NASTAD Monograph

A PUBLICATION OF THE NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS

HIV/AIDS: African American Perspectives and Recommendations *for* State and Local AIDS Directors and Health Departments

NASTAD African American Advisory Committee • December 2001

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
444 North Capitol Street, NW, Suite 339 Washington, DC 20001-1512
FAX 202-434-8092 *PHONE* 202-434-8090 *E-MAIL* nastad@nastad.org www.nastad.org

Julie M. Scofield, Executive Director
Mark O. Loveless, MD, Chair

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National Alliance of State and Territorial AIDS Directors
444 North Capitol Street, NW Suite 339
Washington, DC 20001
202-434-8090 – Phone
202-434-8092 – Fax
nastad@nastad.org – Email
www.nastad.org

CONTENTS

Foreword i

Executive Summary v

Introduction 1

African Americans and the Public Health System: Historic Underpinnings 5

The Role of State and Local AIDS Directors 15

Key Issues

- An Epidemiological Perspective on HIV/AIDS in African American Communities 21
- Capacity Building 27
- Coalition and Partnership Building 33
- Program Implementation 37
- Behavioral Research 41

Recommendations

- Next Steps for Health Departments 45
- Next Steps for NASTAD 49

Appendix

- Suggested Job Description for Minority AIDS Coordinator Position 51

FOREWORD

In 1999, an informal discussion began among three African American AIDS directors who were newly elected members of the National Alliance of State and Territorial AIDS Directors (NASTAD) Executive Committee. These directors began to share thoughts about common issues experienced within their health departments and within NASTAD. At the NASTAD annual meeting in 2000, these directors had their first face-to-face meeting and the group expanded to four. Over time, this informal discussion group wanted to include other AIDS directors who were sensitive to the issues they were discussing regarding HIV/AIDS and related health disparities in African American communities. They asked NASTAD to support their continued and expanded dialogue, and NASTAD responded by providing resources to support activities of the group. In October 2000, this discussion group submitted to the NASTAD Executive Committee an outline for a monograph on HIV/AIDS in African American communities and a proposal for a two-day meeting of NASTAD's membership to address issues related to primary HIV prevention and access to care identified in the monograph.

In 1998, NASTAD, through an annual examination of program priorities, identified "Addressing HIV/AIDS Health Disparities Among Racial and Ethnic Minority Communities" as a top priority. In 2001, NASTAD further refined and strengthened this priority, identifying "Primary HIV Prevention and Access to Care for Communities of Color" as a top policy priority. NASTAD also created a new staff position dedicated to working on the objectives of this policy priority. The African American discussion group was formalized into the African American Advisory Committee and the group's size was again expanded to include African American HIV/AIDS program staff from the Centers for Disease Control and Prevention (CDC) directly-funded jurisdictions and a number of other states.

The African American Advisory Committee was charged with two tasks:

- Completing a NASTAD monograph on "HIV/AIDS: African American Perspectives and Recommendations for State and Local AIDS Directors and Health Departments."

- Advising on planning a two-day “Workshop on African Americans and AIDS" for the full NASTAD membership.

As African American AIDS directors and HIV/AIDS program managers, we can and should take a leadership role in helping to design a governmental response to the HIV/AIDS crisis in African American communities. As both representatives of public health establishments and members of affected communities, we recognize that in order to stop the spread of AIDS in African American communities, responsibilities must be addressed by both public health officials and the communities that they seek to serve. We understand that institutional bureaucracies within the public health care system may potentially create barriers to health care access for African Americans. Having strong ties to African American communities, we also recognize that established community norms may erect further barriers to African American health promotion, disease prevention and access to health care.

With NASTAD, we have developed this document with the intention of building a bridge between the public health system and African American communities. This bridge is essential to halting the devastation of HIV/AIDS in African American communities.

With the recognition that other racial and ethnic communities need focused attention to stop the spread of AIDS in their communities, we also view this document and the process that brought it about as a potential model to be applied to efforts with other communities of color.

NASTAD African American Advisory Committee 2001

The NASTAD African American Advisory Committee

Jacqueline Bacchus	District of Columbia Department of Health
Vanessa Baird	California Department of Health Services
Rashad Burgess	Chicago Department of Public Health
Michael Butler	Indiana State Department of Health
Brenda Crowder-Gaines	North Carolina Department of Health and Human Services
Brenda Del Gado	Connecticut Department of Public Health
Loretta Davis-Satterla	Michigan Department of Community Health
Juliet Dorris Williams	Ohio Department of Health
Ronald Henderson	Florida Department of Health
Steve Jackson	Nebraska Department of Health and Human Services
Glenda Gardner	Houston Department of Health and Human Services
Janice Kopelman	Pennsylvania Department of Health
Linda Thomas	Oklahoma State Department of Health
Rozlyn Zuber	Mississippi Department of Health
Traci Patton	Tennessee Department of Health
Lois Sanders	Virgin Islands Department of Health

NASTAD Staff

Nyedra Booker
Danielle Davis
Latifa Jackson
Gail Perry
Leo Rennie
Damon Smith

NASTAD Consultants

Aplomb Consultants

William Bland
Jason Lorber
Rita Shimmin
Shoshana Rosenfeld

Aplomb Consulting
870 Market Street, Suite 441
San Francisco, CA 94102
415-421-4528 - Phone
414-421-4544 - Fax
www.aplomb.com

EXECUTIVE SUMMARY

HIV/AIDS: AFRICAN AMERICAN PERSPECTIVES AND RECOMMENDATIONS FOR STATE AND LOCAL AIDS DIRECTORS AND HEALTH DEPARTMENTS

NASTAD African American Advisory Committee

INTRODUCTION

A national AIDS crisis confronts African American communities. African Americans have been disproportionately affected by the HIV/AIDS epidemic since its beginning. In 1982, almost one-fifth of initially reported AIDS cases were among African Americans, who represented only 12 percent of the U.S. population.[1] Despite recent treatment advances that have led to dramatic reductions in illness and death across all racial and ethnic groups, there continues to be a disparity in HIV/AIDS related health outcomes between African Americans and all other racial and ethnic groups. African Americans now represent almost half of newly reported AIDS cases, and HIV remains the leading cause of death among African Americans ages 25-44.[2] Sub-populations of African Americans, including women, men who have sex with men (MSM), injection drug users (IDUs) and youth, bear an even greater burden than their non-African American counterparts. Though many health department officials are responding, the current crisis demands that they make greater strides more quickly. It is urgent that officials cultivate a deeper understanding of African Americans' needs and concerns about HIV/AIDS and expand their tools for intervening more effectively with African American communities.

The National Alliance of State and Territorial AIDS Directors (NASTAD) is pleased to release *HIV/AIDS: African American Perspectives and Recommendations for State and Local AIDS Directors and Health Departments*, a monograph developed by NASTAD's African American Advisory Committee, staff and consultants. The African American Advisory Committee is comprised of African American AIDS directors and HIV/AIDS program staff from state health departments and health departments in cities that are directly funded by the Centers for Disease Control and Prevention (CDC) to conduct HIV prevention activities. Convened as a NASTAD advisory body, the members of the committee combined their deep knowledge of public health and their collective experience as African Americans to articulate some of the more subtle and complex issues surrounding African Americans and HIV/AIDS.

PURPOSE

This monograph is a tool to help state and local AIDS directors respond to the national HIV/AIDS crisis in African American communities.[3] It seeks to raise awareness of the importance of race in program and policy development and the role of racism, as well as other historical factors, in health disparities among African Americans infected and affected by HIV.

The epidemic is different in each of the 65 jurisdictions. What does an AIDS director do if there are no funds available for targeted efforts to African American communities or if there are currently no viable "owned and operated" African American organizations that can deliver HIV prevention and care services? What does an AIDS director do if there is little or no trust between health department officials and African American community representatives, or if the number of African Americans in their jurisdiction is less when compared to other ethnic groups? This monograph presents appropriate steps to take in these and other similar situations.

AIDS directors can learn how to understand and advocate for the diverse perspectives of their constituents. Each AIDS director can become aware of how they currently view the different populations in their jurisdictions and how their views impact the delivery of services. This monograph can help AIDS directors make shifts, if necessary, in how the director sees him/herself in relationship to HIV/AIDS in African American communities and to help make it easier for the director to advocate for African American perspectives.

To achieve its purpose, the monograph:

- **Examines the Historic Underpinnings that Affect HIV/AIDS Among African Americans**

  The document examines historical factors that have contributed to current responses of both African American communities and their health departments.

- **Describes Key Issues**

  The monograph explores key issues in the areas of epidemiology, the role of state and local AIDS directors, organizational development, coalition and partnership building, prevention and care, and behavioral research that are specific to the African American experience.

- **Makes Recommendations**

  The document recommends specific steps for improving the quantity and quality of HIV/AIDS prevention and care services for African American communities. Some recommendations may require additional resources in order to be implemented.

- **Acts as a Springboard for Dialogue**

  NASTAD and the African American Advisory Committee intend for this monograph to serve as a springboard for difficult dialogues within African American communities and between communities, health departments, and national leaders.

CENTRAL ROLE OF HEALTH DEPARTMENTS IN ADMINISTERING HIV/AIDS PROGRAMS

State health agencies serve an essential and unique role in the delivery of HIV/AIDS prevention, care, and treatment programs. State public health agencies are entrusted through U.S. law as the "central authorities of the nation's public health system" and as such, bear primary public sector responsibility for health.[4] While the organization of HIV/AIDS programs varies among health departments, as does the position of the health department within the state governmental system, states have broad responsibility for the provision of essential public health services including disease surveillance, epidemiology and prevention; the provision of primary health care services for the uninsured and indigent; and the overall planning, coordination, administration, and fiscal management of public health services.

A national response to the epidemic among African Americans should be cognizant of the central role of state health departments in HIV/AIDS prevention and care service delivery. State and local health departments should be involved as key partners in this response. Consistent with NASTAD's goal of strengthening national, state and local responses to the HIV epidemic, the monograph focuses attention on challenges that state and local health departments face in addressing HIV/AIDS in African American communities, and offers recommendations to strengthen their ability to respond. It is hoped that the document will be a useful tool for AIDS directors and program managers who are charged with shaping, developing and implementing programs to combat HIV/AIDS among African Americans in their jurisdictions.

AFRICAN AMERICANS AND THE PUBLIC HEALTH SYSTEM: HISTORIC UNDERPINNINGS

Historical circumstances create a context for understanding the responses of the public health system to HIV/AIDS and African Americans and the response of African Americans to AIDS and the public health system. When AIDS directors understand this historical context and how it is still influential today, they are better equipped to make the greatest impact in addressing the AIDS epidemic in

African American communities, particularly those constituents at highest risk (transgenders, MSM, IDUs, women and youth.) The particular set of events and issues that African Americans faced and currently face is unique. This legacy influences and drives current behavior. By recounting these incidents, NASTAD's intent is to bring to the foreground some of the issues that have historically divided health departments and African Americans so that future dialogues can begin from an informed perspective.

THE ROLE OF STATE AND LOCAL AIDS DIRECTORS

AIDS directors have a responsibility to take leadership and address the HIV/AIDS crisis in African American communities. An important step AIDS directors can take to fulfill their mandate of preventing and treating HIV/AIDS in African American communities, is to educate themselves about the complex historical underpinnings that affect the HIV/AIDS crisis among African Americans today.

The dynamic between the responses of the public health system to HIV/AIDS and African Americans and the response of African Americans to HIV/AIDS and the public health system in many ways accounts for the soaring HIV/AIDS rates and other health disparities in African American communities. While factors such as the stigma associated with homosexuality and HIV contribute to skepticism of health department prevention and care programs, the legacy left by historical antecedents accounts for much of the hesitancy of large segments of African Americans to engage in even well intentioned HIV prevention and care programs.

To lead well, health departments must develop the willingness to examine themselves, and the skills to accommodate the natural discomfort that can arise when trying to change the status quo. Those who deliver messages of change have the challenge of giving voice to topics that people have historically avoided discussing. When non-African American public health staff members begin to understand the legacy of racism in the public health system, it is not uncommon for them to experience feelings of guilt, shame, fear and denial. Health departments can assist in raising awareness, and supporting action, among all staff by providing training programs in which people feel safe to explore and discuss these issues. A first, bold step towards taking leadership in the African American AIDS crisis is for health departments to deliver resources and support to those who will bring change from within.

KEY RECOMMENDATIONS

The monograph offers concrete steps that state and local health departments can take to address the challenges associated with addressing HIV/AIDS in African American communities. Recommendations are made in the five areas: uses and interpretation of epidemiological data, capacity building, coalition and partnerships building, program implementation and behavioral research.

NASTAD will also use the monograph to open other needed dialogues with traditional (e.g., National Minority AIDS Council, National Black Leadership Commission on AIDS, the Balm in Gilead, local AIDS Service Organizations) and new partners (e.g., National Association for the Advancement of Colored People, Congressional Black Caucus, National Conference of Black State Legislators, National Medical Association, Leadership Campaign on AIDS) in order to build strong networks to stop the spread of AIDS in African American communities.

CONCLUSION

Health departments and AIDS directors have a responsibility to take leadership and address the AIDS crisis in African American communities. An important step that AIDS directors can take to fulfill their responsibility to prevent and treat HIV/AIDS in African American communities, is to educate themselves about the complex historical underpinnings that inform the AIDS crisis in African American communities today. AIDS directors, who understand the historical underpinnings surrounding African Americans and HIV/AIDS can better develop, implement and strengthen plans to respond to the epidemic in African American communities.

References

[1] CDC. HIV/AIDS Surveillance Report (July 8, 1982).

[2] CDC. HIV/AIDS Surveillance Report, Year-end edition 12, no. 2.

[3] In this document, the terms “African American” and “African American communities” refer to, and are inclusive of the many cultural manifestations of people of African Diaspora descent living in the United States (e.g., Afro-Caribbean, African), and the sub-cultures of those manifestations (e.g., women, men who have sex with men, transgenders, adolescents, incarcerated populations, injection drug users).

[4] Institute of Medicine, The Future of Public Health, 1988.

INTRODUCTION

A national AIDS crisis assaults African American communities. African Americans have been disproportionately affected by the HIV/AIDS epidemic since its beginning. In 1982, almost one-fifth of initially reported AIDS cases were among African Americans, who represented only 12 percent of the U.S. population.[1] Despite recent treatment advances that have led to dramatic reductions in illness and death across all racial and ethnic groups, there continues to be a disparity in HIV/AIDS related health outcomes between African Americans and all other racial and ethnic groups. African Americans now represent almost half of newly reported AIDS cases, and HIV remains the leading cause of death among African Americans ages 25-44.[2] Sub-populations of African Americans, including women, men who have sex with men (MSM), injection drug users (IDUs) and youth, bear an even greater burden than their non-African American counterparts. Though many health department officials are responding, the current crisis demands that they make greater strides more quickly. It is urgent that officials cultivate a deeper understanding of African Americans' needs and concerns about HIV/AIDS and expand their tools for intervening more effectively with African American communities.

"Not everything that is faced can be changed until it is faced."

James Baldwin

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PURPOSE

This monograph is a tool to help state and local AIDS directors respond to the national HIV/AIDS crisis in African American communities.[3] It seeks to raise awareness of the importance of race in program and policy development and the role of racism, as well as other historical factors, in health disparities among

African Americans infected and affected by HIV. The monograph offers concrete steps that AIDS directors can take to address the challenges associated with addressing HIV/AIDS in African American communities.

The epidemic is different in each of the 65 jurisdictions. What does an AIDS director do if there are no funds available for targeted efforts to African American communities or if there are currently no viable "owned and operated" African American organizations that can deliver HIV prevention and care services? What does an AIDS director do if there is little or no trust between health department officials and African American community representatives, or if the number of African Americans in their jurisdiction is less when compared to other ethnic groups? This monograph presents appropriate steps to take in these and other similar situations.

AIDS directors can learn how to understand and advocate for the diverse perspectives of their constituencies. Each AIDS director can become aware of how they currently view the different populations in their jurisdictions and how their views impact the delivery of services. This monograph can help AIDS directors make shifts, if necessary, in how the director sees him/herself in relationship to HIV/AIDS in African American communities and to help make it easier for the director to advocate for African American perspectives.

To achieve its purpose, the monograph:

- **Examines the Historic Underpinnings that Affect HIV/AIDS Among African Americans**
  The document examines historical factors that have contributed to current responses of both African American communities and their health departments.

- **Describes Key Issues**
  The monograph explores key issues in the areas of epidemiology, the role of state and local AIDS directors, organizational development, coalition and partnership building, prevention and care, and behavioral research that are specific to the African American experience.

- **Makes Recommendations**
  The document recommends specific steps for improving the quantity and quality of HIV/AIDS program implementation services for African American communities. Some recommendations may require additional resources in order to be implemented.

- **Acts as a Springboard for Dialogue**
  NASTAD and the African American Advisory Committee intend for this monograph to serve as a springboard for difficult dialogues within African American communities and between communities, health departments, and national leaders.

Challenging conversations must occur within affected communities in order to address norms that create fertile ground for the spread of HIV/AIDS. Explicit talk must take place about sexuality and the seeming reluctance of some segments of the African American community to expose perceived socio/cultural weaknesses to the larger society. Direct dialogue must also take place between health departments and African American communities about community norms.

Simultaneously, health departments must acknowledge the antecedents that have left mistrust and hostility by African Americans towards public health officials. This shared history between African Americans and the public health system must be explored and discussed in order to move forward with a shared vision of a future that effectively addresses HIV/AIDS in African American communities.

NASTAD will also use the monograph to open other needed dialogues with traditional (e.g., National Minority AIDS Council, National Black Leadership Commission on AIDS, local AIDS Service Organizations) and new partners (e.g., National Association for the Advancement of Colored People, Congressional Black Caucus, National Conference of Black State Legislators, National Medical Association, Leadership Campaign on AIDS) in order to build strong networks to stop the spread of AIDS in African American communities.

AFRICAN AMERICANS AND THE PUBLIC HEALTH SYSTEM: HISTORIC UNDERPINNINGS

Historical circumstances create a context for understanding the responses of the public health system to HIV/AIDS and African Americans and the response of African Americans to AIDS and the public health system. When AIDS directors understand this historical context and how it is still influential today, they are better equipped to make the best impact in addressing the AIDS epidemic in African American communities, particularly those constituencies at highest risk (transgenders, MSM, IDUs, women and youth).

"We are not makers of history, we are made by history"
Rev. Dr. Martin Luther King, Jr.

The particular set of events and issues that African Americans faced and currently face is unique. This legacy influences and drives current behavior. In response to antecedents, low health care seeking behaviors have become cultural norms in large segments of African American communities. At the same time, health departments may inadvertently exclude African Americans from power sharing and decision making when interacting with the system.

By recounting these incidents, NASTAD's intent is to bring to the foreground some of the issues that have historically divided health departments and African Americans so that future dialogues can begin from an informed perspective.

PUBLIC HEALTH SYSTEM-RELATED ANTECEDENTS

In this document, public health system-related historical events fall under three general groupings:

- Government studies and screening programs
- Misconceptions promoted in the early days of AIDS
- Degree of commitment by health departments to African Americans

GOVERNMENT STUDIES AND SCREENING PROGRAMS

The following are examples of government activities that have impacted the relationship between African Americans and the public health system.

Tuskegee Syphilis Study

From 1932 through 1972, under the auspices of the U.S. Public Health Service, researchers subjected 400 African American men in rural Alabama to an experiment on the effects of untreated syphilis. Researchers withheld treatment and forbade the men from seeking help elsewhere, even though penicillin became available in the 1940s. The experiment was stopped in 1972, only after the experiment came to public light. "In the almost 25 years since its disclosure, the study has moved from a singular historical event to a powerful metaphor. It has come to symbolize racism in medicine, ethical misconduct in human research, paternalism by physicians, and government abuse of vulnerable people." [4]

LA Vaccine Study

In 1989 CDC, Kaiser Permanente, and Johns Hopkins University cooperated to conduct an experiment on 1,500 children in West and East Los Angeles. The children were given an experimental measles vaccine as part of a government-sponsored trial. Most subjects were Latino or African American. Parents were never told that their children were part of an unlicensed drug experiment. This experiment was stopped after two years when questions were raised about the vaccine's relationship to an increased death rate among female infants.[5]

Genetic Testing/Sickle Cell Anemia

John Rennie's 1994 article entitled, "Grading the Gene Tests" in *Scientific American* demonstrates how the impact of a poorly implemented federal program betrayed the trust of African Americans. According to Rennie's article:

> The African American community initially welcomed the federally funded sickle cell screening program in the early 1970s. However, the test, designed simply to detect carriers of the sickle cell gene, a genetic trait, soon became widely misconstrued by governments and businesses as a test for "the disease" sickle cell anemia...In short, the testing did more harm than good by becoming a tool of long-standing prejudices.[6]

Population Control and the Eugenics Movement

Many individuals perceive the government (and by derivation state and local health departments) as complicit in forced attempts to sterilize African American women beginning in the 1920's and continuing through much of

the 1970's. In her book on the interconnections between race and reproductive policy, noted attorney and author Dorothy Roberts argued:

> This …eugenics…helped to shape our understanding of reproduction and permeated the promotion of contemporary policies that regulate Black women's childbearing. Racist ideology, in turn, provided fertile soil for eugenic theories to take root and flourish. It bears remembering that in our parents' lifetime states across the country forcibly sterilized thousand of citizens thought to be genetically inferior.[7]

This legacy of forced sterilization is not lost today, considering that forced sterilizations continued until the 1970's and fueled heated debate in African American communities about the link between birth control and genocide. Similar to the appearance of HIV, many African Americans perceive birth control as a form of African American genocide. Anyone who proposes birth control, including public health officials, is perceived as complicit in a genocidal conspiracy.

MISCONCEPTIONS IN THE EARLY DAYS OF AIDS

The following examples of misconceptions promoted early in the epidemic have influenced many African Americans' perspectives on HIV/AIDS.

The Origin of AIDS

Early in the epidemic, there were a number of theories regarding the origin of AIDS.

> Some said AIDS was caused by a mutant virus, a sort of Andromeda strain. Others favored conspiracy theories suggesting that scientists had created HIV and this agent escaped from germ warfare labs. Although the belief in these theories was not universal, many African Americans did express concern that there was some level of truth. There was a Western medicine disaster theory, which held that the virus was injected into Africans in bad batches of polio vaccine. Then there was the more pedestrian idea that people got HIV from primates in Africa. [8]

Scientists explored the primate connecting theory early because they knew that a virus could move from one species to another, and there was evidence suggesting that this may have been the case for how humans became infected with HIV. Unfortunately, as these theories of AIDS originating in Africa were disseminated in the media, they stigmatized people of African descent, including African Americans, by associating them with the origins of HIV/AIDS. Many African Americans responded by promoting "conspiracy theories" against the government or by discounting all media messages about HIV/AIDS.

The Naming of High Risk Groups

Early reports on HIV/AIDS from CDC identified Haitians as one of the early risk populations.[9] This gave rise to the 4H Theory – Homosexuals, Heroin Users, Hemophiliacs, and Haitians. Even though the CDC removed Haitians as a risk category in 1985, the stigma was reinforced in 1990 when the Food and Drug Administration (FDA) issued a memo which advised blood banks to stop drawing blood from Haitian donors because they were potential HIV carriers. The ban was later rescinded but the damage was done.[10] Many members of the Haitian community have come to view the disease [AIDS] as a conspiracy to exclude them from mainstream America. An ongoing degree of denial and suspicion makes Haitian clients less likely to access services.[11]

DEGREE OF COMMITMENT BY HEALTH DEPARTMENTS TO AFRICAN AMERICANS

The following examples describe how perceptions of health departments' responses to HIV/AIDS in African American communities frame the environment in which state and local public health officials must respond to the epidemic in these communities.

African American Proportion of Early AIDS Cases

In the first reports of the HIV/AIDS epidemic during the early 1980s, the vast majority of cases were noticed among gay white men. Because the first cases were so closely associated with this community:

> ...it seemed that no one, except what appeared to be the predominately white lesbian and gay community, wanted to talk openly about the growing epidemic. Undoubtedly, the lack of action, from the general public on down to the president, was and is directly tied to the conception of AIDS as a disease of white gay men, black and Latino/a drug users, and other marginal people engaged in "immoral behavior. [12]

A closer examination of the early statistics shows that African American gay men and African Americans in general were accounting for a significant portion of early AIDS cases. In 1981, the first year of cases being reported, "23 cases were reported among African American gay men, six African American heterosexual men and women and nine injection drug users."[13] Just one year later (July 8, 1982), the CDC reported a total of 86 cases among African Americans.[14] By December 1986, African Americans represented 25% of the total AIDS cases.[15] Because of the general perception that HIV/AIDS was not an issue for African Americans, much of the early public health response did not focus on African Americans, despite the reality of the emerging epidemic.

Presence of African Americans in Positions of Power within Health Departments

The presence of African American leadership in health departments contributes to better representation of African American needs and concerns within the health department, and enhances the opportunity for trust building and effective program implementation with African American communities. However, there are few African American AIDS directors across the country. In some jurisdictions, African Americans are represented among senior managers, but in many jurisdictions there are no African American staff above middle management. Many health departments have recognized disparities in staff representation, and are taking steps to diversify staffing patterns. Recommendations in this section offer steps to promote continued efforts in recruitment and retention of African American and other minority staff.

THE IMPACT ON AFRICAN AMERICAN COMMUNITIES

The attitudes that African American communities bring to HIV/AIDS are related to the antecedents described above. Questions in the community remain as to whether a conscious or unconscious intent on the part of health departments drove these events. Understanding these events and their impact on African American communities, particularly community norms of mistrust of the public health system and low health care seeking behaviors, will better equip health departments and AIDS directors to mount an effective response to the African American HIV/AIDS crisis.

Significant numbers of African Americans, for instance, believe the government deliberately makes illicit drugs easily available in their communities, introduced the AIDS epidemic to the U.S. to harm blacks, and unfairly targets black elected officials for criminal prosecution. As the Executive Director of Black Leadership Forum Yvonne Scruggs observed, "Over generations there has been a repeated demonstration that there is a basis in the black community for a feeling of attack, a feeling of harassment." Among the cases cited most frequently to explain these fears are disclosures that the FBI spied on civil rights leaders, including Martin Luther King, Jr., and infiltrated black militant groups in the 1960's. The article notes that, "For many years, many southern police departments were suspected of having ties to the Ku Klux Klan, a view sharpened by the cross burnings and other racist attacks on blacks during the civil rights era that often went unpunished."[16]

Studies have documented that African Americans do not believe the government is telling the truth about AIDS.[17] [18] Dr. Sandra Quinn, who conducted a study on the effects of the Tuskegee legacy on HIV/AIDS education and behavior states,

"The belief that AIDS is a form of genocide has serious health consequences. If they [African Americans] believe AIDS is a form of genocide, they are less likely to get tested, less likely to use condoms and less likely to participate in clinical trials."[19]

When surveyed, very few African Americans think that government (whether local, state or federal) cares or does much in the fight against AIDS. When rating how much government cares about the fight against AIDS, fewer than one in four African Americans give the three levels of government credit for caring "a lot;" when assessing action, fewer than one in five says any government is doing "a lot" as well.[20]

It must be acknowledged, therefore, that suspicion, fear, and resentment are community norms that shape African American community attitudes toward health care seeking behaviors. To fight AIDS effectively it is imperative to acknowledge events (past and present) that underlie attitudes of mistrust and may, as Dr. Robert Fullilove states, "blunt the effectiveness" of current health education and intervention programs.[21]

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RECOMMENDATIONS

The following recommendations for health departments and AIDS directors address the antecedents that impact the relationship between African Americans and the public health system. Critical to the implementation of these recommendations will be the recruitment and retention of African American managers and program staff throughout all levels of the organization.

Identify antecedents in each local jurisdiction

Conduct research to identify the historical events and associations that African Americans in your jurisdiction have with the public health system and the government. This can be done through a variety of methods (e.g., focus groups, surveys, key informant interviews). This research will inform health departments of the historical circumstances that may shape African American perceptions of the state/local health department, and help to inform strategies to respond.

Acknowledge and discuss the antecedents with African American communities

Raise the living legacy issues. Health departments should listen to what people tell them about how they feel about these issues. Then departments should facilitate discussions of how to proactively address the issues raised. Before initiating dialogue, expectations about the outcomes of these dialogues and potential follow-up may be discussed, and mutually agreed upon by health department officials and community representatives. Ground rules for dialogue can be delineated. Professional facilitators may be engaged to help in this process. Health departments should also communicate to African American communities in specific and concrete terms, steps that can be taken to address the historical antecedents. They can also take steps to ensure that prevention and care programs funded by the health departments acknowledge and address the antecedents in their program design.

Work with community leaders to maintain ongoing dialogue

Establish relationships and cultivate an ongoing dialogue with African American community leaders and African American health department staff on issues related to the quality of the health department's relationship with African American communities.

One way to cultivate relationships with community leaders is to develop a task force to gather support and act as a bridge between communities and health departments. AIDS directors can get to know and work with gatekeepers who are

viewed as respected community leaders such as ministers, people living with AIDS and CBO administrators. It is essential that African American leadership also includes constituency groups that are highly impacted by HIV/AIDS including transgenders, MSM, IDUs, women and youth.

This chart summarizes suggestions for how to address issues raised by the antecedents:

Issues Raised by Antecedents	Suggested Remedies
Informed consent, patient education, and access to treatment options and information	• Rigorously adhere to existing legal protocols for obtaining informed consent • Establish and enforce protocols for ensuring client/patient comprehension • Consider literacy levels and culturally appropriate/relevant language when creating materials for informed consent or other related materials
Unintended stigma and blame	• Establish protocols for reviewing policies and investigating the potential ramifications before their implementation • Establish (or utilize existing) African American advisory committees to review policies and public statements that will impact African Americans
Forecasting HIV/AIDS trends proactively	• Establish protocol for investigating and forecasting HIV/AIDS trends • Establish protocols for distributing funds to address future trends in the disease
Commitment to developing African American leadership	• Establish initiatives to hire, develop, promote and retain African Americans in senior public health positions
Cumulative effect of antecedents	• Monitor adherence with all policies and procedures suggested above
Full disclosure	• Commit to prompt and full disclosure of issues and events affecting African Americans • Utilize African American advisory committee (as suggested above)

THE ROLE OF STATE AND LOCAL AIDS DIRECTORS

AIDS directors have a responsibility to take leadership and address the HIV/AIDS crisis in African American communities. One of the oldest mandates of the U.S. Public Health Service, now carried out by CDC, is disease control and prevention.[22] An important step AIDS directors can take to fulfill their mandate of preventing and treating HIV/AIDS in African American communities is to educate themselves about the complex historical underpinnings that affect the HIV/AIDS crisis among African Americans today.

The dynamic between the response of the public health system to HIV/AIDS and African Americans and the response of African Americans to HIV/AIDS and the public health system in many ways accounts for the soaring HIV/AIDS rates and other health disparities in African American communities. While factors such as the stigma associated with homosexuality and HIV contribute to skepticism of health department prevention and care programs, the legacy left by historical antecedents accounts for much of the hesitancy of many African Americans to engage in even well intentioned HIV prevention and care programs. AIDS directors will be able to lead effectively only if they act with the full awareness of this sobering dynamic. AIDS directors who understand the historical underpinnings surrounding African Americans and HIV/AIDS can better develop, implement and strengthen plans to respond to the epidemic in African American communities.

Daunting as it may seem for AIDS directors to move forward given this historical context, it is helpful to focus on a goal shared by both African American communities and public health departments: the prevention, treatment and eradication of HIV/AIDS. There is much that AIDS directors can do to repair and advance the relationship between African Americans and the public health system.

When developing programs specifically for African Americans, health departments should understand that there is no single African American community, no monolithic African American culture. Specific groups exist within African American communities. Interventions should be strategically designed and implemented to address the needs and concerns of those networks and communities. When behavioral research is conducted, it should be motivated by the desire to understand the values, norms, and infrastructures of these communities, with the goal of co-creating meaningful prevention and care programs. Health departments can establish appreciative relationships with various

African American communities, pooling resources and talent in health departments with creativity, energy, and leadership within specific sub-groups in African American communities. Health departments should develop programs as equal partners with members and organizations within the communities, and include African Americans as full participants in the decision making process. Finally, by making resources available and delivering technical assistance (TA), health departments can support African American leaders in implementing HIV prevention and care programs within their own communities.

To lead well, health departments must develop the willingness to examine themselves, and the skills to accommodate the natural discomfort that can arise when trying to change the status quo. Those who deliver messages of change have the challenge of giving voice to topics that people have historically avoided discussing. When non-African American public health staff members begin to understand the legacy of racism in the public health system, it is not uncommon for them to experience feelings of guilt, shame, fear and denial. Health departments can assist in raising awareness, and supporting action, among all staff by providing training programs in which people feel safe to explore and discuss these issues, many of them for the first time. A first, bold, step towards taking leadership in the African American AIDS crisis is for health departments to deliver resources and support to those who will bring change from within.

RECOMMENDATIONS

Identify, engage, and train indigenous African American leadership to be involved in HIV/AIDS decision-making processes

Foster and maintain CBOs and AIDS Service Organizations (ASOs) that include African Americans on their boards of directors and as integral members of their staffs. Health departments can facilitate opportunities for these individuals to become involved in community planning groups, Ryan White planning councils and other HIV/AIDS and health care related advisory bodies.

Identify, engage, train and support African American leadership within the health department

Jurisdictions can create a Minority HIV/AIDS Coordinator position to focus attention on this issue. The purpose of this position is to help make all information and processes culturally relevant, and ensure African American participation at all levels of prevention and care program implementation. In jurisdictions with large African American populations, every effort should be made to identify an African American candidate for this position. It is essential that the Minority AIDS Coordinator is fully integrated in the management structure of the health department and not seen as "just a special initiative."

Convene an in-house health department diversity team

The challenge of eliminating racism and healing the relationship between the public health system and African American communities is long term in nature. An in-house diversity council could help provide the leadership necessary to keep the health department focused on the goal of eliminating institutional racism and enhancing its capacity to work effectively with African American communities. The council should be made up of a diverse group of employees and managers from all levels and departments in the organization. Health department leaders including the Commissioner of Public Health, department directors and the AIDS director should convene the council. It may also be helpful to bring in a third party to facilitate the group, at least in the initial stages. Initiatives for the agenda could include department-wide education to eliminate racism and support diversity, and eliminate the institutionalized practices that perpetuate racism, and enhance the recruitment and retention of African Americans and other minorities.

Provide expert capacity building assistance to community-based organizations
Health departments can establish and conduct training and capacity building assistance programs in collaboration with targeted African American communities. African American leadership must participate in all phases of providing capacity building assistance including funding decisions and, choosing of consultants, capacity building program design, implementation, and evaluation. Some jurisdictions have made great strides in targeting capacity building assistance to community-based organizations. However, it is important to recognize that not all jurisdictions have the same resources available. What may be possible in one jurisdiction may not be possible in another, due to lack of resources – not lack of commitment.

Offer educational workshops on the historical dynamics between racism, African Americans, HIV/AIDS and the public health system
Effective training programs will be both didactic and experiential. Health departments should offer workshops that facilitate meaningful dialogue and exchange about the intersection of racism, HIV/AIDS and public health. There are various models for anti-racism training programs including those developed by the People's Institute for Survival and Beyond,[23] and Kansas City FOCUS Plan (Forging Our Comprehensive Urban Strategy) which are dedicated to eliminating racism and other unfair forms of discrimination among all the citizens of the city.[24]

Review institutional policies and practices
By conducting a review of institutional policies and practices health departments can assess where they fall short or reinforce stigma and discrimination in African American communities. Health department policies should acknowledge racist events of the past (e.g., Tuskegee Syphilis Study) and call for the elimination of all forms of racism now and in the future. Refer to models such as the *Draft Declaration of the World Conference Against Racism, Racial Discrimination, Xenophobia and Related Intolerance.* [25]

Fund programs that are culturally based and culturally competent
Health departments should examine funding policies and practices. To the extent possible, funding application processes should encourage and ensure the distribution of resources to the communities in need of African American initiatives, especially those addressing the needs of populations at highest risk of HIV infection. They should also encourage the development of African leadership in communities and organizations.

Support the development of science about African American communities
There are many unanswered questions about the behaviors and motivations of African Americans that are crucial to developing effective prevention and care programs. This includes major gaps in existing knowledge regarding African American at-risk populations, and the effects of individual and community-level interventions. African Americans should be involved from the beginning in the design and implementation of all research projects. To the extent possible, state and local health departments should support qualitative research, such as ethnographic studies, that will elucidate cultural norms and behaviors that facilitate transmission of HIV in African American communities.

Proactively support development of coalitions and partnerships that include key stakeholders from African American communities
Health departments should encourage and participate in partnerships, collaborations, and coalitions with stakeholders within African American communities and from outside the communities who can offer resources and assistance. Bear in mind that partnerships between organizations serving African American communities are more apt to succeed when issues of power, trust, and relevant historical underpinnings and deeply rooted community norms are acknowledged and addressed.

KEY ISSUES:
AN EPIDEMIOLOGICAL PERSPECTIVE ON HIV/AIDS IN AFRICAN AMERICAN COMMUNITIES

This section presents epidemiological data on HIV/AIDS in African American communities and interprets this data from an African American perspective.

THE FACTS

The AIDS epidemic is a national crisis in African American communities. If current trends continue, the majority of new HIV infections in the U.S. will be among African Americans. African Americans also fare poorer than whites on several quality of and access to care measures. For example, African Americans are less likely than white counterparts to receive combination antiretroviral therapy and preventive treatment for Pneumocystis Carnii Pneumonia (PCP). They are tested later in the course of HIV infection and die sooner.[26]

"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. Representative Maxine Waters (D-CA), 1998

Definitive data is lacking about precisely why African Americans are becoming infected and developing AIDS at alarming rates. However, there seems to be agreement that it is not just about race.[27] Socio-economic and cultural factors are likely at work. Some of these co-factors are applicable across a number of populations, but together, they pose a special set of concerns for African Americans:

- A deep mistrust of the public health system (originating from historical events like the Tuskegee Syphilis Study);

- Lack of well-funded, culturally specific interventions (increasing African Americans' sense of alienation from a system they already do not trust);

- Low health-care seeking behaviors (related to mistrust of the public health system, lack of health insurance, and lack of culturally competent health services);

- Stigmatization within African American communities themselves (which may keep gay men, women and injection drug users from accessing care); and

-Higher rates of poverty, unemployment and underemployment, which can adversely affect health outcomes.

However, HIV infection is preventable, and development of new drug therapies makes HIV infection and AIDS increasingly more manageable. In order to craft and implement successful HIV prevention and care strategies, public health officials must take thoughtful, prudent action to intervene quickly and effectively.

Profile of AIDS Cases Among African Americans

This section offers a brief snapshot of the epidemic in African American communities, with some focus on trends in newly reported AIDS cases. In the absence of comprehensive HIV reporting, newly reported AIDS cases provide a way to assess where the HIV/AIDS epidemic is heading. For additional information on HIV/AIDS infection trends among African Americans, the Kaiser Family Foundation is a good source for comprehensive overviews of data and research, including epidemiological data.[28]

African Americans are disproportionately impacted.
The HIV/AIDS epidemic has disproportionately impacted African Americans in the United States. Although African Americans represented only 12% of the U.S. population, they made up over one third (40%) of the more than 320,000 people living with AIDS. The proportion of African Americans living with AIDS has grown and is now similar to that of whites (38%).[29] African Americans also represented almost one half (47%) of the over 46,400 new AIDS cases reported in 1999.[30]

Cases of AIDS among African American women have grown disproportionately.
During the early 90's there was already a clear indication of the disproportionate nature of AIDS among African American women. In 1990, African American females represented 52% of total female AIDS cases while white females represented one fourth (26%) of female cases.[31] Ten years later, African American women continue to comprise over half (58%) of the total female adult/adolescent AIDS cases.[32]

Of all new AIDS cases in women, African American women represent an overwhelming majority.
Newly reported AIDS data from 2000 show a profile of AIDS cases by gender that differs greatly for African Americans and whites. In 2000, African American women accounted for over 60% of new cases among female adults/adolescents, whereas white women accounted for only 18% of these new cases.[33]

African American children represent an overwhelming percentage of pediatric cases.
Although only representing 15% of the total U.S. population under the age of 13, African Americans accounted for almost two-thirds (65%) of the pediatric AIDS cases (AIDS cases in children under 13 years of age) in 1999/2000.[34]

African American men who have sex with men (MSM) continue to have the highest incidence of any risk group in African American communities.
From July 1999 to June 2000, African American MSM represented the greatest proportion of all new African American AIDS cases (21%) and almost one-third (30%) of all new MSM AIDS cases.[35]

THE INTERPRETATION

NASTAD recognizes the critical role of epidemiology in analyzing, understanding and explaining the HIV/AIDS epidemic. However, just like statistics, epidemiology can be a double-edged sword.

On the positive side, epidemiological information can be used to gain the attention of policy makers, service providers and individuals. It can switch on the light bulb of awareness so that organizations and individuals recognize the gravity of the current HIV/AIDS situation and become determined to change the course of projected trends. It can also help individuals and organizations to develop programs geared toward addressing current epidemiological trends.

On the negative side, epidemiological information can be misinterpreted and misrepresented. It can be used to justify decisions that may not be in the best interests of African Americans. It can be misinterpreted by AIDS organizations, the media, and the general public with the disastrous results of increasing the stigma and shame for individuals.

Epidemiological Data Can Be Difficult to Understand

One barrier to understanding epidemiological data is that the terminology can be confusing and difficult to understand. Some health departments may not thoroughly understand the information and therefore may not be able to translate it to the community. It is important to remember that the goal of communicating epidemiological information to the public is to increase understanding and engage them in the fight against the negative trends. Therefore, it is imperative to continue to explore ways that information can be presented accurately, but in layman's terms and concepts.

Public health staff, service providers, and the general public should receive more education about basic epidemiological principles. It can begin with basic explanations of statistics.

Interpretations of Epidemiological Data Can Be Stigmatizing

AIDS stigma is prejudice that discounts, discredits, and/or discriminates against people perceived to be infected with HIV or have AIDS, and the individuals, groups, and communities with which they are associated. Stigma is a barrier that discourages individuals from obtaining prevention information and treatment for HIV/AIDS because of fear of being ostracized by the larger community.[36]

HIV/AIDS epidemiological information can unintentionally stigmatize, alienate and pathologize African Americans. For example, in a 2000 CDC Morbidity and Mortality Weekly Report, researchers reported that in a study of HIV positive-MSM, more African American and Latino men identified as heterosexual then did their white counterparts. CDC noted that "cultural factors, such as stigma of homosexuality" could be playing a role in the disproportionate toll of HIV and AIDS among gay and bisexual men of color.[37] While noting the role of stigma may be present, doing so without explaining a broader context could reinforce or heighten stigma associated with homosexuality. Some may also associate the rising rates of HIV infection among African American women as related to homosexual behavior of their male sex partners, thereby placing blame on the gay and bisexual men and further ostracizing these men.

This results in discouraging African American men (seen as "vectors") and African American women (seen as "unempowered") from engaging in discussions about how to prevent the transmission of HIV. These cycles of blame and stigmatization are counterproductive to the good work health departments are trying to do to prevent the spread of HIV. AIDS directors and health departments should be aware of the potential ramifications of epidemiological statements and endeavor to present information in a way that encourages everyone to be valued for their experiences and perspectives.

Ways To Combat Stigmatizing Interpretations of Epidemiological Data

Frequently, epidemiological information presents purely a quantitative picture of what is happening in a population. This is similar to an aerial photo of a town or viewing the part of the iceberg that is above the water's surface. AIDS directors and health departments should endeavor to take a closer look at what is happening in African American communities and not just accept the epidemiological data at face value. Misinterpretations of data may be avoided if efforts are made to understand the environment in which data will be presented. Recommendations in this section provide steps that may be taken to contextualize epidemiological presentations so as to avoid misinterpretation and unintended stigmatization.

Harm can be done to African American communities, and to sub-populations at highest risk, when data is presented and/or interpreted in a stigmatizing fashion. To avoid stigmatization, it is important to separate people from the behavior, which may place them at risk of HIV infection. It is recommended that health departments take the following steps toward assuring a more comprehensive interpretation and explanation of epidemiological data.

Convene an African American HIV epidemiology work group

This work group would establish an ongoing collaborative relationship with an epidemiologist(s) to interpret and present epidemiological data in layman's terms and in language that is culturally specific, relevant and written at an appropriate reading level. Working relationships can be established with graduate schools of public health to ensure epidemiologists are trained to present data that is culturally relevant and can be understood by the public. Opportunities to develop partnerships and joint programs with historically black colleges and universities can also be explored.

Utilize epidemiological data to inform ongoing dialogue and planning of HIV prevention and care services

Building upon existing planning bodies, such as the prevention community planning groups and Ryan White CARE Act Title I planning councils and Title II consortia, data deemed important and compelling should be used to inform HIV/AIDS prevention and care planning in the jurisdiction. Such an approach would build confidence that data is being used to make resource allocation decisions, and that resources are tracking the epidemic.

Fund and support efforts to increase the participation of African Americans in the field of epidemiology and behavioral science

Jurisdictions may be able to identify resources to support training programs, internships and other career opportunities to encourage African American students and employees to pursue careers in epidemiology and related fields of public health.

CAPACITY BUILDING

One way to provide effective HIV/AIDS prevention and care services to African Americans is through organizations based in African American communities. Members of the target population often lead the most successful of these organizations. They are more likely to understand the needs and perspectives of the communities and deliver information and services in the context of building relationships, trust, and credibility with members of communities over time.

To succeed, these organizations need support from state and local health departments in the forms of funding and capacity building assistance. These organizations need assistance with building their capacities and infrastructures, including financial management, fundraising and board development. They need help with grants management, leadership development, program planning and evaluation. This type of capacity building assistance will promote sustainability and help ensure their continued presence in the community.

Currently, there are a limited number of organizations and institutions that are African American "owned and operated" that can effectively target and serve African American communities. Without solid capacity building assistance these organizations are at risk for failure. Emerging African American CBOs fail for the same reasons that most emerging CBOs fail. They become too big too fast, and try to do too much with too little. Specifically, they can be overly dependent on public funding, have limited experience managing grants, have limited scope of activities, and could benefit from leadership development. The challenge for health departments is to deliver much needed capacity building assistance in culturally aware, sensitive, and appropriate ways. It is imperative that these organizations get the support they need to survive and that when new organizations are established they develop with solid infrastructures and sufficient capacity.

When community members of the targeted populations are empowered and engaged in program design and implementation, programs can be tailored to be culturally sensitive and appropriate. In order to achieve this, members of the target population must be at the table and willing to participate at all levels of activity. They must also receive the training and support necessary to succeed.

CULTURAL SENSITIVITY AND APPROPRIATENESS

State and territorial AIDS directors must be able to effectively advocate within their health departments for policies and practices that are culturally appropriate and relevant to African American communities. They must be able to understand and talk about organizational development issues in ways that reflect the perspectives of collective African American communities and specific African American populations.

Health department staff must have opportunities to participate in training that brings to light the chronic external barriers that African Americans face when attempting to access health care. Staff also need training on the ways in which they may be unintentionally reinforcing these barriers. Simultaneously, health departments must empower groups to address community norms that keep their members from seeking testing, treatment, and care.

The needed critical mass of African American-specific organizations does not exist in every community or state across the nation. However, it is imperative that African Americans feel that they can access health and human services anywhere and be treated in a respectful and culturally appropriate manner. The challenge for health departments is to provide support and affirmation in the areas that help organizations develop sustainable infrastructures and adequate capacities. To achieve this, these organizations will need culturally appropriate capacity building assistance.

RECOMMENDATIONS

The Committee identified and focused on two areas of capacity building: (a) capacity building within health departments – to ensure effective service delivery to African American communities at highest risk and, (b) capacity building within CBOs – to ensure effective delivery of services to African American client populations (particularly transgenders, IDUs, women, MSM, young people as they are at highest risk). The Committee identified a need to support health departments and AIDS directors in developing and providing enhanced capacity building assistance to CBOs, especially African American and other minority CBOs.

Building upon its STATUS Project, NASTAD will identify and disseminate information about effective state level capacity building programs. In assessing state and local health department readiness to deliver capacity building assistance to minority CBOs, STATUS found that state and local health departments offer an array of training and technical assistance opportunities, and that health departments are uniquely positioned to identify and address the technical assistance needs of individual CBOs.[38] *Recently the Department of Health and Human Services Office of Minority Health provided resources to state offices of minority health for capacity building assistance targeting minority CBOs. CDC has implemented an extensive system of capacity building assistance to support its directly-funded CBOs. These federal programs and others will be examined as sources of models that state health departments can begin to implement.*

CAPACITY BUILDING WITHIN HEALTH DEPARTMENTS

Take a top down approach

Capacity building efforts are taken most seriously and tend to be most effective when they originate at the top. AIDS directors in health departments can provide leadership and support for capacity building efforts by communicating that the efforts are a high organizational priority, by getting buy-in from other leaders and managers in the organization, and by allocating adequate funding for capacity building initiatives.

Consider multiple sources for obtaining capacity building in health departments

There are many sources from which health departments can obtain capacity building assistance and engage in collaborative training and research activities. These include national organizations, peer technical assistance coordinated by NASTAD, peer departments within the same health department, local colleges and universities, independent TA providers, and even the CBOs themselves.

Conduct an assessment of cultural competency of the health department (and/or the AIDS office within the health department)

The purpose of conducting a cultural "audit" is to assess the degree of cultural competency or proficiency in health department AIDS offices. Cultural competency will enhance the department's effectiveness in addressing the HIV prevention and care needs of African American populations. Cultural audits generally include gathering data through interviews, focus groups or surveys to diagnose areas of strength and are opportunity specific to workplace inclusion, diversity and cultural competency. Cultural audits can provide the foundation upon which specific capacity building actions (e.g., staff development, management development, organizational development) can be designed and taken.

Offer educational workshops to health department managers and staff on the historical dynamics between racism, African Americans, HIV/AIDS and the public health system

Effective training programs will be both didactic and experiential. They will present the facts and facilitate meaningful dialogue in a non-threatening environment.

Offer management development training with a focus on cultural competency

Areas to address in management development training include skills and best practices for recruiting, hiring, developing, promoting and retaining African American and other minority staff at all levels of the organization. Managers may also want to offer training for less experienced African American health department staff to help with feelings of intimidation, confusion or manipulation.

Create a Minority AIDS Coordinator position in health departments serving jurisdictions with large African American populations

The role of a Minority AIDS Coordinator would be to help make all information and processes culturally relevant within the health department, and ensure African American participation at all levels of HIV/AIDS policy development and program implementation (see Appendix for suggested position requirements). In jurisdictions where African Americans are heavily impacted by HIV/AIDS, every effort should be made to identify an African American candidate for this position. To avoid marginalization of the position and the individual holding it, it is essential that the Minority AIDS Coordinator be fully integrated into the management structure of the health department, so that the position is not seen as "just another special initiative."

CAPACITY BUILDING ASSISTANCE WITH CBOs SUPPORTED BY HEALTH DEPARTMENTS

Consider that there are at least three options for providing capacity building assistance to CBOs:

(a) Capacity building assistance provided directly by the health department
(b) Capacity building assistance provided by a mutually agreed-upon independent third party
(c) Capacity building assistance provided by a peer CBO such as a non-HIV specific agency of comparable size or a peer health department

No matter which model is utilized, the following recommendations apply:

Develop trust with CBOs and deliver capacity building services in a culturally competent manner

Because of the historical relationship between the public health system and African American communities, a fundamental requirement for successful capacity building assistance, a mutually trustworthy relationship, may not exist. Some in African American communities may believe that the health department is not supportive of CBOs. Good faith efforts to help CBOs via capacity building assistance may be perceived as attempts to identify operational weaknesses and subsequently implement punitive measures. One way to establish trust is to work to overcome the historical perception of some members of the African American community that the health department is consistently trying to take resources and control away from the community. This can be done by utilizing independent third party consultants to deliver capacity building assistance, and by including in the process, African Americans who have established relationships with the community. It is also important to allow the technical assistance provider and CBO to have a confidential relationship regarding the specifics of the capacity building assistance delivered.

The CBO should have a role in deciding who actually delivers the capacity building assistance to the organization (e.g., the health department, an independent third party or a peer CBO). Regardless of who is delivering the capacity building services, it is most important that goals and objectives for the initiative be mutually identified and agreed upon by all parties. The more the goals are aligned with the goals and needs of the CBO, the more effective the assistance is likely to be.

Additionally, capacity building assistance should be rooted in the understanding of issues from the CBO's perspective. For example, when assisting with program evaluation, help the CBO understand how evaluation leads to better programs and services for the CBO's constituencies. Making linkages to the big picture builds trust and rapport and increases chances of success.

Conduct capacity building in CBOs from the top down, with buy-in and support from senior management

As in health departments, capacity building efforts are taken most seriously and tend to be most effective when they originate at the top. Executive Directors in CBOs can provide leadership and support for capacity building efforts by communicating that the efforts are a high organizational priority, by getting buy-in from the Board and other leaders in the organization, and by allocating adequate funding for capacity building initiatives.

Assess CBOs and local health departments to determine their capacity building assistance needs

There are a variety of tools that health departments can use to learn about the kinds of capacity building assistance CBOs and local health departments might need. Some direct methods for gathering data include written surveys, online surveys, individual interviews, staff focus groups, and interviews with members of the Board of Directors. Indirectly, health departments can assess capacity building assistance needs by evaluating strengths and identifying areas for improvement in grant applications and quarterly monitoring reports.

Utilize assessment results to identify capacity building needs in CBOs

Results of assessments are likely to identify some areas where CBOs consistently need help such as managing finances, writing grants, working effectively with state and federal agencies, developing and evaluating programs, developing leadership, coaching boards, fostering collaborations and managing volunteers. These areas can be supplemented with additional assistance as determined by the CBOs.

Consult with African American leadership for implementation assistance and ongoing guidance

Work with gatekeepers who are viewed as respected community leaders such as ministers, people living with with AIDS and CBO administrators. It is essential that African American leadership also includes constituency groups that are highly impacted by HIV/AIDS including transgenders, MSM, IDUs, women and youth. When possible, capacity building should be implemented with the consultation and expertise of African American people living with HIV. Such individuals can play a leadership role in determining priorities, gaps in services, evaluating providers and developing standards of care. Task forces can be used to garner support and act as a bridge between communities and health departments.

COALITION AND PARTNERSHIP BUILDING

Currently only a limited number of organizations can effectively target and serve African American communities. One strategy for maximizing the potential of current resources is for organizations to collaborate with one another. When organizations participate in coordinated partnerships the result is synergistic: they further the missions of both organizations, minimize duplication, serve more people, and make a bigger impact. Working together, organizations are also better equipped to address complex prevention and treatment issues in African American communities.

State and local health departments can provide guidance to their constituencies on how to collaborate effectively. To do this, they must understand the subtleties involved in promoting any effective partnership, and address potential pitfalls that can come up when organizations collaborate. For example, health departments can help foster healthy partnerships by being aware of historic underpinnings in African American communities, by openly acknowledging these issues, by identifying models of successful working collaborations and by finding out what has and has not worked well in the past. In general, partnerships are more likely to succeed with clearly articulated goals, clear communication about the roles and responsibilities of each partner, mutual agreement on a decision-making process, power sharing and an equal stake in the issues, and a sense of each partner's equal value to the partnership.

Be aware of the traditional mistakes that health departments make when helping CBOs build collaborations

There are a number of common mistakes that health departments make when helping CBOs build partnerships. One is repeatedly looking to the same organizations to partner simply because their grant prescribed activities are similar. Another is thinking that opinion leaders in African American communities are those individuals with the highest public profile, or those involved in traditional health department planning activities. Successful partnerships can, and often do, originate out of unique or unexpected alliances.

Build coalitions and partnerships with stakeholders who represent a broad range of African American constituencies

Health departments should think creatively when building partnerships. There are a broad range of groups to call upon locally including indigenous African American community leaders, opinion leaders and stakeholders, as well as established coalitions addressing related issues such as teen pregnancy, violence, substance abuse, housing, employment and civil rights. Health departments should work with the faith community, with educators, with writers, artists and media groups. Steps should be taken to educate and involve state elected officials, especially African American representatives in state legislatures, about the HIV epidemic in African American communities. It is imperative to also include those groups that work with African American organizations serving constituencies at highest risk including gay, lesbian, bisexual and transgendered organizations along with women and youth-serving CBOs.

Health departments should also consider partnering with public health departments in other jurisdictions that serve African Americans and build relationships with state and local counterparts of national fraternities, national minority AIDS organizations, national minority trade associations, national African American political, athletic and media organizations as well as educational organizations and universities.

Establish trust between the health department and African American communities and CBOs

In light of the historical underpinnings previously discussed, there are a number of actions that health departments can take to gain the trust of African American communities and CBOs. A good place to start is to acknowledge misrepresentation and mistreatment by the public health system in the past, talk with members of African American communities about the impact of historical underpinnings, and communicate

the willingness to move forward together with a spirit of respect, cooperation and positive change. Initially this may require the health department meeting the community more than half way. Keep in mind that it takes time to build trust and rushing the process can be counterproductive.

There are other concrete steps health departments can take to build trust. Holding relevant meetings at mutually agreed upon locations in the community, rather than at the health department offices is one such step. The parties may also want to bring in an outside facilitator in the early stages of the collaboration. If this is the case, both parties should jointly choose a facilitator with whom everyone feels comfortable. Establish mutually agreed upon ground rules and create norms that foster open and honest communication. Health department staff should speak in language that is accessible to the community, and design written materials that can be easily read by lay people. Identify mutually beneficial goals and set aside time for honest dialogue about what individuals think are the potential risks and benefits of the collaboration. This and other conversations may need to be revisited because the degree of honesty will grow as trust deepens.

Assist in establishing trust between African American CBOs and community members that are forging new partnerships

When health departments are facilitating a new collaboration between CBOs, they need to do so thoughtfully and with consideration. Emphasize that building coalitions and collaborations is about cultivating relationships towards the mutual exchange of resources and information. Establish ground rules that promote inclusion and value the differences that each party brings. Address the balance of power between collaborating agencies and develop a mutually agreed upon system of accountability. Acknowledge differences in capacity, ability, and knowledge among members and take time for partners to mutually agree upon goals, objectives, roles and responsibilities. Together, the partners should establish rules for decision-making and identify a contingency plan in the event of a stalemate. Acknowledge that historic underpinnings may cause groups to proceed cautiously, and validate that people are coming together to move forward and make a positive impact on the community.

Health departments should also acknowledge and address the different levels of coalition building going on in different jurisdictions and actively support the development of new coalitions across various sectors of the African American community, especially those at highest risk for HIV/AIDS (e.g., transgenders, MSM, IDUs, women and youth).

Foster and maintain African American leadership as board members and staff of CBOs and AIDS Serving Organizations

Health departments should take an active role in mentoring and supporting African American leadership in African American AIDS organizations and in the larger ASOs and CBOs in their jurisdictions. Mentoring activities include board and staff development, offering coaching for executive directors, training on board recruitment, or providing dollars for CBOs to hire consultants to help them attract and retain highly talented individuals.

A visible, accessible presence of African American leadership in the health department is an important element for leadership development in the community. African American leaders in the health department can mentor upcoming leaders in the community, offer regular opportunities to gather for support, sponsor leadership development training programs and foster networking between leaders in the HIV and non-HIV communities.

Foster coordination and collaboration within the health department itself

There are many individual departments within the health department itself whose effectiveness in African American communities could be enhanced by coordinating efforts, sharing resources and collaborating. These units include, but are not limited to, maternal and child health, STD prevention and treatment, substance abuse prevention and treatment, juvenile justice, violence prevention and community health.

PROGRAM IMPLEMENTATION

Effective prevention and care program implementation is at the core of addressing the HIV/AIDS needs of African Americans. This section combines prevention and care because they are inextricably linked when discussing HIV/AIDS. Many African Americans are exposed to their first HIV-prevention messages as a result of receiving an HIV/AIDS diagnosis and entering the care system. Many African Americans also seek care at later stages of infection and tend not to remain in treatment as compared to their white counterparts.[39]

The challenge for prevention programs is to identify what is lacking in current prevention strategies that might be effective in reducing HIV infection rates in African American communities, particularly for the groups at highest risk. The challenge for care programs is to determine what is lacking that allows African Americans to continue to get sicker faster and to die sooner. To make an impact on the crisis, it is important to keep and replicate those things that are working, and examine those areas where change is needed.

NASTAD's African American Advisory Committee undertook in-depth discussions about prevention care and program implementation. Initially, the Committee generated an extensive list of components critical to culturally competent prevention and care programs. After more reflection and discussion, the Committee agreed that their list was a restatement of elements included in existing federal guidelines. By consensus, the Committee concluded that CDC, the Health Resources and Services Administration (HRSA) and other federal agency guidelines, standards of care and monitoring requirements were in place. As a result, the challenge for state and local health departments in addressing HIV/AIDS disparities is ensuring and promoting effective program implementation. That is not to say that there is no room for new and innovative prevention and care strategies, and for tailoring best practices for African Americans. However, the Committee agreed that it should offer recommendations to state and local health departments on strategies that could be implemented to address structural or systemic issues related to HIV/AIDS health disparities.

RECOMMENDATIONS

The following recommendations will aid in more effective HIV/AIDS program implementation:

Acknowledge historic underpinnings
Make sure all programs take into account the historical underpinnings that affect how African American's process health-related information and access health care. Service providers and health department staff should participate in cultural sensitivity, anti-racism and diversity trainings that address difficult issues such as privilege, power, socioeconomic status, and discrimination based on race, gender, and sexual orientation. Such trainings must be carefully tailored to meet specific needs of health departments and comfort level of the participants.

Work with African American communities to establish standards of care
There are many points for improving standards of care and access to care in African American communities. These include providing early intervention services, promoting access to facilities that adhere to federal treatment guidelines, addressing unmet needs and implementing quality management. Standards must also focus on creative ways to keep African Americans in care, as norms of community mistrust reinforce the tendency to discontinue care.

Disparities exist for African Americans in all facets of health care -- prevention, primary care, mental health care and dental care to name a few. A holistic approach needs to be taken in which health departments engage stakeholders from all parts of the public health system and African American communities to address the health care disparities, particularly among those at highest risk for HIV

Ensure the presence of culturally diverse staff to implement care and prevention programs
Culturally diverse staff should be present at the state and local levels. The presence of qualified African Americans and other staff of color help ensure that prevention and care programs are designed, implemented and evaluated through a culturally sensitive lens. Many African Americans may feel a degree of distrust towards treatments that are commonly accepted in other communities. This distrust is related to historical underpinnings and the fact that historically, treatment and care in African American communities has been less than adequate when compared to services in other communities.

Support the implementation of reputable programs

In light of the fact that there is a dearth of behavioral science research on African Americans and HIV/AIDS, health departments need to implement prevention and care programs that are high in quality and efficacy. This includes programs favored by the community for achieving positive outcomes despite lack of formal process or outcome evaluations.

Seek out capacity building assistance for the health department

Health departments and AIDS directors may consider seeking out assistance to build their own capacities, which in turn will allow them to be more effective in helping CBOs implement programs. Sources of capacity building assistance include health departments in neighboring states (allowing for the exchange of expertise and experience across health departments) and federal capacity building assistance programs. Capacity building within the health department can strengthen program implementation efforts by identifying and addressing gaps in service and responding to the needs of organizations reaching out to African American communities.

Provide funding and capacity building assistance to CBOs for the evaluation of prevention and care programs

As outlined in the federal guidances, prevention and care programs should be regularly evaluated for the purposes of quality management, and to identify areas in need of improvement. Evaluation data should also be used for designing new programs that are built on strategies shown to be effective.

Provide seed money to encourage and fund community-based African American HIV/AIDS initiatives

Identify agencies that are doing good work, but have never been funded to do HIV/AIDS work, and need to establish a track record to apply for larger funding. Pay special attention to those programs addressing the diverse needs of the highest risk populations within the African American communities.

Develop CBO-friendly processes and procedures for obtaining funding
Expand funding cycles so that organizations can be funded for significant time periods, such as five years, in order to reasonably transition from the start-up of a program to effectively delivering interventions. During this phase, there should be standards and evaluations to measure an organization's progress so that the funding cycle is not perceived as an "entitlement."

Simplify the request for proposal process to require less paperwork (e.g., a two-page concept paper for up to $50,000) and consider funding demonstration grants. Lastly, help handle the up front funding requirements of reimbursement contracts.

Address the known barriers to accessing care
Examples of major barriers to effective program implementation include:

Poor location of services-Bear in mind that some people will feel more comfortable receiving services within their own community and others, fearing stigmatization, will feel more comfortable in locations in which their anonymity is more likely to be preserved.

Stigma- Service providers need support to continue having honest conversations with community members about sexuality and sexual practices, drug use, gender identity, and homophobia to avoid inadvertently stigmatizing clients who are receiving prevention and care services.

Lack of culturally-competent educators, counselors, health care providers-Providers need to be aware and sensitive to the needs and concerns of African Americans, especially people at highest risk.

BEHAVIORAL RESEARCH

The national AIDS crisis in African American communities demands that health department officials make great strides quickly in their understanding of African Americans' needs and concerns about HIV/AIDS. This includes generating deeper knowledge of the specific combinations of co-factors that put African Americans at risk (e.g., deep mistrust of the public health system, low health care seeking behaviors, lack of well-funded, culturally specific interventions, and stigmatization within the communities themselves) and a more thorough understanding of how to effectively intervene with those at highest risk. Historically, there has not been enough behavioral research on how to prevent higher rates of a number of diseases in African Americans, (e.g., hypertension, cancer and diabetes.) HIV has been no exception. To go forward from this point there must be a shift in the public health approach to AIDS in African American communities.

Behavioral science research is needed to learn more about African American communities and their sub-groups at highest risk. This behavioral research must be conducted with an understanding of the historical underpinnings and an awareness of African American perspectives. Forcing organizations to fit their communities into standard molds can damage community well-being. A behavioral intervention that works for one sub-population of African Americans may not work for another. In applying behavioral science, AIDS directors must be able to effectively advocate within their health departments for policies and practices that are culturally appropriate and relevant to African American communities. When possible, African American researchers should be included in the design, implementation and evaluation of behavioral research projects.

Identify opportunities for outcome evaluation

Outcome evaluation focuses on the stated behavioral objectives of the program and should demonstrate that the program causes (or fails to cause) a specific change. Outcome evaluation answers the questions "What worked?" "Did anything work?" "Why did one intervention work better than another?" Evaluations present opportunities to learn from successes and failures, and are often used to drive program design and future program funding. Outcome evaluation results can and should be shared with other agencies, organizations, and health departments.

Use culturally specific language when designing and implementing outcome evaluations

Standard language used in outcome evaluation may have to be modified to fit the varying cultural contexts in which service providers and community organizations work. The one-size-fits-all approach may diminish effectiveness or trust between communities and the health departments. For example, the meaning of "success" varies by culture. The challenge for prevention providers is to find indictators that are meaningful to the populations served, while still providing accountability.

Include representatives from communities at highest risk in outcome evaluation design and implementation

For these groups it would be risky to use standard approaches for developing and measuring outcomes. Organizations serving African American communities must be involved in evaluation design and have creative room to apply outcome evaluation concepts to their own communities.

In addition, including community leaders and peer workers in research activities can help create a greater social pressure to perform safer behaviors, help create positive emotional community response to programs, and help identify program participation with community members' self image.

Support formative research as part of the program design process

Formative research must be done to determine which behavioral science theories and appropriate interventions drive HIV-prevention programs. African American communities cannot be approached as a monolithic entity. Therefore, health departments should incorporate time and funding for formative research to occur prior to the implementation of all programs.

High-risk sub-groups within African American communities must be researched to understand their unique social norms, interventions that produce positive and negative emotional responses, barriers to performing safer behaviors, and the perceived benefits and disadvantages of performing safer behaviors. Traditional approaches have not had a satisfactory impact in stopping the spread of HIV in African American communities, and clearly more research needs to be done.

Understand the impact of historical underpinnings on African American communities

Many stereotypes have been used to describe African American communities, and program interventions have been developed based on these stereotypes. Historical underpinnings drive many negative attitudes African Americans have toward health departments and potentially effective public health measures. In order to engage a paradigm shift in how health departments view African American communities and how African American communities view public health departments, researchers must understand the impact of historical underpinnings on any research done in African American communities. Members from the targeted African American communities must be included in all phases of formative research.

Promote linkages between CBOs and behavioral scientists

Behavioral scientists represent the scientific establishment to African American communities via the public health departments.The CBOs represent African American communities to the behavioral scientists. Based on historical underpinnings this relationship is one of mistrust on one side and condescension on the other.

To change this relationship and address the imbalance of power, representatives from African American communities and CBOs must participate with behavioral scientists in all phases of behavioral research done within African American communities. To ensure successful and positive results from this participation, technical assistance in the form of training and mentoring may be necessary for community representatives. Simultaneously, technical assistance, training, and mentoring may be necessary for behavioral scientists with respect to understanding the historical underpinnings and the perspective of African American communities.

Create a Minority AIDS Coordinator position in each jurisdiction

A Minority AIDS Coordinator position should be created in jurisdictions with high African American HIV/AIDS incidence rates and/or large African American populations. Such a position would ensure African American participation in research efforts and the cultural relevance of all research information and processes.

Include African American community leaders and peer workers in outcome evaluation design and implementation

Within African American communities, education and prevention efforts must be directed at changing community-wide norms, promoting economic opportunity and social stability. The inclusion of community leaders and peer workers in research activities can help create a greater social pressure to perform safer behaviors, help create positive emotional community response to programs, and help identify program participation with community members' self images.

Include health department performance in the program evaluation process

Community trust, power balance, and program effectiveness can all be improved if health department performance is also included in the program evaluation process.

NEXT STEPS FOR HEALTH DEPARTMENTS

The following is a list of the recommendations made in each section of the monograph.

HISTORIC UNDERPINNINGS

Identify antecedents in each local jurisdiction

Acknowledge and discuss the antecedents with African American communities

Work with community leaders to maintain ongoing dialogue

[Please see chart on page 13 for specific strategies to prevent repetition of antecedents.]

THE ROLE OF STATE AND LOCAL AIDS DIRECTORS

Identify, engage, and train indigenous African American leadership to be involved in HIV/AIDS decision-making processes

Identify, engage, train and support African American leadership within the health department

Convene an in-house health department diversity team

Provide expert capacity building assistance to community-based organizations

Offer educational workshops on the historical dynamics between racism, African Americans, HIV/AIDS and the public health system

Review institutional policies and practices

Fund programs that are culturally based and culturally competent

Support the development of science about African American communities

Proactively support development of coalitions and partnerships that include key stakeholders from African American communities

AN EPIDEMIOLOGICAL PERSPECTIVE ON HIV/AIDS IN AFRICAN AMERICAN COMMUNITIES

Convene an African American HIV epidemiology work group

Utilize epidemiological data to inform ongoing dialogue and planning of HIV prevention and care services

Fund and support efforts to increase the participation of African Americans in the field of epidemiology and behavioral science

CAPACITY BUILDING

Capacity building within health departments

Take a top down approach

Consider multiple sources for obtaining capacity building in health departments

Conduct an assessment of cultural competency of the health department (and/or the AIDS office within the health department)

Offer educational workshops to health department managers and staff on the historical dynamics between racism, African Americans, HIV/AIDS and the public health system

Offer management development training with a focus on cultural competency

Create a Minority AIDS Coordinator position in health departments serving jurisdictions with large African American populations

Capacity building with CBOs supported by health departments

Develop trust with CBOs and deliver capacity building services in a culturally competent manner

Conduct capacity building in CBOs from the top down, with buy-in and support from senior management

Assess CBOs and local health departments to determine their capacity building assistance needs

Utilize assessment results to identify capacity building needs in CBOs

Consult with African American leadership for implementation assistance and ongoing guidance

COALITION AND PARTNERSHIP BUILDING

Be aware of the traditional mistakes that health departments make when helping CBOs build collaborations

Build coalitions and partnerships with stakeholders who represent a broad range of African American constituencies

Establish trust between the health department and African American communities/CBOs

Assist in establishing trust between African American CBOs and community members that are forging new partnerships

Foster and maintain African American leadership as board members and staff of CBOs and ASOs

Foster coordination and collaboration within the health department itself

PROGRAM IMPLEMENTATION

Acknowledge historic underpinnings

Work with African American communities to establish standards of care

Ensure the presence of culturally diverse staff to implement care and prevention programs

Support the implementation of reputable programs

Seek out capacity building assistance for the health departments

Provide funding and capacity building assistance to CBOs for the evaluation of all prevention and care programs

Provide seed money to encourage and fund community-based African American HIV/AIDS initiatives

Develop CBO-friendly processes and procedures for obtaining funding

Address the known barriers to care

BEHAVIORAL RESEARCH

Identify opportunities for outcome evaluation

Use culturally specific language when designing and implementing outcome evaluations

Include representatives from communities at highest risk in outcome evaluation design and implementation

Support formative research as part of the program design process

Understand the impact of historical underpinnings on African American communities

Promote linkages between CBOs and behavioral scientists

Create a Minority AIDS Coordinator position in each jurisdiction

Include African American community leaders and peer workers in outcome evaluation design and implementation

Include health department performance in the program evaluation process

NEXT STEPS FOR NASTAD

DEVELOP A TOOL KIT OF MATERIALS, GOOD IDEAS AND INFORMATION THAT FURTHER EXPLAINS AND EXPOUNDS UPON THE MONOGRAPH RECOMMENDATIONS

DEVELOP AND OFFER A SERIES OF IN-DEPTH TRAINING PROGRAMS BASED ON THE CONTENT OF EACH SECTION OF THE MONOGRAPH

ESTABLISH RELATIONSHIPS WITH OTHER PARTNERS SUCH AS NATIONAL ORGANIZATIONS AND FEDERAL AGENCIES THAT CAN SUPPORT THE IMPLEMENTATION OF THE MONOGRAPH'S RECOMMENDATIONS

PURSUE OPPORTUNITIES TO PROMOTE THE MONOGRAPH'S CONTENT AT LOCAL, STATE, AND NATIONAL HIV/AIDS GATHERINGS

CONDUCT AN EVALUATION OF THE EFFECT OF THE MONOGRAPH ON THE POLICIES AND PROCEDURES OF HEALTH DEPARTMENTS

APPENDIX

SUGGESTED JOB DESCRIPTION FOR MINORITY AIDS COORDINATOR

Position: Minority HIV/AIDS Coordinator

Description: The Minority HIV/AIDS Coordinator is responsible for coordinating all HIV/AIDS initiatives that impact communities of color within health departments. The Minority HIV/AIDS Coordinator will help make all information and processes culturally relevant and ensure African American participation at all levels of policy development and program implementation.

Major Duties/Responsibilities:

- Coordinates and maintains a Minority Advisory Council (a diverse work group within the health department) and identifies key community stakeholders, including health professionals, educators and faith leaders to serve on this advisory council.
- Leads the Minority Advisory Council in identifying community problems, prioritizing problems and identifying community, state and federal resources. Assisting in the development and implementation of prevention services and strategies.
- Establishes collaborative relationships with minority based or focused community organizations in the state as well as other health departments.
- Provides or coordinates technical assistance to community agencies, organizations, health departments and other entities that provide HIV/AIDS services and/or prevention services to communities of color.
- Presents information at conferences, agencies, private industries or public hearings.
- May oversee, create and present grant proposals to private institutions or government agencies to secure grants and other forms of funding.
- Routinely assist with budget preparation and monthy reporting, etc.

Recommended Qualifications:

- Trained across the board in all issues
- Able to mobilize minority/African American communities
- At least 5 years experience working with African American communities
- An established rapport with communities
- Group process facilitation skills
- Experience in program development, management, administration, and fiscal management
- Working knowledge of non-profits with knowledge of HIV/AIDS and STDs
- Comfort with talking about sexuality, drug use, sexually explicit risk behaviors, gay, and transgender issues.
- Ability to deliver technical assistance
- Ability to identify experts to fill in when needed
- Ability to find and communicate funding opportunities
- Strong public presentation skills, oral and written skills

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