The Honorable Julia Carson
Indiana, 10th District
U.S. House of Representatives
1541 Longworth House Office Building
Washington, DC 20515
202-225-4011

The Honorable Donna Christian-Christensen
Delegate, Virgin Island
U.S. House of Representatives
1711 Longworth House Office Building
Washington, DC 20515
202-225-1790

The Honorable William Clay
Missouri, 1st District
U.S. House of Representatives
2306 Rayburn House Office Building
Washington, DC 20515
202-225-2406

The Honorable Eva Clayton
North Carolina, 1st District
U.S. House of Representatives
2440 Rayburn House Office Building
Washington, DC 20515
Ph:202-225-3101

The Honorable James Clyburn
South Carolina, 6th District
U.S. House of Representatives
319 Cannon House Office Building
Washington, DC 20515
202-225-3315

The Honorable John Conyers, Jr.
Michigan, 14th District
U.S. House of Representatives
2426 Rayburn House Office Building
Washington, DC 20515
202-225-5126

The Honorable Elijah Cummings
Maryland, 7th District
U.S. House of Representatives
1632 Longworth House Office Building
Washington, DC 20515
202-225-4741

The Honorable Danny Davis
Illinois, 7th District
U.S. House of Representatives
1218 Longworth House Office Building
Washington, DC 20515
202-225-5006

The Honorable Julian C. Dixon
California, 32nd District
U.S House of Representatives
2252 Rayburn House Office Building
Washington, DC 20515
202-225-7084

The Honorable Chaka Fattah
Pennsylvania, 2nd District
U.S. House of Representatives
1205 Longworth House Office Building
Washington, DC 20515
202-225-4001

The Honorable Harold Ford, Jr.
Tennessee, 9th District
U.S. House of Representatives
1532 Longworth House Office Building
Washington, DC 20515
202-225-3265

The Honorable Alcee Hastings
Florida, 23rd District
U.S. House of Representatives
1039 Longworth House Office Building
Washington, DC 20515
202-225-1313

The Honorable Earl Hilliard
Alabama, 7th District
U.S. House of Representatives
1314 Longworth House Office Building
Washington, DC 20515
202-225-2665

The Honorable Jesse Jackson, Jr.
Illinois, 2nd District
U.S. House of Representatives
313 Cannon House Office Building
Washington, D. C. 20515
202-225-0773

The Honorable Sheila Jackson-Lee
Texas, 18th District
U.S. House of Representatives
410 Cannon House Office Building
Washington, DC 20515
202-225-3816

The Honorable William J. Jefferson
Louisiana, 2nd District
U.S. House of Representatives
240 Cannon House Office Building
Washington, DC 20515
202-225-6636

The Honorable Eddie Bernice Johnson
Texas, 30th District
U.S. House of Representatives
1123 Longworth House Office Building
Washington, DC 20515
202-225-8885

The Honorable Carolyn Cheeks Kilpatrick
Michigan, 15th District
U.S. House of Representatives
503 Cannon House Office Building
Washington, DC 20515
202-225-2261

The Honorable Barbara Lee
California, 9th District
U.S. House of Representatives
414 Cannon House Office Building
Washington, DC 20515
202-225-2261

The Honorable John Lewis
Georgia, 5th District
U. S. House of Representatives
229 Cannon House Office Building
Washington, DC 20515
202-225-3801

The Honorable Cynthia McKinney
Georgia, 4th District
U.S. House of Representatives
124 Cannon House Office Building
Washington, DC 20515
202-225-1605

The Honorable Carrie P. Meek
Florida, 17th District
U.S. House of Representatives
401 Cannon House Office Building
Washington, DC 20515
202-225-4506

The Honorable Gregory W. Meeks
New York, 6th District
U.S. House of Representatives
1035 Longworth House Office Building
Washington, DC 20515
202-225-3461

The Honorable Juanita Millender-McDonald
California, 37th District
U.S. House of Representatives
419 Cannon House Office Building
Washington, DC 20515
202-225-7924

The Honorable Eleanor Holmes Norton
Delegate, District of Columbia
U.S. House of Representatives
1424 Longworth House Office Building
Washington, DC 20515
202-225-8850

The Honorable Major Owens
New York, 11th District
U.S. House of Representatives
2305 Rayburn House Office Building
Washington, DC 20515
202-225-6231

The Honorable Donald M. Payne
New Jersey, 10th District
U.S. House of Representatives
2244 Rayburn House Office Building
Washington, DC 20515
202-225-3436

The Honorable Charles B. Rangel
New York, 15th District
U.S. House of Representatives
2354 Rayburn House Office Building
Washington, DC 20515
202-225-4365

The Honorable Bobby Rush
Illinois, 1st District
U.S. House of Representatives
131 Cannon House Office Building
Washington, DC 20515
202-225-4372

The Honorable Robert C. Scott
Virginia, 3rd District
U. S. House of Representatives
2464 House Office Building
Washington, DC 20515
202-225-8351

The Honorable Bennie Thompson
Mississippi, 2nd District
U. S. House of Representatives
1408 Longworth House Office Building
Washington, DC 20515
202-225-5876

The Honorable Edolphus Towns
New York, 10th District
U. S. House of Representatives
2232 Rayburn House Office Building
Washington, D. C. 20515
202-225-5936

The Honorable Stephanie Tubbs Jones
Ohio, 11th District
U. S. House of Representatives
2365 Rayburn House Office Building
Washington, DC 20515
202-225-7032

The Honorable Maxine Waters
California, 35th District
U.S. House of Representatives
2344 Rayburn House Office Building
Washington, DC 20515
202-225-2201

The Honorable Melvin Watt
North Carolina, 12th District
U. S. House of Representatives
1230 Longworth House Office Building
Washington, DC 20515
202-225-1510

The Honorable Albert Wynn
Maryland, 4th District
U.S. House of Representatives
407 Cannon House Office Building
Washington, DC 20515
202-225-8699

Notes

1. The NIA Plan uses the terms "African American" and "Black" interchangeably throughout the document in reference to Americans of African descent. At the same time, we do recognize the inadequacy of any single term to represent the diversity of our people and communities.

2. The Seven Principles of Kwanzaa are Umoja (unity), Kujichagulia (self-determination), Ujima (collective work and responsibility), Ujamaa (cooperative economics), Nia (purpose), Kuumba (creativity), and Imani (faith).

3. Sources for Chronology include *Washington Post* Archives; *Washington Blade* Archives; The Library & Center for Knowledge Management, University of California San Francisco "Chronology of AIDS in San Francisco," http://www.library.ucsf.edu/sc/ahp/chron1985.html; National Minority AIDS Council Update, Sep. 1998; U.S. Food and Drug Administration, "HIV/AIDS Milestones," http://www.fda.gov/oashi/aids/miles81.html; Cynthia Rose, Real Time Hot Tips, "Eazy-E Obituary," http://www.state51.co.uk/hottips/395/eazyobit.html; Cohen, Cathy, *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics*, 1999; "The History of AIDS," http://www.avert.org/his87_92.htm; Kaiser Family Foundation, "National Survey of African Americans on HIV/AIDS," Mar. 16-17, 1998.

4. Early education campaigns, such as the 1983 advertisement shown on this page, tried to teach the public that HIV could not be transmitted by casual contact.

5. *HIV/AIDS Surveillance by Race/Ethnicity: L238 Slide Series*, U.S. Centers for Disease Control and Prevention, National Center for HIV, STD and TB Prevention, Divisions of HIV/AIDS Prevention, www.cdc.gov/nchstp/hiv_aids/graphics/minority.htm.

6. Remarks by Donna E. Shalala, U.S. Secretary of Health and Human Services, Feb. 25, 1999. Secretary Shalala also cited a study by Dr. David Kindig at the University of Wisconsin Medical School that "HIV is now one of the leading contributors to the gap in life expectancy between African Americans and whites."

7. Ibid.

8. "[T]here continues to be a health gap between African American and white Americans in general, as shown by the HIV epidemic as well as other health indicators." Kaiser Family Foundation, National Survey of African Americans on HIV/AIDS, 3., citing CDC Office of the Associate Director of Minority Health. Martin Shapiro of the Rand Corporation has presented research data indicating a disparity between the CDC estimates for Black HIV infection and the percentage of Blacks actually receiving care. In addition, Blacks and Latinos are more likely than whites to use emergency room services for primary care.

9. Bennefield, Robert, *Current Population Reports: Health Insurance Coverage: 1997*, P60-202, U.S. Census Bureau, Issued September 1998.

10. The costs for "providing the standard of care are between $10,000 and $12,000 per patient (or higher depending on the stage of disease)." Thomas, Stephen B., Presentation Before Congressional Briefing, Jul. 26, 1999; In 1996, the average patient cost per year was about $20,000, according to Martin Shapiro of the Rand Corporation; Fifty-two percent of "beneficiaries" of the federal AIDS

Drug Assistance Program are racial and ethnic minorities. Fox, Claude Earl III, M.D., M.P.H., 'Perspectives on Ryan White, Medicaid, and Medicare," Prepared remarks for presentation before National Conference on African Americans and AIDS, 2, Feb. 25, 1999; But see, Cooper, Mario, "Two Nations Under Plague: Wake up, my gay, white brothers and sisters! AIDS is ravaging people of color," *POZ*, 20, Jan. 1999 ("For the poor and uneducated who are eligible for ADAP assistance, the procedures can be "cumbersome.").

11. O'Neill, Joseph F., 'Perspectives on Ryan White CARE Act and Medicaid," Prepared remarks for presentation before National Conference on African Americans and AIDS, 1, Feb. 25, 1999; Minorities with HIV are more likely to receive services through public programs. Fox, Claude Earl III, M.D., M.P.H., 1, 3, Feb. 25, 1999 (citing HIV Cost and Services Utilization Study, New England Journal of Medicine, Dec. 1998).

12. "While the proportion of AIDS diagnoses among gay and bisexual men has decreased dramatically among white men since 1989 — from approximately 60 percent to about 30 percent — the proportion of cases among African Americans has increased dramatically, from approximately 25 percent to over 40 percent." Thomas, Stephen B., Presentation Before Congressional Briefing, 2, Jul. 26, 1999; See also, Cooper, Mario, "Two Nations Under Plague: Wake up, my gay, white brothers and sisters! AIDS is ravaging people of color," *POZ*, 20, Jan. 1999. According to Cooper, "One gay activist I know even had the nerve to announce that names reporting was no longer 'that big of a deal' because 'those' people are used to being manipulated by society."

13. The primary mechanisms for transmission of the HIV virus are blood, semen, and vaginal fluids. Unprotected sex and injection drug use are two efficient means of transmitting the virus through these bodily fluids.

14. Fullilove, Robert E. and Fullilove, Mindy Thompson, "HIV Prevention in the African American Community," 8, Feb. 1999.

15. Coleman, Chrisena, "An Extraordinary Girl: 14-year-old AIDS activist continues her mission," *New York Daily News* AIDS Awareness Special Supplement, May 1999.

16. Ibid.

17. Adolescents and young adults are defined by CDC as those within the 13-24 year-old age range. We recognize that one limitation of such a broad age range among youth is that the needs and concerns vary widely. For example, the messages that effectively motivate 13 year-olds are likely to be very different from the messages that motivate 24 year-olds.

18. National Minority AIDS Council.

19. Poulson, M., "'You Gotta Represent': Analysis of a Series of Focus Groups Concerning HIV in the African American Community Conducted in Conjunction with The NIA Plan," Aug. 1999, 8. Michael Poulson, of the Center for Urban Epidemiological Studies, conducted the focus groups for The NIA Plan. Focus groups were conducted for adolescents and young adults, women, drug users, and gay and bisexual men. Each of the focus groups conducted lasted from 1 to 2 hours. They were held at the sites of four community-based organizations dealing with HIV/AIDS and substance abuse in the population targeted. They were recorded anonymously (no names were used) via audiotape, and all informants verbally consented to participate before the sessions began. Informants were paid $20 for their time. Refreshments were provided and round-trip local transit cards were provided to those who required them. Another study showed that young African Americans are 'much more likely to have received information in the last month about HIV/AIDS" from television, street signs/billboards, or friends, family and acquaintances. Kaiser Family Foundation, "National Survey of African Americans on HIV/AIDS," 7.

20. Kaiser Family Foundation, "National Survey of African Americans on HIV/AIDS," 7.

21. Filippelli, Belinda, "Love's Recovery: Rusti Miller-Hill gains momentum," *POZ*, 58, Jan. 1999. All quotations and background information about Miller-Hill from *POZ* magazine.

22. Ibid.

23. Ibid.

24. Thousands of Black gay men and lesbians gather each spring for the annual Black Lesbian and Gay Pride Day in DC, as seen in this photo from the Black Lesbian and Gay Pride Day, Inc. website, www.dcBlackpride.org.

25. Poulson, M., 14. According to Poulson, "Drug use in the African American community is generally gender specific. In this sample, males were primarily heroin users whereas females were predominantly crack users."

26. Fullilove, Robert E. and Fullilove, Mindy Thompson, "HIV Prevention in the African American Community," Citing CDC data, Report presented before National Conference on AIDS, 2, Feb. 1999.

27. Ibid, 6.

28. For the purposes of this study, civil rights organizations also includes the Congressional Black Caucus, a representative body of the African American members of the United States Congress.

29. Poulson, M., 15, "It should be remembered that most civil rights organizations are associated with or derivative from Black Churches. Similarly, most historically Black colleges and universities also have connections to the Black Church. . . [A]ny intervention targeting the African American community must take into consideration that the Black Church is the most powerful and viable structural entity remaining in this community.

30. Poulson, M., "'You Gotta Represent': Analysis of a Series of Focus Groups Concerning HIV in the

African American Community Conducted in Conjunction with The NIA Plan," Aug. 1999.

31. Cooper, Mario, "Two Nations Under Plague: Wake up, my gay, white brothers and sisters! AIDS is ravaging people of color," *POZ*, **20, Jan. 1999.**

32. Media are defined broadly to includes newspapers, magazines, journals, other publications, radio, paid advertisements, public service announcements, television, satellite links, public access television, cable television, video, film, electronic media, email, the Internet, and public spaces such as billboards and bus shelter signs.

33. Nurses and social workers organizations might also be included as professional organizations.

34. See, e.g., Harvard AIDS Institute recommendations.

35. See Attachment A for a list of meeting participants.

36. Presenters included Wayne Duncan of the Centers for Disease Control and Prevention (CDC), Michael Johnson of the Human Resources and Service Administration (HRSA), Martin Shapiro of the Rand Corporation, Eric Flowers of Ramsell Corporation, John Peterson, Ph.D., of Georgia State University, Dr. Diana Williamson of Mt. Sinai Medical Center, Ernest Hopkins of San Francisco AIDS and CAEAR, Bill Barnes of the Office of San Francisco Mayor Willie Brown, Michelle Lopez of the New York Daily News, Ramona Wiley of AMD Pharmacy, Belynda Dunn of Touch Me Ministries, Hydeia Broadbent of the Hydeia Broadbent Foundation, Craig Washington of Southerners on New Ground, and Roscoe Cooper of the Mayor's AIDS Task Force.

37. Facilitators for the working group sessions included Pernessa Seele of the Balm in Gilead, Maurice Franklin of AAAPTI, author and consultant Keith Boykin, George Bellinger, Jr. of AAAPTI, and Craig Washington of Southerners on New Ground.

38. Poulson, M.

39. Amaro, Hortensia, "Love, Sex, and Power: Considering Women's Realities in HIV Prevention," *American Psychologist*, **439, June 1995.**

40. Fullilove, Robert E. and Fullilove, Mindy Thompson, "HIV Prevention in the African American Community," 9, Feb. 1999.

41. Fox, Claude Earl III, M.D., M.P.H., 'Perspectives on Ryan White, Medicaid, and Medicare," Prepared remarks for presentation before National Conference on African Americans and AIDS, Feb. 25, 1999.

42. The research component may also draw on data or assistance from the Minority Health Professionals Foundation, a nonprofit organization whose focus is, in part, to "promote and support research that contributes to the advancement of scientific knowledge and treatment of diseases, with a special emphasis on health issues that disproportionately or differently affect minority and poor people."

43. Nathanson, Neal, M.D., "AIDS in Minorities: NIH Response and Initiatives," Presentation before National Conference on African Americans and AIDS, Feb. 1999.

44. This suspicion is most clearly documented by the numerous articles and books linking the infamous Tuskegee syphilis experiment to the HIV epidemic. Although Tuskegee was not a clinical trial, in outreach, prevention and grassroots efforts, the similarities cannot be overlooked. In addition prominent Black leaders have publicly stated beliefs in genocide and or a deliberate government plot to rid the nation of undesirables and minorities. See also, Thomas, Stephen B., Curran, James W., "Tuskegee: From Silence to Conspiracy to Metaphor," *The American Journal of the Medical Sciences*, **Vol. 317, No. 1, Jan. 1999.**

45. Ibid (citing National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. Belmont Report: ethical principles and guidelines for the protection of human subjects of research. Washington, DC, Government Printing Office, GPO 887-809, 1988).

46. A study conducted by the Rand Corporation, for example, found about half of those receiving treatment for HIV/AIDS in 1996 had less than a high school education and about half had household incomes under $10,000. (Information provided by Martin Shapiro of the Rand Corporation.) These co-factors do not necessarily lead to HIV but they are factors often associated with those living with the virus.

47. This passage is paraphrased from Phill Wilson, The Wall, *Essence* **magazine, December 1998.**