



# NASTAD™

NATIONAL ALLIANCE OF STATE  
& TERRITORIAL AIDS DIRECTORS

## BLACK WOMEN

### Issue Brief No.2

March 2010

# Black\* Women and HIV/AIDS: Findings from Southeast Regional Consumer and Provider Focus Group Interviews

## INTRODUCTION

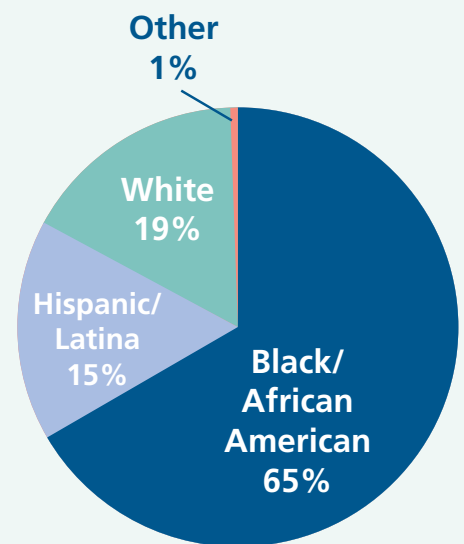
In 2008 the U.S. Centers for Disease Control and Prevention (CDC) reported that women accounted for 26 percent of annual HIV/AIDS diagnosis.<sup>1</sup> Black women represent a disproportionate number – 65 percent – of the total number of women currently living with HIV/AIDS<sup>2</sup> (Figure 1).<sup>3</sup> Additionally, one in 30 black women is estimated to be diagnosed with HIV in their lifetime.<sup>4</sup> When NASTAD published *African American Women Issue Brief No. 1* in May 2008, “African American women were 20 times more likely to acquire HIV than white women” and “HIV was the third leading cause of death for African American women between 25 and 34 years of age.”<sup>5</sup>

In response to this alarming data, in 2007 the National Alliance of State and Territorial AIDS Directors (NASTAD) developed an initiative focusing on health department capacity and programming to deliver effective and culturally appropriate HIV prevention activi-

ties for black women. NASTAD invited over 24 city and state health departments to participate in regional forums, alongside community partners and consumers of HIV/AIDS services, to strengthen partnerships and collaborate more effectively to implement prevention, care and treatment programs specifically targeting this population. Intensive technical assistance was offered to all city and state teams following the forums, resulting in increased engagement and activities specifically focused on and targeting black women in over 18 jurisdictions.

Despite a redoubling of efforts, there is still a need to do more to prevent the spread of HIV/AIDS among black women in the U.S. Regionally, the Northeast and the South bear the disproportionate burden of new AIDS cases among black women.<sup>1</sup> “Six of the ten states with the highest case rates among women are in the South, with the District of Columbia topping the list at 100.0 per 100,000, or 12 times the national rate for women.”<sup>6</sup>

Figure 1: Estimated Numbers of Women Living with HIV/AIDS at the end of 2007, by race/ethnicity-34 states with confidential name-based HIV infection reporting<sup>10</sup>



\*Other includes Asian/Pacific Islander, Native American/Alaskan Native women.

In consideration of the significant incidence and prevalence of HIV among black women, *African American Women Issue Brief No. 1* highlights research, resources and interventions focused on the indicators of risk that increase the vulnerability for HIV infection among black women. NASTAD has since sought to document the efforts and activities directed toward black women in the Midwest, Northeast and Southeast. To facilitate this effort, jurisdictional-level focus groups were conducted to obtain

\* Please note: The use of the term “black” is utilized by NASTAD in an effort to comprehensively recognize the historical and contextual impact of HIV/AIDS on African Americans, as well as all people of African descent, including those born in Africa and the Caribbean.

qualitative data on HIV facilitators, as well as program successes, challenges and suggestions for health departments to assist in the development of women-focused HIV activities. Jurisdictions were identified based on their participation in NASTAD's black women's regional forum series. These focus groups provided rich details regarding state- and community-level responses to the HIV crisis among black women.

This issue brief provides the preliminary data analysis from the Southeast regional focus groups. Particular attention is given to the voice of people living with and affected by HIV/AIDS to provide a clear and fresh perspective on issues and suggestions for health departments to consider when designing, targeting and implementing culturally relevant programs or interventions for black women in their jurisdictions. Other stakeholders may also find this document useful, particularly capacity building assistance providers and HIV/AIDS, substance use and mental health service providers.

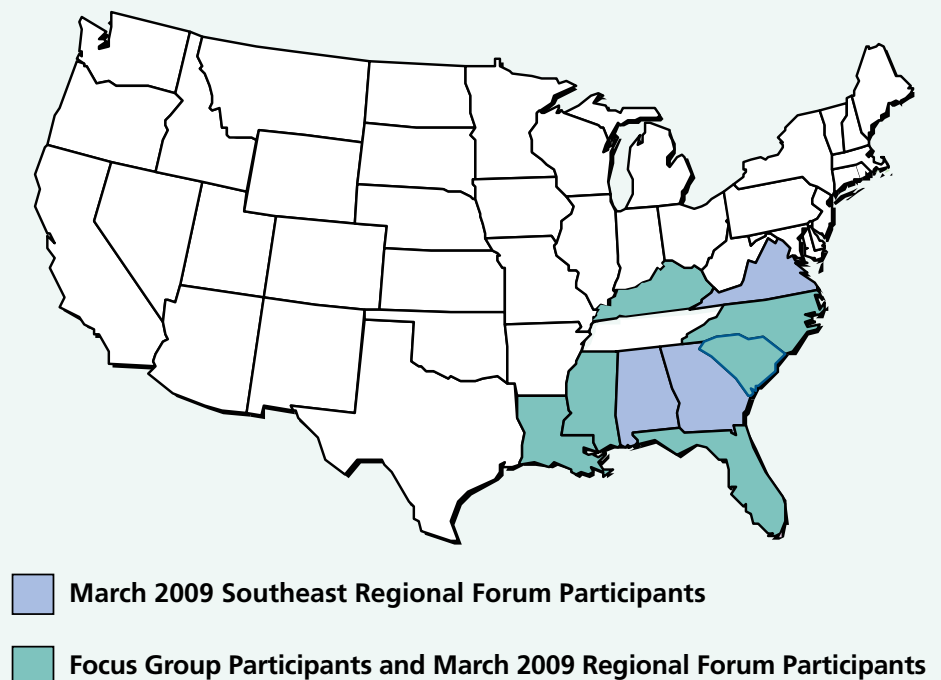
## METHODOLOGY

Semi-structured focus group interviews were conducted between April and August 2009. Participants included stakeholders in six states located in the Southeast region of the United States, including Florida, Kentucky, Louisiana, Mississippi, North Carolina and South Carolina. Participating states were selected based on their participation in NASTAD's 2009 Black Women's Southeast Regional Forum. Each state hosted a minimum of three separate focus groups comprised of health department staff, community service providers or consumers of services. Groups ranged in size from three to 18 participants. State health

## TABLE OF CONTENTS

INTRODUCTION .....	1
METHODOLOGY .....	2
MAJOR THEMES AND FINDINGS: UNDERSTANDING THE COMPLEXITY OF BLACK WOMEN'S LIVES .....	3
MAJOR THEMES AND FINDINGS: CONSIDERATIONS AND STRATEGIES FROM CONSUMERS AND PROVIDERS .....	6
CONCLUSION .....	10
ENDNOTES.....	10
IN THEIR WORDS .....	11
ACKNOWLEDGEMENTS.....	12

Figure 2



departments were charged with recruiting participants and coordinating the groups. Individual health department staff were eligible to participate regardless of their role within the health department. Community service providers represented service organizations providing HIV prevention and care and treatment services specifically targeting black women. Participants who were consumers of services were black women who were currently or previously involved with

a program or intervention provided by a community based organization or service provider.

Interviews covered a variety of topics. Broad questions were used to facilitate and guide discussions. Questions asked included: "How would you describe the HIV epidemic among black women in your state?"; "How would you describe the specific issues and problems that put black women in your area at risk?" and "How would you describe access

to prevention services for black women at risk for HIV?” Probing questions were used to explore issues and salient points mentioned by participants. All focus group facilitators shared similar backgrounds, race and/or gender as participants.

All interview recordings were transcribed and personal identifiers were removed from transcripts to ensure the anonymity of participants. A multi-step process was employed in analyzing the focus group transcripts. The process was guided by the principle of Grounded Theory<sup>7</sup> and included the following steps: (a) transcript review and note-taking, (b) creation and refinement of a codebook used to organize the qualitative data and capture themes, (c) systematic coding of the transcripts by four coders, (d) discussion of coding disagreements and finalization of the codebook and code definitions and (e) use of the qualitative data analysis program NVivo 8 to organize the data and assist in the identification of themes. In total, over 250 codes were defined and used to document and organize the qualitative data. These codes were classified into three overarching categories: 1) Health Department, 2) Providers and 3) Consumers.

Several themes were identified and the frequently recurring themes are described below. It should be noted that themes were examined across states to better understand the key findings. For the sake of brevity, findings specific to the Southeast region are examined in this issue brief, with particular emphasis given to consumer and provider responses. Given that participants shared a great deal, the data analysis revealed multiple topic areas and themes. It is impossible to highlight all of the

topic areas and themes that participants shared in one document and give adequate emphasis to each theme. Therefore, it is necessary to limit the scope of this issue brief to the most recurring themes across the Southeast jurisdictions.

## MAJOR THEMES AND FINDINGS: UNDERSTANDING THE COMPLEXITY OF BLACK WOMEN'S LIVES

As part of the focus group discussion, participants provided a comprehensive perspective on some of the shared issues and challenges that increase black women's vulnerability for HIV/AIDS infection in the Southeast. The following section provides a brief synopsis of the unique and nuanced experiences of these women who are both infected and affected by HIV/AIDS. The picture that is painted provides the necessary context for more meaningful conversations about targeted programs and activities for this population.

### History, Culture, Faith and the Black Family

*“...responsibility for the community's children, combined with a broad kinship and caretaking culture brought from Africa, was experienced as an inevitable way of life in the South for decades after slavery.”<sup>8</sup>*

Collective responsibility for the community is a by-product of the African experience. This tradition was reinforced by the confines of slavery and remains a core element of modern black families.<sup>8</sup> The findings from the focus group data supports this assertion, particularly for rural communities and the critical role that black women play as care-givers [past and present]. Older generations are still relied on

to provide trusted guidance and care across topic areas, including health and well-being. Intergenerational communication is common within the black community and serves as a mechanism to preserve historic and cultural norms. Focus group participants spoke about the responsibility of the extended family to educate and protect the next generation from HIV infection. An HIV-positive woman from South Carolina stated, “I know my family is very tight knit, like they'd rather talk to each other and give bad information and wrong information to each other.” A participant from Kentucky added:

*The foundation would be having a family unit, having stories that were told, passed from generation to generation, that instills more values. Role models within our own community instead of from television. That's been chopped up, and when you don't have those things in place, and the rules have changed over the years, then we as educators have to start to make a foundation so that they can see some hope.*

**The foundation would be having a family unit, having stories that were told, passed from generation to generation, that instills more values. Role models within our own community instead of from television. That's been chopped up, and when you don't have those things in place, and the rules have changed over the years, then we as educators have to start to make a foundation so that they can see some hope.**

Historically, black churches have also played a pivotal role in developing and maintaining community and social infrastructure for the black community, particularly in the South. According to participants, the black church remains a core foundation for most black communities and its influence is pervasive. As such, participants felt that the church bears some responsibility for promoting, accepting and dispelling misinformation about HIV/AIDS. A participant from Mississippi added, “We’re in the South, Southern Baptist, whatever, Bible Belt. If it’s not coming across the pulpit it’s not happening.”

### Sexuality and Sexual Communication

The providers interviewed felt strongly that the implications of history and culture have a direct correlation to the high incidence of HIV among black women. Numerous participants highlighted that from an early age, black girls do not receive communication about their bodies, sex or love. Providers mentioned that the result is a heightened insecurity about their bodies, leading to diminished communication with sexual partners. Sex is either not talked about at all, or as one participant from Kentucky stated, young black girls are taught that “sex is bad, just don’t do it.” Moreover, the portrayal of black women in the media influences their perceptions of sexuality and sexual identity. A provider from North Carolina stated:

*Our culture is constantly changing and the fact that the culture now is misogyny, women are being exploited, looked upon in a lot of the music, a lot of the videos, a lot of the images. African American women are just looked upon as sex toys and that has placed – some*

*women feel like, “I have to do what I have to do to keep my man. If he don’t wanna wear a condom I don’t have to put on a condom if he doesn’t want one.*

This sexual uncertainty is exacerbated by the belief that young black women are being sexualized and sexually active at younger ages than previous generations, and that they lack the emotional and mental maturity to communicate with partners or future generations of black women. This assertion is supported by Paxton and Robinson (2008) who state, “African American adolescents report earlier ages of sexual debut than their non-African American counterparts.”<sup>9</sup>

Consumers generally agreed with this assessment and added that this lack of sexual communication and immaturity prevented effective relationship communication, particularly around condom negotiation.

Consumers discussed how relationship models and love witnessed within the black family and broader social community affected how they defined love. A consumer from Florida articulated:

*I saw my parents fight, like knives and guns fight, not arguing fighting, but fighting, really fighting. You know, so when I grew up that’s all I knew, you know? If a man hits me, he loves me, you know?*

***I saw my parents fight, like knives and guns fight, not arguing fighting, but fighting, really fighting. You know, so when I grew up that’s all I knew, you know? If a man hits me, he loves me, you know?***

Women are left emotionally and sexually unsatisfied and willing to put themselves at risk for HIV/AIDS for the pursuit of a loving and fulfilling relationship, particularly a relationship with a black male partner. Both provider and consumer participants articulated that many black women do not know what a loving and fulfilling relationship looks like; therefore, they may not know how to seek, acquire or maintain it without putting themselves at risk for violence, abuse, unwanted pregnancy or HIV/STD acquisition.

### Impact of Abuse and Violence

The historical lack of communication and the acceptance of the abuse of black women are identified as contributing to the low self-esteem of black women which makes them vulnerable to HIV infection. For example, a provider from Mississippi stated:

*My grandmother married this man, and his friends and them sexually abused my aunt, my grandmother’s sister... Now, to this day we don’t talk about it, it didn’t happen, it never happened... So I mean that was a reality. We don’t talk about it to this day, nobody says anything about it, but my aunt is still hurt about it...*

Other participants spoke about the mental, physical and sexual abuse that occurs within families, communities and intimate relationships. Providers explained that many of the black women they provide services to in their agencies have experienced some form of abuse in their childhood. The cycle of abuse continues into adulthood and presents itself in relationships, which leads to distrust and further abuse. Abuse becomes the norm, the expectation

and often inhibits a woman's ability to negotiate for safer sex practices. Black women who experience violence are more likely to experience sexual coercion which can lead to HIV and other STDs.<sup>10</sup>

## Stigma and Disclosure

The consumer participants discussed the historical impact of stigma on black women's experiences with HIV/AIDS. As HIV positive women, many have first-hand accounts of how stigma delays getting tested and disclosure of one's status. One consumer mentioned that after disclosing her status her family accepted her but insisted that she keep her dishes separate from the rest of the family, so as to not pass on the disease. Providers also discussed stigma in the context of service providers not being comfortable engaging HIV-positive clients. This was raised as a particularly difficult issue for the rural South where the number of service providers is limited and results in many of them knowing their patients or clients personally. Many consumers noted insensitivity on the part of providers and fear of status being disclosed prevents many black women from seeking services, including obtaining free condoms and informational pamphlets. Further, participants expressed that if women do access services, it is often in another town or county to prevent being recognized. A participant from South Carolina noted:

*I find that a lot of times women are dealing with a lot of the stigma that's around HIV and not accessing healthcare. One of the things is I feel like Charleston is so much smaller, and so you have relatives that work in hospitals in healthcare and cousins and booboos and them, and so they're*

*just not going, and then some of the problems that I've dealt with, with women that are HIV positive too is still being involved in relationships and not disclosing their status to their partner.*

*I find that a lot of times women are dealing with a lot of the stigma that's around HIV and not accessing healthcare. One of the things is I feel like Charleston is so much smaller, and so you have relatives that work in hospitals in healthcare and cousins and booboos and them, and so they're just not going, and then some of the problems that I've dealt with, with women that are HIV positive too is still being involved in relationships and not disclosing their status to their partner.*

## Dependency

High risk heterosexual contact is the primary mode of HIV transmission for black women.<sup>3</sup> According to focus group participants, the black female/male relationship dynamic perpetuated by the larger community facilitates the HIV epidemic among black women. Women are taught to seek men for financial and emotional support and social status regardless of their own personal, professional or economic success. Both provider and consumer participants explained that many black women are dependent on men to pay bills, provide housing, food and transportation, particularly in rural communities. It is believed that less-educated black women are most

likely to be dependent on men because they are unable to access the resources themselves. One Florida provider described:

*He can go out, do whatever he wants to do and I'm okay with it as long as he buys the food. He works. He pays the rent. He buys the kids' clothes, whatever he does. Matter of fact, I'm gonna press his clothes to make sure he looks good when he goes out. Just come home and bring the money home and I'm okay with it and I ask no questions. So I ask no questions of my man.*

Black women's ultimate concern and goal is to provide for their families "at any cost," even at the expense of their own health and well-being. Even if these needs are provided without the assistance of men, consumers spoke about feeling incomplete and "less than" without a man in their lives. As a result, participants felt that black women overall are more tolerant of men having multiple partners and less likely to negotiate condom use or safe sex behaviors for fear that the man will leave them destitute.

## Perceived Risk

In addition to the risk-taking behavior that can result from an imbalanced female/male relationship, participants felt that black women still do not perceive themselves to be at risk for HIV/AIDS. The overall perception is that they still believe HIV is a gay, white man's disease. As a participant from Louisiana discussed, "I think a lot of us we had got into trouble because we were saying, 'I'm not a white gay man, so it doesn't image me'. So we looked at it as a label and not as a behavior." Additionally, if a woman is not exchanging sex for money, drugs or

injecting drugs herself, she is not considered part of the risk population by either black women or the larger HIV/AIDS service community. The providers acknowledged that they do not aggressively target women who do not fit the narrowly defined high-risk criteria due to grant restrictions and limited dedicated funds and resources. A provider from South Carolina stated:

*...when you talk about criteria, when you start to talk about high-risk, like when [participant's name] was saying, professional women, and then the money says we must test high-risk women or we think they don't fall into what is actually a snapshot of what our epidemic really is, so we're getting a false sense of what we're supposed to be fighting.*

*...when you talk about criteria, when you start to talk about high-risk, like when [participants name] was saying, professional women, and then the money says we must test high-risk women or we think they don't fall into what is actually a snapshot of what our epidemic really is, so we're getting a false sense of what we're supposed to be fighting.*

The participants agreed that this leads to a false sense of security among black women. Women who have been in monogamous relationships for several years do not believe or do not want to believe that their partners could be engaging in sex with other women or men and therefore do not take measures to protect themselves from HIV/AIDS

and other STDs. Women in monogamous relationships, married women, professionals and older women are less likely to consider themselves at risk for HIV because their image is not projected in materials that are distributed.

### Substance Use and Mental Health

The focus group data underscores that substance use and undiagnosed, untreated mental health issues are primary factors driving the HIV/AIDS epidemic among black women. Substance use includes the use of: injection drugs, alcohol, prescription drugs, non-injection cocaine (crack) and heroin. The influence of these substances can lead to high risk behavior, such as the prostitution of themselves or a child and sex without a condom. Participants also felt that the path to drugs was usually initiated by mental health issues and used as a coping tool. Additionally, the influence of substances makes HIV prevention and care efforts extremely difficult, as articulated by a Florida consumer:

*HIV testing, blah, blah, blah, tell you this and that. But at that point in time, you on drugs, you ain't trying to hear that. That ain't something you want to hear. All you waiting for is y'all giving us a \$10.00 gift certificate. You can sell that for \$5.00. Sell that for \$5.00 to the dope man or whatever, get us a hit, and it's okay. That's the only reason why we taking the test.*

Another consumer from Louisiana added:

*There has to be a mental issue for them to allow yourself and subject*

*yourself to the violence and the abuse, and what you said earlier about seeing clients that have been physically abused, I think it's a mental issue and the issue is their inability to decipher between making conscious decisions, not putting themselves in jeopardy of contracting HIV or exposing someone to the virus once they've already converted to positive.*

Issues related to HIV/AIDS prevention or care and treatment are not likely to be adequately addressed until mental health and substance use issues are resolved. According to a consumer in Kentucky, "when I got past all that and, and got it resolved, that's when I went for help for my HIV."

### MAJOR THEMES AND FINDINGS: CONSIDERATIONS AND STRATEGIES FROM CONSUMERS AND PROVIDERS

The following suggestions were gleaned from consumers and providers and serve as ideas for health departments on how to respond to black women who are living with and affected by HIV/AIDS. In some cases, examples of existing health department initiatives and insights are presented, which can be useful in adapting current efforts or creating new ones. It is our goal to encourage health departments and community service providers to respond to the needs of black women with strategies that are specific to them.

### Holistic and Varied Support Groups

Participants underscored the need for more readily available and accessible support groups to reflect the different life stages of black

---

*I was diagnosed two years ago and the people that were there was either just starting to go through that, what I already went through. I didn't have no support... I didn't have no one to talk to, but the things they went through, they was going through was being depressed. I have my days, but what they were going through, I already went through that, and for instance, side effects of medicine.*

---

women – particularly groups that address a range of topics relevant to the “entire person” (e.g., relationships, children, work, family and spirituality). Consumers expressed that many women are dealing with multiple issues (e.g., abuse, violence, working poor and unstable housing), and access to a regular support group can increase one’s quality of life and diminish potentially poor health outcomes. Participants suggest that providing information and resources regarding childcare, employment and healthcare, in particular, are paramount. Participation in support groups is dependent on the availability of childcare, transportation and flexible schedules.

HIV-positive consumer participants voiced a need for peer-to-peer support in managing their HIV status and the challenges associated with navigating the healthcare system and everyday life circumstances. Participants expressed that many current support groups made available to women are geared toward women who are newly diagnosed

and coping with the initial shock of an HIV-positive diagnosis. Women who have been successfully living with HIV/AIDS for years do not benefit from participation in these groups and desire groups that provide support for the later stages of life. An HIV-positive woman from South Carolina said:

*I was diagnosed two years ago and the people that were there was either just starting to go through that, what I already went through. I didn't have no support... I didn't have no one to talk to, but the things they went through, they was going through was being depressed. I have my days, but what they were going through, I already went through that, and for instance, side effects of medicine.*

### **Affordable Housing**

Participants identified a vital need for affordable housing for women and families living with HIV/AIDS, particularly as they manage HIV/AIDS medication adherence. Almost all jurisdictions mentioned minimal to no available transitional housing, which left many women homeless or transient with limited options. Some providers described how resources for housing are insufficient compared to the need. Housing programs designed to help people living with HIV/AIDS have terms and conditions that landlords will not usually agree to and the housing market will not support. A Kentucky provider stated, “*The Housing Program can only, you know, say your rent is \$500.00 a month, well, they can only cover \$375.00.*” This was reinforced by another Kentucky participant, “*so they won't include the utilities.*”

HIV-positive mothers have even fewer options for housing because many of the housing programs do not accommodate women and children. Overall, housing policies need to provide for women and their children, offer rent support that reflects the housing market in each community, establish terms and conditions that are in line with what landlords can provide and expand to include more units to accommodate the growing number of homeless and transient populations.

### **Transportation**

Transportation was voiced as a major need for many HIV-positive black women in the Southeast. A provider from South Carolina stated that in rural communities, consumers must “*travel for miles to even get to a medical provider...*” Participants also expressed how the lack of reliable transportation, limited public transportation and infrequent [bus] routes make transportation options scarce and influence a woman’s ability to participate in programs.

### **Prevention Messages, Media and Social Marketing**

Participants identified a need for prevention messages, materials and programs that take into consideration various literacy levels among women. It was recognized by focus group participants that health departments are charged with serving, treating and educating diverse populations. Considering the wide use of written materials to disseminate accurate information, the literacy and educational levels of the communities and individuals being served must be considered.

Participants also noted the need for media and social marketing that

reflects images of black women. Participants often spoke about how there are too few messaging campaigns that indicate that HIV/AIDS should be a concern for black women. Moreover, many of the existing media efforts targeting black women are not presented in ways that resonate with the population. A robust response requires a variety of culturally relevant social marketing efforts that reflect the diverse face of HIV/AIDS as it exists domestically. A participant from Mississippi stressed, *“If I was in charge, there would be more information on the internet, more information on the radio, commercials on television about HIV.”* Another participant from North Carolina added:

*They still had the confidence it can't happen to me. It's not happening to me because I don't live like that. I don't do this. Until they heard people talking or this young lady got up and said, 'I lost both my parents to HIV and AIDS and thankfully neither one of my siblings, we have it.' That kind of thing. So it put a face on the name, somebody we see in services that actually has the virus and I could be another person like that. So it was very empowering.*

### **Comprehensive Sex Education for All Women**

There is a need for comprehensive sexual education for black women and girls of all ages. It was noted by participants that many adult women served by health departments have misconceptions about reproductive health, contraceptive methods and HIV/STD prevention. As previously discussed, participants noted that misconceptions are often passed on to children, adolescents and young adults, further perpetuating generational misinformation and

silence on sexual and reproductive health. Targeted and comprehensive education could create opportunities for women to access prevention services and health care in their communities. A Kentucky participant noted:

*...I work with African-American youth, females... but it just surprises me how little they know or how little they want to know. I don't know if it's not necessarily something that the prevention's not getting out to them, but for some reason it's not being retained or absorbed.*

Even with these educational barriers and challenges, consumers identified that it is imperative to educate black women in order to challenge their perceptions regarding their sexual health and to provide sustainable prevention efforts in these communities. By addressing the educational needs, constructing messages that translate accurately for a variety of populations and providing comprehensive sex education, health departments can create avenues to address the sexual and reproductive health of young women.

### **Clinician Education and Sensitivity**

Several consumers across jurisdictions noted that there is a need for provider education around sensitivity and cultural competency. Many patients have trouble discussing issues related to their sexual and reproductive health, and may assume that if the doctor does not bring it up, then it is not important. Participants also noted that many healthcare providers are not trained to ask vital questions that can help determine the patient's HIV risk.

Other participants noted that posi-

*I work with African-American youth, females... but it just surprises me how little they know or how little they want to know. I don't know if it's not necessarily something that the prevention's not getting out to them, but for some reason it's not being retained or absorbed.*

tive experiences with their healthcare providers can produce sustained health-seeking behavior. A participant shared that the presence of accurate information immediately following her HIV-positive diagnosis made a difference in her long-term health. The information led this participant to make her routine medication adherence a priority.

Other participants noted that some health care providers make a quick assessment of their patients' risk based on the general characteristics of a patient's gender, age, sexual orientation, marital status or history of reported substance use, which can minimize the perceived need to test a person for HIV. A provider in Kentucky supported this assertion by stating, *“it takes about nine trips to the Emergency Room before they even diagnose that, 'Let's check HIV.' And on the second or third trip we should have been checking.”*

### **Interventions (including “Home-grown” Interventions) Specific to Black Women**

Participants suggested a variety of approaches, modalities and interventions that create opportunities to reach black women in the South. Specifically, participants spoke about the need to provide both group-level

and individual-level interventions in the community that cut across the various aspects of a woman's identity. As one Florida participant noted:

*The black women initiative with SOS, Sistas Organizing to Survive...that itself means that you have to empower me and...because of the pledge...it empowers me to empower my other sisters to talk about this disease and to go get tested. And I had never thought about this before, but... I pledge that I would talk about this disease where I live, where I play, where I work and where I worship. I never broke it down like that before because at each place I know different people.*

**The black women initiative with SOS, Sistas Organizing to Survive...that itself means that you have to empower me and...because of the pledge...it empowers me to empower my other sisters to talk about this disease and to go get tested. And I had never thought about this before, but... I pledge that I would talk about this disease where I live, where I play, where I work and where I worship. I never broke it down like that before because at each place I know different people.**

As the participant points out, approaches such as Florida's Sistas Organizing to Survive (SOS) draws on black women's common role of being gatekeepers, nurturers and

spiritual leaders in their community. It also engages the existing social networks of black women to provide accurate HIV prevention information. Further, participants spoke of models that allow flexibility in the approach and consider the time of the day or week that interventions are offered.

### Advocacy

Participants spoke of the need to advocate on behalf of black women at the local, state and national levels. Participants reflected on their own "wins" in terms of their own local advocacy efforts (e.g., the fight to allow people on their AIDS Drug Assistance Program (ADAP)). These policy triumphs reinvigorate community advocates to continue the battle toward health equity. This point was reinforced by a participant from Florida who stated:

*...becoming advocates, getting out and using that power that they have. Because until we get people in office that understand our views, nothing is ever going to change.*

### Community Collaborations and Partnerships (including Faith)

Participants discussed the need for collaborations with traditional and non-traditional community partners to facilitate awareness and support to meet the needs of black women. A Florida participant noted:

*We do have certain partnerships that we work to really address our medical providers. But really, public health and medicine are interconnected that you really can't have one without the other, almost. So I'd really like to see them come on board more – even our nursing associations to really*

*– you know primary care. Prevention in the primary care setting.*

Participants also discussed strategies for partnering with churches and the broader faith community to reach black women. For example, some constituents in the focus groups represented communities who have had some successes collaborating with faith leaders who were willing to integrate HIV/AIDS education, risk reduction and testing into larger community health events. These partnerships and collaborations are necessary to initiate, and can be very effective, since they allow faith leaders to better respond to the realities and challenges of their parishioners. One provider from Kentucky said:

*Our pastor said, 'Sit those condoms out. I want those condoms gone.' And the condoms in the Christian church, you know, were taken, because he understands if the kids were having sex behind the stairwells you need to have those condoms out.*

### HIV Positive Black Women in Decision-Making

In order to prioritize black women, focus group participants strongly suggested that health departments do more to specifically engage women who are living with HIV to become civically engaged in their local and regional community as both political advocates and community partners. Many consumers provided feedback about their experiences on community planning groups (CPG) where funding and program recommendations are made concerning people living with and affected by HIV/AIDS. Some of these women did not feel represented in this process. They also felt that the outcomes and decisions of these meetings were not always representative of the constituents they

aimed to serve. It was suggested that health departments do a better job of recruitment and education to get a greater response and participation from people who are currently living with HIV. A South Carolina consumer describes her experience:

*Everybody at the table is non-consumers except three people. I don't understand that, but you came up with a whole plan, and I don't see anything in your plan that I see, what I need. Right, and that's what I feel they need to know.*

## CONCLUSION

The findings presented in this issue brief give voice to the needs of black women in the fight against HIV infection and provide suggestions to health departments and community based organizations to better serve

***Our pastor said, 'Sit those condoms out. I want those condoms gone.' And the condoms in the Christian church, you know, were taken, because he understands if the kids were having sex behind the stairwells you need to have those condoms out.***

this population. Both the regional forums and this issue brief provide a springboard for dialogue and action surrounding holistic approaches to addressing the prevention, care and treatment needs of black women in the United States. This issue brief is the second in a series highlighting black women and HIV from differ-

ent regions of the U.S. Additional resources developed by NASTAD that target black women and HIV include a video tool-kit, an upcoming podcast focusing on young black women and a profiles project highlighting targeted activities and interventions in different jurisdictions.

As a means to assist health departments with advocacy, NASTAD and its members developed an advocacy tool-kit. NASTAD is committed to the continuous collaboration between state and local health departments, CBOs, black women affected by the virus and other stakeholders to take an active role against the spread of HIV/AIDS among this population.

## ENDNOTES

- 1 Center for Disease Control and Prevention. (2008). *CDC HIV/AIDS Fact Sheet- HIV/AIDS among Women*. Atlanta, GA: Center for Disease Control and Prevention.
- 2 The Henry J. Kaiser Family Foundation. (2009). *HIV/AIDS Policy Fact Sheet, The HIV/AIDS Epidemic in the United States*. Washington, D.C.: The Henry J. Kaiser Family Foundation.
- 3 Centers for Disease Control and Prevention. (2007). *HIV Statistics and Surveillance. Cases of HIV Infection and AIDS in the United States and Dependent Areas*, Table 10. Atlanta, GA: Centers for Disease Control and Prevention.
- 4 Sutton, M., Jones, R., Wolitski, R., JC, C., Dean, H., & Fenton, K. (2009). *A Review of the Center for Disease Control and Prevention's Response to the HIV/AIDS Crisis Among Blacks in the United States, 1981-2009*. *American Journal of Public Health* , 351-359.
- 5 National Alliance of State and Territorial AIDS Directors . (2008). *African American Women-Issue Brief 1*. Washington, D.C.: National Alliance of State and Territorial AIDS Directors.
- 6 The Henry J. Kaiser Family Foundation. (2007). *HIV/AIDS Policy Fact Sheet, Women and HIV/AIDS in the United States*. Washington, D.C.: The Henry J. Kaiser Family Foundation.
- 7 Strauss, A. and Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage Publications.
- 8 Jimenez, J. (2002). *The History of Grandmothers in African-American Community*. *Social Services Review* , 523-551.
- 9 Paxton, K., & Robinson, W. (2008). *Depressive Symptoms, Gender, and Sexual Risk Behavior Among African-American Adolescents: Implications for Prevention and Intervention*. *Journal of Prevention & Intervention in the Community* , 49-62.
- 10 El-Bassel, Nabila, Caldeira, Nathilee A., Ruglass, Lesia M., and Gilbert, Louisa (2009). *Addressing the Unique Needs of African American Women in HIV Prevention*. *American Journal of Public Health*, 996-1001.

# In Their Words...

**African-American women are not – we're not gonna address our needs in a silo. We never have. We never did. We always address our needs in the context of family, so we need to begin to design interventions in the context of family.**

*And it's like the shorter your skirt and the lower your shirt, and if that man give you some attention, then that's where I get my identity.*

**I FEEL LIKE I'M THE ONLY PERSON IN LEXINGTON HAS HIV. I'M THE ONLY AFRICAN-AMERICAN WOMAN IN LEXINGTON HAS HIV.**

*At least I got to experience love.*

*'Cause that was my always my biggest fear.*

*Would I ever find love with – would somebody ever love me again?*

*I think the self-esteem issues come from – and tolerating stuff is because we were built and made to be strong, strong women, and we can't back down, and we can't do anything, so that ran all the men away.*

***Beat me, cheat on me, do whatever you want, just love me, because the place where you should've gotten it from it did not come. And that's what I think – that's what I see, especially in a lot of these young girls.***

*I think one of the most important things...*

*We're suffering from identity crisis. We don't know who we are, and we are allowing other people to dictate who we are.*

WE HAVE TO NORMALIZE THIS DISEASE TO THE POINT WHERE PEOPLE ARE GETTING TESTED AND PEOPLE ARE TAKING CONTROL OF THEIR DIAGNOSIS AND OF THEIR HEALTH AND BEING MORE PROACTIVE WITH THIS THING.

Like, I could come in a room and I could see this lady working on the computer – I didn't know how to work on computers, so that alone had me feeling inadequate. I didn't feel – you know, even though I looked good on the outside, but there was still things that I couldn't do. I didn't know how to balance a checkbook. I didn't know how to – I didn't know how to do anything. I didn't know – there's still, like, certain things that people are still helping me with today, you know, and that's because I ask for that help.

**Like if you say you had like blood transfusion, the community will embrace you.**

The Bible is good, God is good, I love the Word, I love the Lord. But sometimes you – especially with the teen girls and stuff, you kind of got to get down to the nitty gritty, you know, and talk to them on their level.

*I've got to use a condom. I've got a condom in my back pocket. What is she going to think? The female got the condom in her purse; what is he going to think about me if I pull this condom out?*

**We don't know our bodies to even communicating with our partners because we can't communicate with our self, which leads to the inability, again, to have a voice, to have power...**

It's just like turn on the TV, on the BET or maybe sometimes you see a commercial about wrap it up.

**We all have – we all get to a certain point in life where we got two roads. Some of us take the wrong road. You just have to learn how to back it up and go back the right road.'... some of these women felt that the road they were on, they had no choice...**

## ACKNOWLEDGEMENTS

This publication was supported by Cooperative Agreement Number 5 U62 PS0011782-02 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: Michelle Batchelor, M.A., Senior Manager, Racial and Ethnic Health Disparities (REHD); Joy Mbajah, M.A., Manager, Prevention; Lynn Shaull, M.A., Senior Associate, Prevention and REHD; Sophia A. Nur, M.A., Fellow, REHD; and Niasha A. Brown, M.A., NASTAD consultant, were responsible for the overall development, production and quality control of this document. Jacqueline Coleman, M.A., NASTAD consultant, provided facilitation and guidance throughout the focus group process. NASTAD thanks all of the health department and community stakeholders who participated in the focus group process for their honest and open participation.

March 2010

Heather Hauck, Chair

Julie M. Scofield, Executive Director



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