AIDS IN BLACK AMERICA

Findings from Focus Groups

Chicago, IL
August 2009

"The stigma attached to HIV is just a big fear in itself. No one wants to be, "Oh she got that package." No one wants that. That's too much."
(Female, 18-29)

"There's a lot of people that don't get involved because of the stigma attached to it… the people that do get involved is the people that became affected."
(Male, 30-49)

"My opinion on it – my true opinion on it is Magic Johnson got that HIV thing and then it got blown up, and now he's better and it got blown down. Ain't nobody famous got it no more."
(Male, 30-49)

"At the end of the day, sitting down at dinner with your brothers, your sisters, your family, just talk about it. Talking about it and it will lead – it's the next step, maybe going to get tested. You have to open the conversation up and talk about it at least and then maybe next time, next month, it'll be something else. It's a very uncomfortable situation for a lot of people."
(Female, 18-29)

"[The Greater Than AIDS campaign is] about I, we, us, and together. It's about being greater, but it's better to do something and say something, then not do anything and be quiet."
(Male, 30-49)

To inform the Black AIDS Media Partnership's *Greater Than AIDS* campaign, the Black AIDS Institute and the Kaiser Family Foundation held a series of focus groups in Chicago, IL on August 12 and 13, 2009. Additional focus groups are planned in other locations. Michaels Opinion Research recruited and led the four groups, which consisted of a total of 33 Black adults segmented by gender and age, 18-29 and 30-49. Participants were not screened for any specific association with HIV/AIDS and were not informed in advance about the focus of the research, other than that it would address health issues facing Black Americans.

The objective of the focus groups was to provide insight into how HIV/AIDS is viewed in the Black community. Additionally, public service ads and other outreach elements developed for the *Greater Than AIDS* campaign were shared to help inform future campaign messaging and development.

While the participants represented a random selection from the Chicago area, the views of these individuals are not intended to represent the opinions of all Black Americans. Rather, the focus groups are seen as providing a useful means of hearing first-hand, in their own words, how some in the target population perceive the impact of HIV/AIDS in their lives and community, as well as response to the *Greater Than AIDS* campaign.

"…a lot of people really scared of the results. If you go get tested and you got AIDS, now what? Don't nobody want to hear they got AIDS."
(Male, 18-29)

"From what I see, I've got a cousin that just died from it and I've got a close friend of the family, she's like a sister and she's got it. You know what I'm saying? We don't talk about it, but we know. If the conversation comes up, we would talk about it, but other than that, if you don't say nothing about it, they not going to say nothing about it."
(Female, 30-49)

"Most people it's not an issue for them unless it's facing your loved one and you, or somebody that you know. It usually is not an issue. It's like it don't concern me. I'm not involved."
(Male, 30-49)

"I think sometimes people want to get some education, want to know, just curious… Sometimes people will be scared to initiate stuff like that because, "Why is she asking, she got it?"
(Female, 30-49)

"…it's a mood killer. If you bring up, "Have you got tested?" The first thing I'll be thinking is, "Why you asking me? What you sick?"
(Male, 18-29)

HIV/AIDS AS AN ISSUE FACING BLACK AMERICANS

In all of the focus groups, HIV was named as one of the primary health issues facing Black America, generally among the first few issues named. It is notable that participants had no prior knowledge that the groups would specifically be about the topic of HIV/AIDS, and so were not primed to be thinking about this issue over any other. Other sexually transmitted diseases (STDs) were also top of mind among health issues facing Black Americans, along with some chronic conditions and diseases, namely diabetes, obesity, and forms of cancer. Several participants named lack of access to health services as a concern.

There was strong consensus among participants that risks are high for contracting HIV and other STDs and that the incidence of these diseases is increasing within the Black community. Participants across all age groups identified youth in particular as being at higher risk for contracting HIV and other STDs, which was mainly attributed to irresponsible behaviors (it should be noted these are *perceptions* voiced by the focus group participants and do not necessarily reflect actual contributing factors). The focus on young adults was especially true in sessions with women age 30 and older, many of whom had children of their own. For these individuals it was difficult to refocus the discussion back to personal risk as children and youth were the primary concern. Gay men were also recognized as a higher risk group, and many participants were aware that Black women were being affected. Most participants, however, understood that anyone may be at risk for HIV.

Among all groups misconceptions about HIV/AIDS were evident, in particular regarding treatment. A number of participants mistakenly stated a belief that a cure or vaccine was available (with several women confusing the HPV vaccine as providing protection against HIV and other STDs). Often this was connected with a sense that these treatments were available if one had enough money, referring to the "Magic Johnson treatment." There was also confusion about HIV/AIDS statistics, with some female participants misunderstanding rates among Black women as higher than they are actually reported. For the most part the misinformation was self-corrected within each group, that is, others in the group responded with correct information.

The biggest perceived challenges to addressing HIV/AIDS was stigma, both in terms of talking about HIV/AIDS generally and taking actions such as using protection or getting tested. Concerns about the affordability of treatment were also seen as a barrier. There was a perception that even bringing up topic of HIV/AIDS would raise questions about one's own status. Many described the prospect of

getting tested as "too scary." Participants also discussed in depth the issue of lack of acceptance facing someone if positive.

Importantly, in all focus groups, participants revealed knowing a person with HIV or AIDS and many indicated having family members and friends living with the disease. In several instances, even though the person living with HIV/AIDS was close to them, many participants still made references to stigma within a household or community.

RESPONSE TO HIV/AIDS IN BLACK AMERICA

Despite high levels of awareness about HIV/AIDS and its impact on Black America, many participants perceived decreased attention to and dialogue about HIV/AIDS, both nationally and locally.

Outside of doctors' offices and clinics, most participants said HIV/AIDS is not widely discussed "in the neighborhood" or among friends and family. Participants attributed a reluctance to talk openly about HIV/AIDS to the stigma still attached to the disease. Several commented that people would wonder why they are talking about HIV, as if talking about the disease meant that an individual was infected.

Many noted less street canvassing on HIV/AIDS in their communities as compared to past years. Churches were mentioned by at least one participant in all groups as one place where HIV was discussed. Planned Parenthood was another outlet participants were aware of that one could go for information or care.

Participants commented that HIV prevention and testing tends to be stressed by most groups only during special events, like health fairs at schools or during Black History Month, Black AIDS Awareness Month, and World AIDS Day.

Among media sources, *Rap It Up*, an HIV/AIDS campaign of BET and the Kaiser Family Foundation, was mentioned in all groups as a rare media source of attention to HIV/AIDS. A few participants commented about having seen HIV/AIDS-related articles. Generally these comments pertained to having seen or read about someone living with HIV/AIDS, which appeared to have left a lasting impression. Otherwise, the perception was that attention to HIV/AIDS was relatively limited in the media.

"It's been talked about, but ain't nothing been done about it. Once they put it out there, that's it, it's gone. There ain't been too much foot work done. Like my mom and my dad always said, "you learn it at home, you recite in the streets." They promote it if it's in their backyard. That's the only way it's going to come out."
(Female, 30-49)

"I haven't heard nobody talk about AIDS since Magic Johnson."
(Male, 30-49)

"A lot of the time we don't ask. It's usually in the middle of the conversation somebody crack a joke about "that package" or something like that, but… Usually a girl will be like, "When's the last time you got tested?" or one of us will be like, "Since we was joking about it, when's the last time you got tested." It'll usually ease into it."
(Male, 18-29)

"Well, you may have the churches talking about it, but if you got a group just sitting amongst each other they won't just be talking like man what would you do if this happened or something like that. You won't get it."
(Male, 30-49)

"If you're not in the school, or church, or community center it's not going to be talked about."
(Male, 30-49)

"I've seen black leaders come together to do the Million Man March, so I think they can come together and get it where at least the school kids can be tested once a year or something, where they can find out some accurate numbers about what's going on. If they can get together for the million men to march, they can come together and pull this off, where we can get some type of ritual testing going on, instead of maybe she'll take and maybe she won't."
(Female, 30-49)

"They've taken more action in other countries than they have over here. They're more concerned about AIDS in Africa, than they are over here."
(Male, 30-49)

LEADERSHIP ON HIV/AIDS IN BLACK AMERICA

With the exception of Magic Johnson, participants did not readily associate any one individual as taking up the issue of HIV/AIDS. While a few celebrities and entertainers were named for occasional activities to address general social issues, no one stood out as making an effort to talk about HIV or making HIV a priority issue. Overall, there was a sense among participants that HIV/AIDS was not a priority for Black leadership organizations. One young woman observed, "I don't think anyone makes it a priority to talk about HIV." Even when organizations were recognized for taking on social causes, there was no real awareness of what actions the organizations had been taking on HIV/AIDS.

When asked to describe what they consider to be the major obstacles to Black leadership paying greater attention to HIV in the Black community, many said that there is not anyone willing to take up the cause. Many participants commented on a general lack of "caring." Money was also mentioned as an obstacle to bringing more attention to the issue. Some participants discussed an increase in attention to AIDS in Africa, rather than in the U.S.

On a more personal level, others noted that people taking personal responsibility for their own actions is a barrier. "It's up to the individual," said one participant.

"I like how [the Greater Than AIDS campaign] tied in history and how they say that what we overcame, without even saying it. If you know your history, you know what we overcame through, the slave trade and Jim Crow, Civil Rights Movement and all that. You know what we overcame. They're saying we overcame that, then we can overcome this."
(Male, 18-29)

"They're saying, "We are greater than." They're saying let's get tested. Let's get active in the community so that we can battle these statistics because we're not what they say we are."
(Female, 18-29)

REACTION TO THE GREATER THAN AIDS CAMPAIGN

The focus groups viewed a series of public service ads (PSAs) produced for the *Greater Than AIDS* campaign, including visual images produced for outdoor placements (such as billboards and transit shelters) and print (such as magazines and newspapers); audio from two radio spots; and a video produced for the web to communicate the campaign's message.

The campaign was positively received across all groups, especially among the youth. All groups recognized the campaign's > (greater than) logo, which was also referred to as the peace sign and described as "better than AIDS." While the campaign was viewed as targeted more towards youth, the takeaway message was clearly understood by all groups. The idea of contextualization and relating the campaign to other African American struggles throughout history resonated well with all groups, especially in relation to the video.

The images in the print ads generally resonated across the groups with participants tending to identify most strongly with those that

"I loved the campaign overall because it is conveying the message of communication as a key solution to putting an end to HIV or maybe even a beginning to an end."
(Female, 18-29)

"I loved the campaign because as of today, I don't think I would have ever talked about AIDS or anything close to it. Just knowing a little about it would just make me spread the word."
(Female, 18-29)

"It started out with an individual and then it started out with a family, and that family went into the community and the community turned into people. They're basically telling you that it starts with you and then from you, you can take it to your family. You can change your family and from your family you can change the community and the community can change an entire race of people."
(Male, 18-29)

"It's like a personal resolution to get tested, to get active."
(Female, 18-29)

"It's just made me think. They're saying I'm doing something, what are you doing?"
(Male, 30-49)

appeared most similar to them. Virtually all participants understood the intended take away message from the ads. For example, the image featuring three young women and the text "talking>silence" was read as promoting communication among friends about HIV.

The ad featuring a couple and the text "knowing>doubt" was particularly compelling with many remarking that the message was testing among couples.

Messaging with a family component resonated most strongly with older participants (those over age 30) and reinforced a sense of commitment to speak more openly with young people. Family relationships also proved to be an authoritative channel that spoke to younger participants as well.

The radio PSAs conveyed to some a message of personal resolution to become active about HIV, get tested, and "talk about it." Participants liked hearing a mix of voices and people from "different walks of life." One noted that the PSAs convey the idea that "you aren't alone" and "anybody can be a leader."

The video developed for the website elicited positive reactions in all groups with higher levels of enthusiasm evident among younger men and women. Subtle links to African American struggles and history in the video also resonated for some. The video served as an inspiration for viewing HIV as a challenge that can be overcome. Youth saw the possibility for the video to spread the message of the campaign virally, with several suggesting they planned to share it with friends.

The *Greater Than AIDS* campaign was seen as a positive effort to heighten a sense of urgency about the threat of HIV/AIDS, while conveying a sense of togetherness in addressing the issue.

About the Black AIDS Media Partnership

The **Black AIDS Media Partnership (BAMP)** is a sustained commitment among major U.S. media companies to work together to address the AIDS crisis facing Black Americans. Organized as part of **Act Against AIDS**, a multi-year effort by the **U.S. Centers for Disease Control and Prevention (CDC)** to help refocus national attention on the HIV/AIDS crisis in the United States, the Partnership is undertaking a coordinated campaign presented under a common brand – ***Greater Than AIDS*** – to reach Black Americans with life-saving information about HIV/AIDS and to confront the stigma surrounding the disease.

The **Kaiser Family Foundation** – a leader in health policy and communications – is providing strategic direction and day-to-day management for BAMP, as well as overseeing campaign production and helping to support member company commitments. **The Black AIDS Institute** is also providing strategic leadership, guidance, and technical assistance to BAMP. Other AIDS service organizations as well as the CDC's Act Against AIDS Leadership Initiative, a collaborative of fourteen highly respected and influential organizations serving African American communities, are providing additional counsel and support for community mobilization efforts.

The Kaiser Family Foundation is a non-profit private operating foundation, based in Menlo Park, California, dedicated to producing and communicating the best possible analysis and information on health issues. For more information, visit www.kff.org.

The Black AIDS Institute is the first Black HIV/AIDS policy center dedicated to reducing HIV/AIDS health disparities by mobilizing Black institutions and individuals in efforts to confront the epidemic in their communities. Their motto describes a commitment to self-preservation: "Our People, Our Problem, Our Solution." For more information, visit www.blackaids.org.