

BUILDING BLACK LEADERSHIP ON HIV/AIDS ISSUES: UNLEASHING THE POWER OF EXISTING COMMUNITIES AND ORGANIZATIONS

Black AIDS Institute
Los Angeles, CA

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SUMMARY: In 1999, with HIV/AIDS tearing through the African-American community, Phill Wilson and his colleagues began to identify black stakeholders and offer them strategic ways to respond to the epidemic. They are having a substantial impact. Their underlying philosophies and the ways in which these manifest programmatically, include the following:

- **Offer No Recriminations for Past Inaction:** The Institute does not begin relationships with anger or blame, only with how to move forward.
- **Integrate HIV/AIDS Into What Organizations Are Already Doing:** They do not dictate solutions, but instead help communities and groups figure out where and how to integrate HIV/AIDS work, for example, into their educational programs.
- **Intentionally Groom Future Leaders:** The Institute offers intensive, multi-year trainings and follow-up with trainees. These include everything from the biology of HIV/AIDS to strategies for community advocacy, media and lobbying.
- **Get the Word Out:** Strategies for getting the word out include feeding stories to black media representatives, publishing a newsletter that circulates to over 20,000, and appealing to others’ self interest through offering inserts and other literature to black publications.

The following case examples describes how, with the powerful motivation of community survival, the Black AIDS Institute is raising the participation of African-Americans in the fight against HIV/AIDS:

“SAVING OUR OWN LIVES”

Black AIDS Institute (Formerly African American AIDS Policy and Training Institute)

Writer: Jonathan Walters

Co-researchers: Phill Wilson (Award Recipient) and Jennifer Dodge (NYU/LCW)

When the Black AIDS Institute, formerly the African-American AIDS Policy and Training Institute, called a meeting of the top African-American-run magazines in the country to discuss the epidemic of HIV/AIDS among Blacks in the U.S., it had concerns about attendance. Those who read black media in the U.S. were mostly middle class and straight. "It's not an issue for their community," says an African-American board member of the Institute. "They think, 'Well yes, of course it's an issue for the community, but they're not *our* part of the community. You know, we're straight and upper middle-class and we're fine. It's the poor people, the drug users and the gay black people who have to worry about it.'" But the Institute's philosophy – to operate on the assumption that success will come because failure is not an option – spurred them to plan a meeting that no one in this community could refuse to attend.

And so on the morning of the meeting it was with a good deal of excitement that the Institute's staff and board members entered the room. "We had to have faith that the right people would come," says Phill Wilson, the Institute's Executive Director. "And we walked into that room and every single major black magazine was there except one." It was a strong signal that the Institute had potential allies in powerful places. But with so much at stake and with HIV/AIDS tearing through the African-American community, it only partially answered a very serious question: How could one small organization operating on a shoestring budget mobilize all of the diverse interests necessary to tackle an issue that for so long has been at the margins of the mainstream?

Sobering statistics

To get some sense of how pressing the issue of HIV/AIDS is among African-Americans, it only takes reciting a handful of sobering statistics:

- AIDS is the leading killer of black men ages 18-44;
- AIDS is the second leading killer of black women in the same age range;
- African-Americans account for 13 percent of the U.S. population, but almost 60 percent of the 40,000 new cases of HIV reported in 1999-2000;
- One in 160 black women and one in 50 black men is HIV positive;
- Black senior citizens represent more than 50 percent of HIV cases among persons over age 55;
- It is estimated that one third of those infected with HIV in the United States are unaware of their infection.

In fact, Wilson is convinced that it's not apathy on the part of the African-American community as much as it is fundamental ignorance of those kinds of numbers that has led to such widespread silence on the subject. For example, as soon as he made contact with the President of the American Radio Network, which represents African-American radio stations nationwide, "He just asked what it was he could do to work with us," says Wilson. A computer consultant who

serves on the Institute's Advisory Board adds, "What we saw at that magazine executive's meeting was a level of real engagement and interest. I was impressed with their willingness to acknowledge what they didn't know, and that they needed to help."

"Saving our own lives"

Contacting black media was just one part of a broader strategy for tackling the issue of HIV/AIDS among African-Americans. In 1999, the Institute launched its "Nia Plan" ("nia" is Swahili for "purpose") to identify black stakeholders and to develop strategic ways in which they could respond to the AIDS epidemic. Dedicated to creating black, community-based leadership on the HIV/AIDS issue, the Institute has developed the NIA Plan on a fundamental and bold premise: It is up to African-Americans themselves to deal with the issue of HIV/AIDS in their community. "We're talking about saving our own lives," says Wilson.

And in doing that, Wilson is convinced that the most effective strategy for moving forward is to unleash the power of existing African-American communities and organizations. "These are our experiences, our organizations, our churches and our leaders. We are the people we must target."

"Start where they are"

In moving ahead, the Institute realized two things about winning allies and partners. First, there could be no recriminations for past inaction on the part of any organization when it came to responding to the rapid spread of HIV/AIDS among African-Americans. It would be easy, says Wilson, to be angry. But the Institute chooses not to play the blame game, says a board member of the Institute. "We say, 'Okay, you're here now. The fact that we dragged you in here is irrelevant. So how can we structure an approach for you to play a role in the resolution to this problem?'"

This is the second piece of its overall strategy for working with potential stakeholders, says Wilson. From the smallest church or community group, to the largest, most powerful association, the question is what each is ready to do, and *not* what the Institute or anyone else thinks they *should* do. "We don't come across with, 'We know exactly what it is you should be doing,'" says a director at the Institute. "We have a conversation with a specific community to find out where they are in HIV/AIDS work and what they think we can do to help them with the work they're already doing."

A key piece of that operating philosophy—working with organizations to figure out where they can help, versus dictating where and how—is the Institute's push to show where the HIV/AIDS issue fits into an organization's existing agenda. "Part of our approach is *not* to say to people, 'Add HIV/AIDS to what you're already doing,' because many of the organizations we're working with already have a full plate," says Wilson. "We try to work with them to show them, 'This is part of what you're already doing,' so just integrate into what they're doing anyway."

Critical Stakeholders

Working thoughtfully with organizations is how the Institute came to be working with Delta Sigma Theta, the largest African-American sorority in the country. The Deltas had decided independently that HIV/AIDS was an issue that potentially touched each of its members, but

they weren't sure exactly how to act on that concern and so they contacted the Institute for some advice. The Institute didn't dictate ideas; it worked with the Deltas to refine some of its own. For example, the sorority was planning a day of leafleting at local malls. Staff at the Institute suggested that whoever was doing the leafleting should also be knowledgeable about the disease because they'd probably be asked questions as they handed material out. "At first we recommended three training sessions, but the sorority's feeling was that people wouldn't come to three. So we said, 'Okay, how many will they come to?'" As the effort evolved, the Institute came up with a plan for providing information to sorority members through their regular meetings, rather than having them attend three special sessions. "In the end, they actually had three training sessions," says Wilson, "but they were all integrated into what they were doing anyway. It would clearly have backfired on us if we had said, 'No, you have to have three training sessions and that's that.' Instead, you back away and you say, Okay, how can we help you be successful?' because at the end of the day, that's what it's all about."

Nor is the Institute shy about appealing to others' self interest when it comes to getting the word out. Wilson knows, for example, that there is genuine interest on the part of the black media to tackle the issue of HIV/AIDS, which is why the Institute launched its Black Media Roundtable project, designed to help the black media find and put together stories about the disease and how it is impacting African-Americans. And he knows that there is a huge industry out there—hospitals, clinics, pharmaceutical manufacturers looking to get the word out about their services, treatments and products. "AIDS is big business," says Wilson. "If you're a hospital, a clinic, a pharmaceutical company and you know there's somewhere where people go to get information about HIV/AIDS then you might buy ads in those places." Toward that end, the Institute works both with businesses and the media on such things as special inserts and advertising sections. It's a triple win, says Wilson. Companies are able to publicize what they have to offer. The media gets advertising dollars. The Institute gets the word out about prevention. "It's not our business to really worry about why people do things," says Wilson. "It's our business to urge people to do the right thing. So in this case, they may be doing it for two reasons, to save people's lives, but also to make money. But at the end of the day, they do save people's lives and that's *our* bottom line."

Growing your own leaders

As it works with various stakeholders to help them figure out ways to lead on the HIV/AIDS issue, the Institute is also doing a little growing of its own. It's a hard reality that many of those currently fighting the HIV/AIDS battle are themselves infected, and may not be around to see the whole fight through. And so through its African-American HIV University (AAHU), the Institute hopes to groom future leaders, who will scatter into communities and spread the word. The AAHU program offers training to 40 future leaders over a two-year period, bringing them together for a series of intensive six-week sessions, teaching them everything from the biology and epidemiology of HIV/AIDS, to strategies for community advocacy, press relations, lobbying and policy action. "This is a long-term process of educating people so that they'll have the skills needed to be educators and leaders themselves," says a director at the Institute. "Nor does it stop after two years. We give these folks the tools they'll need to keep on learning and growing."

At the same time, the Institute has been active at international conferences, putting on similar, intensive training programs aimed at teaching others how to work with and motivate logical allies in the fight against HIV/AIDS.

Getting the word out

Besides running the university, the Institute also publishes *Kujisource*, a regular newsletter aimed at a wide range of audiences, from those who have HIV/AIDS, to activists, alumni of AAHU and the general public. The newsletter includes everything from research and science articles, to editorials on policy. It profiles "every day heroes" working on and/or living with HIV/AIDS, and first-person narratives by AAHU graduates.

The newsletter has gained so much credibility that it's now going out to 20,000 readers. Recently, the federal Centers for Disease Control in Atlanta did a special mailing of *Kujisource* to 3,000 specialists and activists on the HIV/AIDS front, including all state HIV/AIDS directors and every member of the President's Advisory Council on HIV/AIDS. "That means the CDC puts a lot of credence and value into the Institute's work," says a board member at the Institute.

More recently, the Black AIDS Institute has focused attention on its Black Media Project. When it developed the Nia Plan, the Institute had identified the black media as one of its key stakeholders. Now the Black Media Project has blossomed so much so that staff members at the Institute are frequently on the phone with black media representatives feeding them stories about HIV/AIDS. "It's no longer a fight about getting media attention, instead it's simply a question of timing," says Wilson. In fact, the Black Media project has been so successful lately, that the Institute has recently produced a ten-part series about HIV/AIDS issues relevant to the black community for black newspapers across the country.

Take small steps and leave the credit

In pushing such a variety of programs and in working with as many partners and communities as possible, Wilson says the Institute may not be shaking the world, but it is certainly laying the groundwork. "It's about taking small steps even if you're not sure where they fit into the big picture," says Wilson. "And it's also about not worrying who gets the credit."

But mostly it's about getting every possible community and potential leader energized and involved, he says. "Our core mission is to expand the number of people involved," says Wilson. And according to a supporter of the Institute, that universe is potentially large and needs the continuing wakeup call of an organization like the Institute's: "I'm amazed after 20 years at the number of people who still say, 'Well, that's not really one of my issues.' There shouldn't be any African-American leader—true African-American leader—who can say that in 2002."

If the Black AIDS Institute has anything to say about it, the number of African-American leaders will continue to rise on the strength of a shared sense of crisis and mission. "This is about survival," says Wilson. "And I think black people are committed to survival. But that's going to be our legacy, surviving, simply because we refuse not to."

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