

Called to Action

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When the Black AIDS Institute looked at the soaring national HIV infection rates among African Americans, the solution seemed clear: No one can save us but us. To start the rescue mission, the institute mobilized an army of black treatment advocates.

While exploring ways to lower the disproportionately high rates of HIV among African Americans, the Black AIDS Institute (BAI) made an astute observation. Community leaders were not provided with the support networks and scientific knowledge they needed to become motivated, successful advocates for HIV prevention and treatment. To fill this void, this summer BAI created the Black Treatment Advocates Network (BTAN).

The group has its work cut out for it. “Black Americans account for an estimated 50 percent of all people living with HIV and represent the largest group affected by HIV/AIDS, but they number among the least in care,” says Raniyah Abdus-Samad, a training and capacity building manager with the Black AIDS Institute. “[We knew we had to] mobilize African Americans to change the trajectory of the epidemic in our communities.”

One of those communities is Philadelphia, rated among the 10 most populated cities in the United States. Philly also ranks high on the list of locations where African Americans are particularly hard hit by the HIV/AIDS epidemic. In a city where blacks make up roughly 43 percent of the population, almost 66 percent of those living with HIV in Philadelphia are black. And Philadelphia isn't alone. Houston, the largest city in Texas and the fourth-largest city in the United States, has an HIV rate two times greater than the national average. African Americans comprise almost 50 percent of all people living with HIV/AIDS in the city, despite the fact that they are less than 25 percent of the city's total population.

Further southeast, in Mississippi—a state where African Americans make up only 37 percent of the state's population—blacks represent an estimated 73 percent of the total number of people living with HIV and an estimated 77 percent of total new HIV cases in 2009.

The list continues, but one question remains: What can we do about the numbers?

In answer, the Black AIDS Institute proposed creating BTAN, a national program to provide existing

community leaders with appropriate HIV/AIDS science literacy and treatment training. The goal? To engage and mobilize black communities in the fight against HIV/AIDS.

“BTAN’s goal is to create sustainable programs to give black people the tools to respond to the AIDS epidemic in their communities,”

Abdus-Samad says. “We believe to do so, you must also create networks of advocates to strengthen local leadership and give them the skills they need to end the AIDS epidemic in black America.”

So the institute partnered with Merck, a manufacturer of HIV pharmaceuticals, to create an advocate training program. But BTAN also wants to build a better bridge connecting black Americans living with HIV/AIDS to quality care and treatment.

To achieve this goal, BTAN plans to meet several objectives: build a trained network of black HIV/AIDS advocates; strengthen local and national leadership; raise HIV/AIDS science literacy; increase awareness of HIV/AIDS clinical trials among people living with the virus, and solicit them to volunteer for those trials; boost the number of qualified black Americans who serve on scientific advisory boards; advocate for HIV policy change; and identify and mobilize more peer advocates and organizational leaders.

Another huge BTAN objective is more psychological: Dispel myths in the black community about HIV/AIDS care. “There is a widespread distrust of medical institutions in black communities,” Abdus-Samad says. “This distrust stems from a legacy of mistreatment of black people by medical institutions. And though the most famous example may be the Tuskegee syphilis experiment, there are countless other instances.”

These instances are what created myths regarding treatment and care, plus caused a lower level of science literacy, Abdus-Samad says. “Because we don’t trust the messenger, consequently we don’t trust the message being given.”

In 2010, BTAN trained 100 black treatment advocates through pilot programs in three cities ravaged by HIV/AIDS: Philadelphia, Houston, and Jackson, Mississippi.

“All three cities have large black populations with high HIV prevalence rates,” Abdus-Samad says. “How the program works in these three pilot cities will also provide us with information as we move forward to expand the network in cities with similar epidemics.”

To solicit advocates for the pilot programs, BTAN contacted local AIDS service organizations and community boards. Those accepted into the program participated in a week-long training session coordinated by the institute. Topics ranged from a basic HIV science review to HIV testing and diagnosis, treatment strategies, key challenges in HIV care, patient-provider relationships and community mobilization. Participants also addressed the ways social issues and stigma influence treatment and care.

Once pilot-program participants complete formal science and advocacy training from the institute

and its partners, they will be tasked with pursuing BTAN's agenda, previously outlined. These trained advocates from each city will then move forward with their own advocacy projects, creating resources to help patients and professionals stay informed and current on HIV treatment and science, local issues and advocacy skills, Abdus-Samad explains.

"Recruitment is very important for BTAN as this is a national movement working to change the HIV science and treatment landscape," Abdus-Samad says. "We are planning to expand the network into a few more cities next year as well as expand the national network. This will allow interested people from any city to become part of BTAN."

The group plans to roll out these initiatives into other cities during the second half of 2011. "We are currently looking at numerous cities we think would be good locations for the 2011 expansion project," Abdus-Samad says. "There is no right or wrong city to go into, but we want locations that will provide good lessons on how to continue our network's growth."

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