NASTAD™
NATIONAL ALLIANCE OF STATE & TERRITORIAL AIDS DIRECTORS

AFRICAN AMERICAN WOMEN
Issue Brief No. 1

May 2008

The Landscape of HIV/AIDS among African American* Women in the United States

INTRODUCTION

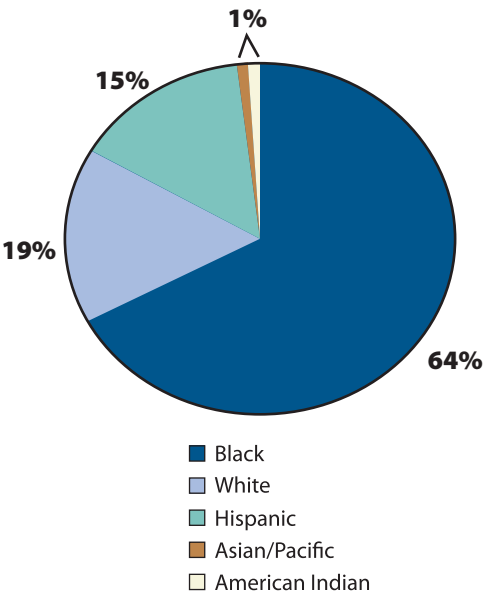
Today, the HIV/AIDS epidemic continues to disproportionately impact African American men and women across the United States. Although African American communities make up less than 13 percent of the U.S. population, African Americans accounted for nearly 50 percent of all HIV/AIDS cases diagnosed in 2006.[1] African American women comprise only 12 percent of the female population in the United States, yet they accounted for 64 percent of women living with HIV/AIDS at the end of 2006, as illustrated in Table 1.[2] The rate of AIDS diagnosis for African American women was 20 times the rate of White women by the end of 2006.[3] Despite successes in HIV/AIDS treatment and marked declines in HIV infection rates in other risk groups[4], HIV disease was the third leading cause of death for African American females, ages 25-34, in 2004[5].

High-risk heterosexual sexual contact and injection drug use are the primary modes of HIV transmission for African American women.[6] Seventy-five percent of African American women were infected through heterosexual contact.[7] Because African American women are less likely than other women to date men outside their racial/ethnic group[8], high rates of HIV infection among African American men has important implications for African American women's HIV risk. The rate of HIV/AIDS cases among African American males is greater than rates for any other ethnic/minority group.[9] Twenty-three percent of African American women were infected with HIV by injection drug use.[10] Further, being under the influence of any substance may facilitate engagement in high risk behaviors such as unprotected sex and sharing of injection drug paraphernalia.

Evidence suggests that power dynamics in a relationship and socioeconomics related to gender difference in drug use patterns can precipitate exposure to HIV.[11] While high risk heterosexual sexual behavior and drug use are important factors influencing HIV infection rates among African American women, other factors also contribute to circumstances that can lead to

Table 1: African American Women's Issue Brief:

Estimated Number of Female Adults or Adolescents Living with HIV/AIDS at the End of 2006 by Race – 33 states



Source: US Centers for Disease Control and Prevention. *HIV/AIDS Surveillance Report, 2006.* Vol. 18. Atlanta, GA: U.S. Department of Health and Human Services, CDC; 2006: 1-54.

*Please note: The use of the term "African American" is consistent with its use in the NASTAD monograph, *HIV/AIDS: African American Perspectives and Recommendations for State and Local AIDS Directors and Health Departments*, and its recognition of historical circumstances that have created a legacy of mistrust for many African Americans in this country. Paramount to both documents, however, is an acknowledgment of the devastating impact of HIV/AIDS on **all** people of African descent, including those born in Africa and the Caribbean.

HIV disease was the third leading cause of death for African American females, ages 25-34

TABLE OF CONTENTS

HIV transmission. These factors include biological vulnerabilities; unique characteristics and nuances of heterosexual relationships in African American communities; structural influences impacting issues such as poverty, employment, and education; and incarceration.

Federal and state resources must be used to reduce the unacceptable rate of HIV infection among African American women. Although African American women and their allies are working closely with the Centers for Disease Control and Prevention (CDC) leadership to address this crisis, but the responsibility to curb HIV infection trends among African American women is not CDC's alone. The U.S. needs a comprehensive response across all sectors – government agencies, non-governmental organizations, national AIDS policy organizations, community-based organizations (CBOs), AIDS service providers and state and local health departments.

INTENDED AUDIENCE

The primary audience for this issue brief is CDC-funded HIV prevention providers, including the 65 directly-funded state and city health departments, HIV prevention community planning groups and CDC directly-funded community-based organizations. CDC's National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention (NCHHSTP) received approximately $692 million for domestic HIV prevention activities in FY2008, slightly more than half of which are allocated for health department HIV prevention programs. With these resources, health departments are charged with coordinating a comprehensive HIV prevention response in their jurisdiction. To support these efforts, CDC requires that each jurisdiction implement HIV prevention community planning. Community planning groups develop a comprehensive prevention plan to guide HIV prevention efforts in the jurisdiction, advising health departments on priority populations and HIV prevention interventions. Another $40 million of CDC's FY2008 funding is granted to directly funded CBOs which are tasked with implementing HIV prevention interventions, including HIV counseling, testing and referral programs (CTR); interventions targeting HIV-positive individuals; and other evidence-based behavioral interventions.

In addition to CDC grantees, other stakeholders will find this document useful. These include CDC-funded capacity building assistance (CBA) providers which are charged with strengthening HIV prevention organizational infrastructure, interventions and activities and community planning, as well as community access and utilization of HIV prevention services. With CDC's emphasis on increasing knowledge of serostatus and routinization of HIV testing, this document may also be instructive to health care providers and their organizing bodies. Other agencies in the Department of Health and Human Services (DHHS) including the Health Resources and Services Administration (HRSA), the Substance Abuse and Mental Health Services Administration (SAMHSA), and the Office of Minority Health (OMH); their grantees; and their

affiliated planning bodies can also use this document to bring leadership and resources to bear in responding to the HIV epidemic among African American women.

UNDERSTANDING THE COMPLEXITY OF HIV/AIDS AMONG AFRICAN AMERICAN WOMEN

The interplay between behavioral risk factors and psychosocial determinants greatly increases African American women's vulnerability to HIV infection in the U.S. Because these factors often occur simultaneously, it is critical for HIV providers to approach these interconnecting factors utilizing a syndemic framework to effectively address the needs of African American women. A syndemic is defined as two or more afflictions interacting synergistically, contributing to excess burden of disease in a population.[12] Table 2 illustrates a syndemic that links HIV risk, STD risk, substance use, unintended teen pregnancy and low literacy.

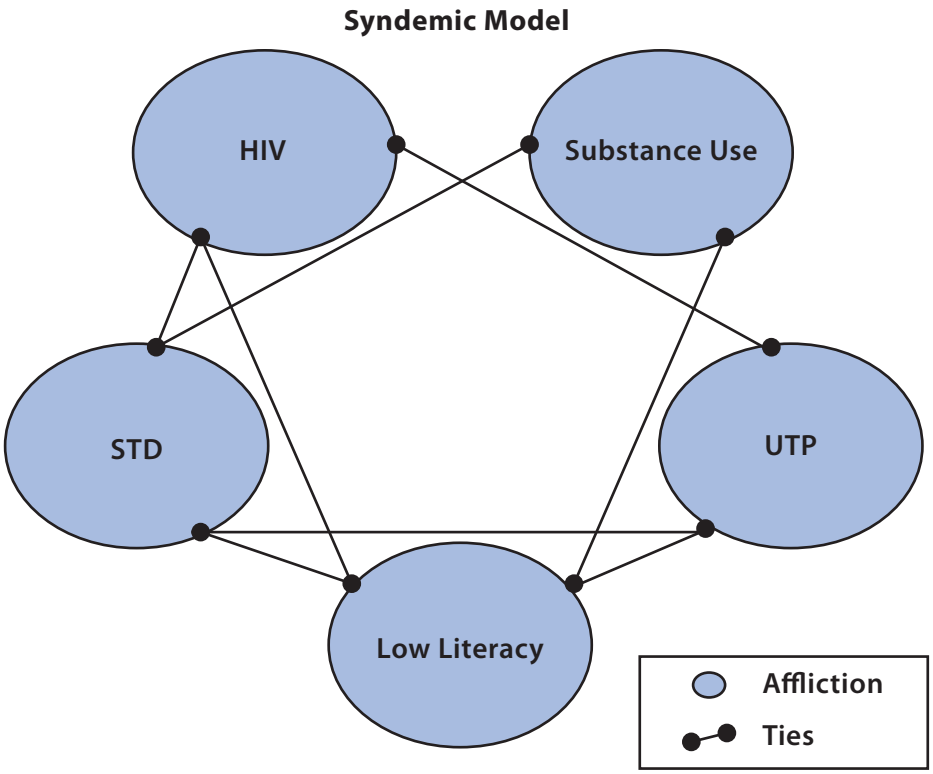
Epidemiological studies and surveillance data make is clear that African American women must be a central focus of national HIV prevention efforts, though the connections between the risk for disease and the unique circumstances that African American women face have not been firmly established.[13] Currently, there is only one CDC-sanctioned evidence-based HIV prevention intervention targeting African American women - Sisters Informing Sisters on Topics about AIDS (SISTA). SISTA is a gender and culturally-relevant group level intervention that is designed to increase condom-use among African American women. Three additional interventions are tentatively slated for release in 2008:

- Sistering, Informing, Healing, Living, and Empowering (SiHLE)—a small group, skills-training intervention to reduce risky sex behaviors among African American adolescent females;
- Women Involved in Life Learning from Other Women (WiLLOW)—a small group, skills-training intervention targeting women living with HIV; and
- Sister to Sister—both a group and individual level skills-building intervention delivered by African American female nurses to increase self-efficacy, correct condoms use and condom negotiation among inner-city African American female clinic patients.

More research is needed to understand the extent to which CBOs are implementing interventions targeting African American women. Research is also needed to help tailor existing behavioral interventions that have been demonstrated to be effective for African American women. However, extensive research examining some of the primary factors and determinants impacting HIV/AIDS among African Americans has been conducted, which should be taken into consideration when developing programs targeting this at-risk population.

Those developing programs targeting African American women must recognize the complexities of HIV

Table 2: A Syndemic Network



risk among African American women and address the web of social and cultural issues that together place them at the crossroads of the HIV epidemic in the U.S. Interventions and services targeting African American women need to address the reality of the "whole-person" or the interaction that exists between multiple, co-occurring issues. In addition to the numerous opportunities for HIV, viral hepatitis and STD prevention interventions, African American women must also have access to treatment for HIV, substance use and mental health concerns like depression and those stemming from childhood sexual abuse.

BIOLOGICAL VULNERABILITIES AND SEXUALLY TRANSMITTED DISEASE (STD) PREVALENCE

Heterosexual women's reproductive biology puts them at greater risk of HIV compared to heterosexual men.[14] For purely biological reasons, a heterosexual woman is about twice as likely as a heterosexual man to contract HIV infection during unprotected vaginal intercourse with an infected partner.[15] Additionally, the presence of some STDs greatly increases the likelihood of acquiring or transmitting HIV infection.[16] Information from a CDC study released in March 2008, based on an analysis of the 2003-2004 National Health and Nutrition Examination Survey (NHANES), indicates that one in four (26 percent) female adolescents in the U.S. has at least one of the most common sexually transmitted infections (STIs), which include cancer- and genital wart-associated human papillomavirus (HPV) (18.3 percent), followed by chlamydia (3.9 percent), trichomoniasis (2.5 percent), and herpes simplex virus type 2 (HSV-2) (1.9 percent). The study further indicated that among the teenage girls who had an STI, 15 percent had more than one, and that race maintained a significant relevance – African American teenage girls had the highest prevalence, with an overall STI prevalence of 48 percent compared to 20 percent among both Whites and Mexican Americans. In 2004, African Americans had the highest rates of gonorrhea, syphilis and chlamydia among all racial groups.[17] One study found that the rate of STDs in the African American population remains high because of the high prevalence of STDs and that African Americans are more likely than any other racial group to have a sexual relationship with other African Americans. As a result, STD rates remain high within the population.[18]

AFRICAN AMERICAN WOMEN AND RELATIONSHIP DYNAMICS

African American women are less likely than women of other ethnicities to get married. In 2002, 42 percent of African American women were not married.[19] The imbalance in the number of African American women and men results in fewer available male partners; therefore, women have less interpersonal power in relationships because men have more options available to them.[20] African Americans are more likely than any other race to be in concurrent relationships (overlapping) which could factor into higher rates of HIV and STDs. Concurrent relationships involve having more than one sexual partner in a given period and increases the probability for transmission, because earlier partners can be infected by later partners.[21] Some researchers contend that concurrency is higher among African Americans due to lower marriage rates.[22]

African American women feel that they cannot insist on condom use because they do not have the power to make that decision.

Furthermore, the sex-ratio imbalance in African American communities can give rise to women's difficulties in discussing and negotiating condom use with male sexual partners.

Lower levels of interpersonal power interfere with women's ability to initiate discussions about condom use, due to concerns that the topic can lead to conflict and threaten the future relationship.[23] The challenge of sexual communication and intimate relationships plays a critical role in the effective use of condoms as a prevention method. Sexual inequality is also a significant issue in relationships between young women and older men. In a CDC study of urban high schools, more than one-third of African American and Hispanic women had their first sexual encounter with a male who

was three or more years older.[24] These young women, compared with peers whose partners have been approximately their own age, had been younger at first sexual intercourse, less likely to have used a condom during first and most recent reported intercourse and were less likely to have used condoms consistently.[25]

Until there are female controlled prevention methods such as microbicides, women remain dependent upon men to take precautionary measures to protect themselves against HIV and other STD. Condom use requires the man's consent. In circumstances where women are not financially dependent or where traditional gender roles are adhered to, the introduction of condom use is often difficult.[26] Though there are limited studies on power dynamics in African American relationships, African American women often feel that they cannot insist on condom us because do not have the power to make that decision.[27] Furthermore, women who are already in abusive relationships were found to be four times more likely to be threatened verbally and nine times more likely be threatened physically if they requested condom use.[28]

STRUCTURAL BARRIERS: RACISM, POVERTY AND DISCRIMINATION

In order to have holistic discussions regarding the disproportionate impact of HIV/AIDS among African American women, issues of racism, discrimination, and socioeconomics are important underpinnings that must be examined. These issues have implications for access to jobs, education and health care. Though these complex factors are not the core risk factors that cause HIV infection among African American women, they are intricately woven into structural constructs that contribute to HIV infection. Even though African Americans have made significant progress in areas such as education and employment, significant disparities continue to exist. Not surprisingly, data from a 2007 Pew Research Center social and demographic trends report indicates that African Americans hold a glum view of the future. When asked the question: "Thinking about the future, all in all would you say that life for Blacks in this country will be better, about the same, or worse than it is now?", only 44 percent of African American respondents replied that they would be better off, and about one in five indicated that they would be worse off (21 percent).[29]

Over 24 percent of Blacks lived in poverty in 2003, compared with eight percent of Whites. Furthermore, 22 percent of U.S. families living in poverty were Blacks, compared to ten percent of all families, 21 percent of Latino families, and eight percent of White families.[30] A study conducted in North Carolina in 2006 to assess HIV transmission among heterosexual African Americans found that poverty could be a determining factor for HIV risk even if one does not engage in high-risk behaviors.[31] In 2002, single women were heads of 43 percent of Black households, and one study found that children living in households headed by single women were five times more likely to be living in poverty than children living in two-parent households.[32] Some psychologists say that this has a long-term effect on young African American women, who may have grown up without ever having a significant relationship with a male, and as they begin dating, may be prone to devalue themselves in relationships they develop.[33]

In 2005, six percent of the labor force was unemployed. The unemployment rate for African Americans not completing high school was 24 percent, compared to 11 percent for those who had completed high school and four percent

Poverty, lack of education and lack of employment resulting from racial and gender based discrimination often place African American women in a position in which they are forced to make choices that negatively impact their health in order to support themselves and their families

for those with a bachelor's degree or higher. Studies have shown that adults with high levels of education on average earned higher salaries and were less likely to be unemployed.[34] In 2006, 17 percent of Blacks adults in the U.S. (25 years and older) had earned a college degree, compared to 30 percent of Whites.[35] Poverty, lack of education and lack of employment resulting from racial and gender based discrimination often place African American women in a position in which they are forced to make choices that negatively impact their health in order to support themselves and their families (e.g. engaging in transactional/survival sex for money, food, shelter, and drugs and alcohol to support substance use).

INCARCERATION

According to Bureau of Justice statistics, by the end 2005 there were 2.2 million adults under the jurisdiction of Federal or State adult correctional facilities in the United States.[36] Sixty-three percent of prisoners are Blacks or Hispanic, although these groups constitute only 25 percent of the U.S. population. By the end of 2004, 1.9 percent of state prison inmates and 1.1percent of Federal prison inmates were known to be HIV positive. Overall, women accounted for 2.4 percent and men for 1.7 percent of inmates known to be HIV positive. The rate of confirmed AIDS cases is three times higher among prison inmates than in the general U.S. population.[37] The lack of condoms in prisons inevitably leads to unprotected sex in correctional facilities. With HIV testing not a routine part of the discharge plan of inmates exiting correctional facilities, many inmates reenter society unsure of their HIV status, and frequently engage in behaviors that put their partners at risk. The disproportionate incarceration rates among African American men has led to a reduction in the ratio of men available to African American women, increased the chances of concurrent relationships, disrupted relationships (including familial) and potentially increased chances of male-to-male sex while incarcerated.

In April 2006 the CDC released findings from their epidemiologic investigations into the risk behaviors and modes of transmission among inmates within the Georgia Department of Corrections in a Morbidity and Mortality Weekly Report (MMWR). The report found that between July 1988 and Feburary 2005, 88 male inmates known to be HIV negative when entering the correctional system, subsequently tested positive. Sixty-seven percent of these inmates were Blacks. Having unprotected sex with other men, tattooing, being 26 years and older, having served more than five years, and being Black were the primary factors placing this group of inmates at the greatest risk of contracting HIV.[38]

TRAUMA: THE IMPACT OF SEXUAL, PHYSICAL, AND SEXUAL ABUSE

Childhood physical trauma, as well as sexual abuse and intimate partner violence in adulthood, are related to increased risk for HIV infection among women.

Approximately 4.8 million women are raped and physically assaulted by an intimate partner annually in the United States.

Approximately 4.8 million women are raped and physically assaulted by an intimate partner annually in the U.S. Furthermore, one in three women in the U.S. report sexual abuse before the age of 18.[39] Childhood sexual abuse is considered one of the factors that increase the risk of HIV infection. Sexual risk taking for the most part is connected to early sexual debut and little to no or inconsistent use of condoms.[40]

Physical and sexual trauma is linked to risk taking behavior that not only increases the risk of HIV infection and transmission, but also can explain reduced medical adherence.[41] Even though more research needs to be done in the area of sexual abuse and HIV, some studies have found that HIV-positive African American women with histories of trauma met the criteria for AIDS more frequently than other women who were HIV positive

without histories of trauma.[42] Victimization history, drug use, and depression can converge to form a "web of risk" that increases HIV risk for African American women, such that women with all three factors reported a greater number of risky sexual behaviors (e.g. unprotected sex, sex trading, multiple sexual partners, and having a partner who uses intravenous drugs).[43]

ACCESSING QUALITY CARE AND TREATMENT SERVICES

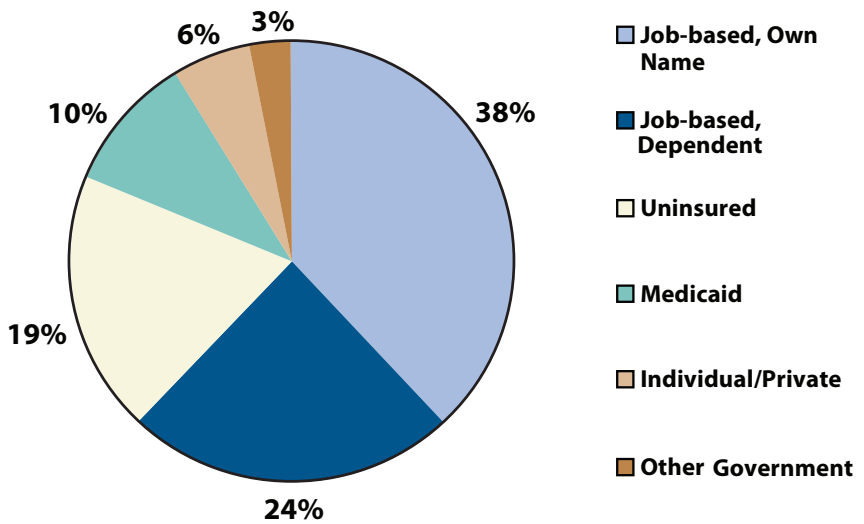
Adults with HIV in the U.S. are one fifth more likely to lack health insurance than the general population, but three times as likely to be insured by Medicaid and nine times as likely to have Medicare coverage.[44] Health care coverage in the U.S. general population affects coverage for those infected with HIV and is a chief factor in access to care. The effects of health care coverage are especially important to HIV patients' access to needed HIV care and treatment health services including primary care and prescription drug benefits. In 2005, 19 percent of all women in the U.S. were uninsured, ten percent were covered by Medicaid, and 72 percent were covered through private insurance, employer-based insurance and other public health care programs.[45]

Women represent almost half of adult HIV patients. Sources of coverage for women with HIV come from several private and public sector programs including Medicaid, individually purchased private insurance, employer-sponsored insurance and other government programs including the Ryan White Program. Coverage for women compared to men across the private and public sector varies. According to a study on care of HIV-infected adults in the US, women living with HIV were as likely as HIV positive men to be uninsured, less likely to be privately insured, and more likely to be covered by Medicaid (61percent women, 39percent men) due to qualifying factors of pregnancy and parent of a dependent child.[46] Regionally, in both the Midwest and West, HIV patients were nearly twice as likely as others to have private insurance. Furthermore, there were only two uninsured patients for every 10 patients covered by Medicaid in the Northeast and 11 for every 10 in the South.[47]

Medicaid is the largest source of public funding for HIV related health care and the chief source of coverage for people with HIV/AIDS. Since the majority of those covered by Medicaid are women, it becomes an even more critical source of health care coverage for women with HIV. Medicaid coverage examined by race and sex also shows that Black and Latino women were more likely to be covered by Medicaid than White women.[48] Employer-sponsored insurance covers to approximately 62 percent of women through their own or spouse's employer. This type of coverage is disconcerting because many women covered by employers are covered as dependents through a spouse's coverage plan and circumstances of divorce, death, or a spouse losing coverage make women susceptible to losing coverage.[49]

The Ryan White Program is the single largest federal program specifically for people with HIV/AIDS. It was designed to fill gaps

Table 3: Kaiser Family Foundation, Women's Health Insurance Coverage, 2005



where other health care coverage was absent and is the payer of last resort for care and support services to individuals infected with HIV and their families. Most who utilize the Ryan White services are people of color, male, and uninsured or publicly insured. However, the Ryan White Program includes designated funding for women and children living with HIV and their families. Part D program funding includes primary and specialty medical care and psychosocial services for women and their families as well as children and youth.[50] While having health care coverage available is necessary for access, African American women living with HIV can face further barriers to HIV treatment.

BARRIERS TO CARE AND TREATMENT SERVICES

When assessing access to care for African American women, looking across race and ethnicity as a whole demonstrates that African American's continue to fare more poorly than others on several health care access and quality of care measures[51]. Several factors limit access to care, either by causing women to postpone care, preventing them from receiving quality care, or inhibiting access to care and treatment altogether. These factors include barriers to care, service gaps and health disparities.[52]

Barriers limit access to health care and therefore often overlap with service gaps and disparities that clients may be experiencing. African American women face barriers that can be classified into three: primary, secondary and tertiary barriers:

- Primary barriers are direct obstacles to health care. These include:
  - » Health insurance barriers such as lack of insurance or incomplete coverage;
  - » Dissatisfaction with service providers and health care plans;
  - » Financial restrictions including high health care costs for out of pocket expenses and medications;
  - » Transportation to and proximity of service providers, and;
  - » Child care, housing and other family responsibilities. Most women with HIV/AIDS receiving medical care have children under age 18 in their homes. This may complicate their ability to manage their own illness.[53]

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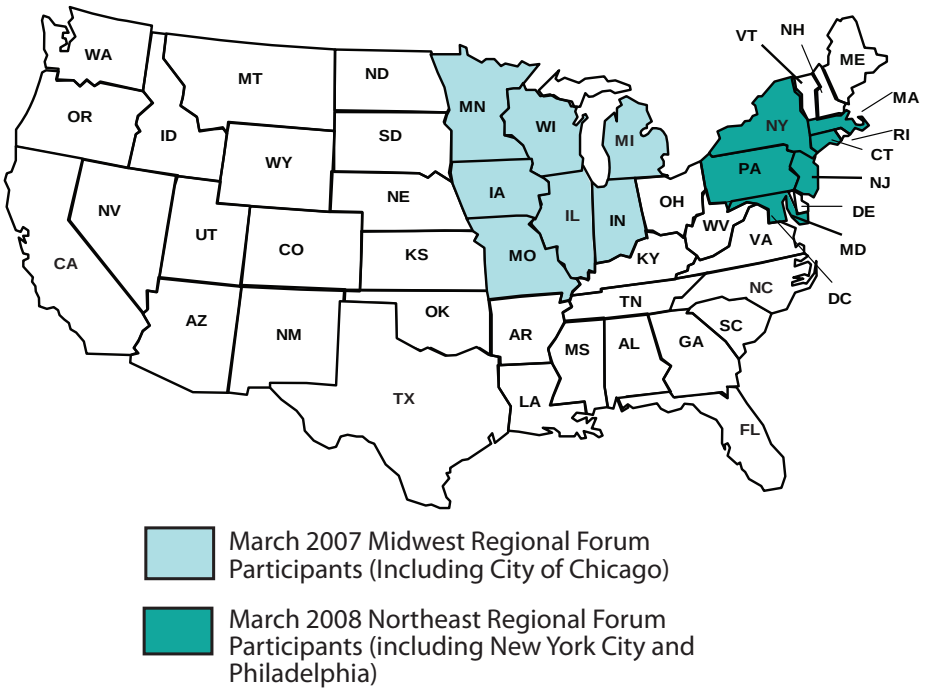
- Secondary barriers are structural barriers internal to an organization or service provider. These include:
  - » Limitations on public programs with eligibility restrictions and/or lack of comprehensive coverage;
  - » Lack of information on available services;
  - » Inconvenient hours of operation;
  - » Difficulty getting appointments, and;
  - » Lack of coordination between primary and specialty providers/ referrals.

- Tertiary barriers reflect the ability of providers and the health care system to address the health care needs of women. These include:
  - » Low cultural competency – limited cultural sensitivity of staff towards female clients, lack of culturally appropriate services such as language and religious differences, and acceptability at male oriented agencies;[54]
  - » Socio-cultural understanding of African American female needs across orientation (heterosexual, lesbian, transgender); and
  - » Clinician lack of knowledge and skills to deal with underlying issues affecting African American women with HIV such as stigma, domestic violence, substance abuse, and mental health.

Determining and strengthening provider capacity, as well as capability is a key step in improving access and retention in care for African American women.[55] Providers should assess the availability, accessibility, and appropriateness of their services when evaluating delivery of services to their female clients. This includes assessing which services they offer, the extent to which

Table 4: NASTAD Regional Forum Series to Address HIV Among African American Women



HIV-positive women in need of care have access to the services and the extent to which available services are appropriate for this population.

NASTAD'S RESPONSE

In March 2007, NASTAD conducted a regional forum to address HIV among African American women. The forum, entitled, *African American Women and HIV/AIDS: Confronting the Crisis and Planning for Action*, was held in Chicago with eight Midwestern jurisdictions and was part of NASTAD's ongoing Regional Forum Series to Address Racial and Ethnic Health Disparities. The purpose of the regional forum was to: (1) provide a platform for participants to share strategies and lessons-learned around the implementation of effective HIV/AIDS programs targeting African American women, (2) engage participants in dialogue about the socio-economic and psychosocial factors impacting African American women, and (3) support teams in the development and implementation of a one-year action plan to address African American women in their jurisdiction. Each participating jurisdiction brought a team to the meeting ranging in size from five to ten members. Teams were comprised of the jurisdiction's AIDS Director or senior designee, staff from health department funded CBOs providing services for African American women, clients/consumer of services provided by the participating CBO, and CPG members. Based on the success of the March 2007 regional forum, NASTAD replicated the meeting with eight Northeastern jurisdictions in March 2008, and plans to continue implementing regional forums to address HIV among African American women. NASTAD will utilize the information gleaned from both the March 2007 and 2008 regional forums, in addition to data gathered from African American women's focus groups conducted with identified jurisdictions that have participated in the regional forum series, to help identify barriers, facilitators and strategies to providing effective prevention and care and treatment services to stem the severe impact of HIV on African American omen.

CONCLUSION

NASTAD is working in collaboration with CDC, state and local health departments, and other stakeholders, including CBOs and women infected and affected by HIV/AIDS, to address this issue at the national level. NASTAD's Regional Forum series has included the issues in this issue brief as a springboard for conversations surrounding holistic approaches to addressing the prevention and care and treatment needs of African American women. This issue brief is the first in a three-part series to examine the impact of HIV/AIDS on African American women in the United States. The next issue brief in this series will provide an overview of the data obtained from NASTAD's African American women's focus group series and profile activities of Northeast and Midwestern health departments to address this population.

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ACKNOWLEDGEMENTS

This publication was supported by Cooperative Agreement Number 5U62PS323958-05 from the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the author and do not necessarily represent the official views of the Centers for Disease Control and Prevention.

NASTAD staff: Kellye McKenzie, Senior Manager, Racial and Ethnic Health Disparities; Joy Mbajah, Manager, Prevention; Angela Seegars, Manager, Care and Treatment; and Celeste Davis, Senior Associate, Prevention were responsible for the overall development of this document. NASTAD thanks members of its African American Advisory Committee for their guidance and review of the document prior to publication.

444 North Capitol Street, NW • Suite 339
Washington, DC 20001-1512
www.NASTAD.org
Phone: 202-434-8090 • Fax: 202-434-8092