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African American community leaders' policy recommendations for reducing racial disparities in HIV infection, treatment and care: results from a community-based participatory research project in Philadelphia, PA

Amy Nunn, ScD[1], **Julia Sanders**[2], **Lee Carson, MSW, LSW**[3], **Gladys Thomas**[2], **Alexandra Cornwall**[1], **Caitlin Towey**[2], **Hwajin Lee**[2], **Marian Tasco**[4], **Waheedah Shabazz-El**[5], **Annajane Yolken**[2], **Tyrone Smith**[3], **Gary Bell, MSW**[6], **Sophie Feller**[7], **Erin Smith**[2], **George James**[8], **Brenda Shelton Dunston**[9], and **Derek Green, JD**[4]

[1]The Miriam Hospital, Providence, RI, USA

[2]Brown University, Providence, RI, USA

[3]Black Gay Men's Leadership Council, Philadelphia, PA, USA

[4]Philadelphia City Council, Philadelphia, PA, USA

[5]U.S. Positive Women's Network, Philadelphia, PA, USA

[6]Bebashi, Inc., Philadelphia, PA, USA

[7]Jefferson University, Philadelphia, PA, USA

[8]Council for Relationships, Philadelphia, PA, USA

[9]Black Women's Health Alliance, Philadelphia, PA, USA

Abstract

African Americans account for 45% of new HIV infections in the United States. Little empirical research investigates African American community leaders' normative recommendations for addressing these disparities. Philadelphia's HIV infection rate is five times the national average, nearly 70% of new infections are among African Americans, and 2% of African Americans in Philadelphia are living with HIV/AIDS.

Using a community-based participatory research (CBPR) approach, we convened focus groups among 52 African American community leaders from diverse backgrounds to solicit normative recommendations for reducing Philadelphia's racial disparities in HIV infection. Leaders recommended: 1) Philadelphia's city government should raise awareness about HIV/AIDS with media campaigns featuring local leaders; 2) Local HIV prevention interventions should address social and structural factors influencing HIV risks rather than focus exclusively on mode of HIV transmission; 3) Resources should be distributed to the most heavily impacted neighborhoods of Philadelphia; and 4) Faith institutions should play a critical role in HIV testing, treatment and prevention efforts.

Contact Author: Amy Nunn, 401-863-6568, Amy_nunn@brown.edu.

We developed a policy memo highlighting these normative recommendations for how to enhance local HIV prevention policy. This policy memo led to Philadelphia City Council hearings about HIV/AIDS in October 2010 and subsequently informed local HIV/AIDS prevention policy and development of local HIV prevention interventions. This CBPR case study offers important lessons for effectively engaging community leaders in research to promote HIV/AIDS policy change.

Keywords

Community Leaders; HIV; African Americans; Racial Disparities Policy Change

Background

African Americans represent 14% of the total United States population but account for over 45% of new HIV infections, and have HIV infection rates seven times that of Whites (CDC, 2013). Behavioral risk factors, including number of lifetime sexual partners, drug use and condom use rates, do not fully explain the extent of these disparities (Hallfors, Iritani, Miller, & Bauer, 2007). Complex social and structural factors influence these racial disparities in HIV infection (Aral, Adimora, & Fenton, 2008;Millett et al., 2012).

Many of the greatest policy successes in the fight against HIV/AIDS are attributed to social movements, community activism and political leadership, including in the United States, Brazil, Uganda, South Africa and Thailand (Crimp, 1988; Nattrass, 2007; Nunn, 2009; Piot, Bartos, Larson, Zewdie, & Mane, 2008; Plagerson & Mathee, 2012). In the United States, community mobilization and activism, particularly among men who have sex with men (MSM), who were the most heavily impacted community at the beginning of the epidemic, has been a critical component of the US response to the AIDS epidemic. Community mobilization by MSM helped propel AIDS treatment, non-discrimination policies, and many other positive policy developments forward (Shilts, 1987) (Killen, Harrington, & Fauci, 2012).

Community based participatory research (CBPR) is an approach to conducting research that focuses on equitably partnering researchers and community members in all aspects of a research, advocacy and policy process (B. A. Israel et al., 2010; Wallerstein & Duran, 2010). By engaging diverse partners, CBPR can be particularly effective for promoting policy change, community mobilization, capacity building for engaging community members in the policy process, and promoting policy action related to advancing health equity (B. Israel, Eng, Schulz, & Parker, 2005).

Although African Americans are disproportionately affected by and infected with HIV, little research explores African American community leaders' opinions on how to address racial and geographic disparities in HIV infection, particularly normative policy recommendations. Although somewhat limited, most existing research exploring African American leaders' opinions related to HIV/AIDS explores the perspectives of African American clergy related to HIV/AIDS (Coleman, Lindley, Annang, Saunders, & Gaddist; Cunningham, Kerrigan, McNeely, & Ellen, 2009; Davis, 2008; Foster, Cooper, Parton, &Meeks; Liverpool &

Francis, 2009; Nunn et al., 2012; Nunn, Cornwall, Thomas, Callahan, et al., 2013; Wilson, Wittlin, Munoz-Laboy, & Parker, 2011). Few empirical studies demonstrate the impact of CBPR on public policy (B. A. Israel et al., 2010), including for HIV/AIDS. Similarly few empirical studies explore African American community leaders' perspectives on how to reduce racial disparities in HIV prevention, treatment and care with a focus on policy change. Given the critical role community leaders have played in developing effective policy responses to the AIDS epidemic, exploring community leaders' recommendations for addressing the HIV/AIDS epidemic can help inform policies to reduce HIV/AIDS disparities.

Philadelphia, Pennsylvania has HIV infection rates five times the national average (Philadelphia, 2011). Approximately 66% of the new HIV cases diagnosed in Philadelphia in 2010 were among African Americans, and 2% of African Americans in Philadelphia are living with HIV(Schwartz & N. Feyler, 2009). Approximately 55% of new infections in Philadelphia are attributed to heterosexual contact (Shpaner, Brady, & Eberhart, 2010). Philadelphia also has wide geographic disparities in HIV infection; a few neighborhoods account for the majority of the city's new infections (PPG, 2011).

We convened focus groups among 52 African American community leaders from business, public health, non-profit, and other sectors to solicit normative recommendations for reducing Philadelphia's racial disparities in HIV infection. Because many participants expressed keen interest in using the focus group findings to influence policy, we also used the focus group findings to develop a policy memo that included normative recommendations for how to enhance local HIV prevention policy to reduce these disparities. This policy memo was requested by then Majority Leader and Director of the Health Committee of the Philadelphia City Council, Marian Tasco.

This empirical CBPR case study highlights the key findings from the focus groups, explains how the findings contributed to a 2010 Philadelphia City Council Resolution about HIV/AIDS, as well as the implementation of Philadelphia's local plan to implement the National HIV/AIDS strategy (“National HIV/AIDS Strategy for the United States,” July 2010; PPG, 2011).

Case Study

We convened nine focus groups with 52 African American community leaders in June 2010. We recruited African American community leaders from diverse sectors, including the private sector, the non-profit sector, the public sector, and other diverse advocates. We used a combination of purposeful and snowball sampling. We recruited some leaders based on their expertise in HIV/AIDS, others because of their leadership on public health issues and social justice advocacy, and African American clergy because of their important leadership roles in the Philadelphia community. Most (47) were senior executives in their respective institutions; those who were not senior executives were selected based on their expertise related to African American health or HIV/AIDS.

To ensure that the content of the focus groups were locally tailored, culturally appropriate, and reflected the topics local community leaders deemed most important, we solicited

participants' viewpoints during 43 key informant interviews prior to conducting focus groups. This participatory process also informed development of our focus group discussion guide and helped build rapport with participants. Informed by our key informant interviews, final focus group topic guides included questions regarding knowledge about Philadelphia's HIV/AIDS epidemic; opinions about the social, behavioral, and structural factors influencing Philadelphia's HIV/AIDS epidemic; barriers to more effective HIV prevention and treatment policies in the community; and recommendations for enhancing local HIV testing, treatment and prevention policies.

Each focus group was comprised of eight to ten participants. Participants were older than 18, self-identified as African-American, and provided written and verbal informed consent. This research was approved by the Institutional Review Board of the Miriam Hospital. A semi-structured interview guide was used to direct focus group discussions; semi-structured interview guides generally include a list of topics to cover but allow both the moderator and participants to introduce topics freely (Weiss, 1994). Focus groups were conducted by professional African American moderators and were approximately one to two hours in length. To help ensure reliability and validity of the study's findings, approximately 20% of the interviews were coded by more than one data analyst; discrepancies were discussed and resolved among data analysts. Final themes that emerged are presented here and in Table 1.

Following analysis of the focus group transcripts, we convened a community forum for which we invited all study participants to discuss findings distilled from the coding process. Of the original 52 focus group participants, 22 attended the subsequent community forum in which participants discussed primary focus group findings and worked collaboratively to develop ten concrete policy recommendations to reduce racial disparities in HIV infection. All participants in the community forum had participated in the focus groups.

Because of the keen interest in using the study findings to influence policy and practice, during the community forum, we discussed and developed a policy memo including the primary themes and policy recommendations to present to Philadelphia City Council. The memo was circulated to all participants, who were given the opportunity to endorse the policy memo; thirty-two individuals and institutions signed the policy memo presented to Philadelphia City Council. This effort culminated in a City Council Resolution and hearing on October 27, 2010 (Avril, 2010; Jones, 2010). Much of the language included in the City Council Resolution was borrowed from the policy memo (“Resolution No 100565,” 2010). In addition, many of the focus group participants testified at the subsequent City Council hearing.

Policy Recommendations

Four main themes and policy recommendations emerged from these focus groups and community meetings (Table 1). The group recommended 1) The Philadelphia Department of Public Health should increase educational and media efforts to raise community awareness about the local epidemic, including locally tailored media campaigns promoting HIV testing. 2) HIV prevention efforts should address social and structural drivers of the local epidemic rather than focusing exclusively on behavioral interventions and mode of HIV transmission. 3) Publicly funded HIV/AIDS resources should be distributed to the mostly highly impacted

neighborhoods, noting that addressing racial disparities requires addressing the city's geographic disparities in HIV infection. 4) African American faith leaders should play a greater role in local HIV prevention and promote HIV testing in their houses of worship. We examine each of the following results below in more detail, highlighting illustrative quotes that reflect each theme and subsequent recommendations.

Promote Increased HIV/AIDS Awareness and Testing through Media Campaigns—Many participants were unaware of the gravity Philadelphia's HIV/AIDS epidemic and did not realize that both African Americans and select neighborhoods within Philadelphia were so disproportionately impacted. Most focus group participants agreed that Philadelphia needs greater educational and media campaigns to raise awareness about the local epidemic. Participants recommended that the city implement a locally tailored social marketing campaign to raise awareness and promote HIV testing; the Mayor and City Council declare a public health emergency; and the public schools implement HIV education and testing as part of health curricula. Two participants commented:

> We have to talk about it. We have to get celebrities and athletes, to come out and talk. We need more than Magic Johnson. This has to be a discussion from the top down.

> We need more media and more imagery; we need the radios inundated with HIV testing information!

Nearly all participants underscored the importance of adding HIV testing and education to public school health curricula. Two participants' recommendations reflect this common theme:

> I would suggest that the health commissioner and Mayor develop a health curriculum that is standardized and includes prevention of many diseases, particularly sexually transmitted diseases and HIV. It should not be a lecture, it should be interactive and provide kids an opportunity to talk about HIV in a safe environment.

> I'd say to Mayor Nutter: “Would you please consider a health campaign to defend the new HIV infections among youth by having a policy that includes testing for HIV, AIDS and STD for all public school students?”

The final policy memo recommended that the Philadelphia public schools implement a comprehensive HIV education and testing program in schools, including a training program for teachers. The final policy memo also recommended that Philadelphia develop locally tailored media campaigns to promote HIV and STD testing.

Respond to Social and Structural Drivers of the Local HIV/AIDS Epidemic—Nearly all focus group participants agreed that larger social and structural factors, such as poverty, incarceration, and homelessness contribute to high HIV infection rates and racial disparities in HIV/AIDS in Philadelphia. Respondents also noted the importance of sexual networks (the way people are connected directly and indirectly through sexual contact) and concurrent sexual partnerships, and the concentration of HIV within those networks, in potentiating racial and geographic disparities in HIV infection.

> With concurrent partnerships, I have my boyfriend but I have somebody on the side, or serial partnerships, I have my boyfriend, we broke up, two months later I'm with somebody else, now we're having sex, we broke up a week later. So, it's just multiple sexual partners across so many different contexts…if one of those partners has HIV…That's it!
>
> I don't believe that Black people are having or doing things at any more risk than White folks in Philadelphia or Asian folks…. I'm more likely to contract HIV because I only have sex with people that primarily live within a four to five block radius of where I live. There's just more disease. Disease follows poverty, it follows homelessness, it follows drug use.
>
> Any person of color with low socioeconomic status has a higher chance of becoming infected because of the concentration of where they live, and what services are available for them particularly around health. I don't think we should be nearly as concerned about whether you're gay or straight, but should be looking at interventions that address social issues.
>
> Let's think about the sex ratio. A lot of men are incarcerated. More women are available for men. Poverty makes women vulnerable. She doesn't lie down and get HIV because she doesn't know better. She does it because this man is bringing home extra milk and bread. He doesn't want to put a rubber on, and it comes down to dollars and cents. Her vulnerability is not always because she's not getting messages, but because she has to make these choices because of poverty or economic class. I think that incarceration causes concurrent relationships far more than alcohol or drugs.

Many respondents commented that Philadelphia should dedicate local resources for public housing for people living with HIV/AIDS, citing New York, Chicago and other cities' exemplary housing programs for people living with HIV/AIDS. Several participants noted the positive impact that housing can have on AIDS treatment and adherence to medications:

> The cornerstone of fighting the AIDS epidemic is to get people with HIV out of the shelters and get them in some place where they can have some control over taking their medicines.

The final policy memo included recommendations that the City Council endorse prison reform. The final policy memo also suggested that local prevention policy address the important role of sexual networks in contributing to local geographic and racial disparities in HIV infection.

Resource Distribution Should Reflect Geographic Need—One common theme was much of that Philadelphia's nearly $15 million HIV/AIDS budget does not reach the most heavily impacted neighborhoods. Three participants commented:

> If they'd only have to walk down the street to get HIV/AIDS services as opposed to coming across the city, more of them would get tested for HIV.
>
> Rather than focusing so much on “mode of HIV transmission,” we really need to focus on the neighborhoods that have the highest rates of infection, like North

> Philadelphia and Southwest Philadelphia. HIV infections cluster in this city and we need to focus far greater efforts on getting our resources to the most heavily impacted communities.
>
> I think where we already have significant health disparities in our community, HIV incidence is going to be higher. Southwest Philadelphia, which was a highly industrialized area for a long time, has a lot of environmental issues and so you have a higher incidence of other disparities, diabetes, hypertension, asthma. You also have people that are then prone to other kinds of infections.

The final policy memo recommended that local HIV testing, treatment and care resources be directed to the most heavily impacted neighborhoods of the city, and that the city consider earmarking HIV prevention funds for organizations that serve African Americans as a core function of their mission. The final policy memo also underscored the importance of directing a larger share of Pennsylvania state HIV prevention and treatment funds to the City of Philadelphia.

Engage African American Clergy in HIV prevention—Many participants noted the unique role that faith institutions and leadership play in the African American community; dozens of leaders recommended engaging the faith community in HIV testing and prevention in a coordinated citywide testing and anti-stigma campaign. One participant commented on the potential impact of African American churches:

> The churches need to take a stand and become more comfortable standing up in front of their congregation in saying that this is a war, that we need to go to battle! They have the greatest opportunity because they're talking to the largest number of people at one time on a regular basis.

While many participants agreed that churches could play a role in local HIV/AIDS programs, many participants cited that churches need greater financial and capacity building resources to create HIV/AIDS ministries.

> Churches need some resources. It's one thing to have a church with a ministry but it's another thing to have a church with resources and people who are skilled and trained.

The policy memo written by the focus group participants recommended that the city, state and federal government dedicate greater resources to engaging faith leaders in HIV prevention, and consider making greater efforts to engage local clergy.

Discussion

There is now widespread scientific agreement that social and structural factors contribute to racial disparities in HIV infection, treatment and linkage to care in the United States (Aral et al., 2008; Espinoza et al., 2007; Hall, 2012; Millett et al., 2012). However, little research explores the opinions and recommendations of community leaders about how to tailor HIV prevention interventions to local contexts or how to translate community leaders' recommendations into local policies.

This case study highlights how a CBPR and advocacy process can impact local HIV prevention policy. This CBPR process first identified community leaders' recommendations for how to reduce local HIV/AIDS disparities with focus groups, and then invited them to community forums to interpret study findings and make policy recommendations. Table 1 includes a summary of their recommendations. Working collaboratively, researchers and community leaders developed and presented a policy memo highlighting the study's key recommendations to the Philadelphia City Council. The primary recommendations included: 1) develop social marketing campaigns that address the local epidemic; 2) focus less on mode of HIV transmission and more on social and structural drivers of the epidemic; 3) allocate resources to the most heavily impacted neighborhoods of the city; and 4) develop innovative programs to engage African American clergy in HIV prevention and treatment efforts.

This CBPR project has impacted local programs and policy, thereby fostering sustainability of the aforementioned policy recommendations. In October 2010, City Council Majority Leader Marian Tasco and Jannie Blackwell introduced City Council Resolution 100565 calling for hearings about HIV/AIDS in Philadelphia(“Resolution No 100565,” 2010). The resolution drew language from the policy memo submitted to City Councilwoman Marian Tasco. Hearings based on the proposed resolution were held on October 27, 2010. Many of the focus group and community forum participants, as well as other local experts, testified about the aforementioned policy recommendations for enhancing HIV prevention in Philadelphia.

Several HIV prevention programs also emerged out of these recommendations. In 2011, Philadelphia launched a condom campaign to address high rates of HIV and STD infection among local youth, holding a contest to select the best condom package design. The winning campaign was entitled “The Freedom Condom” (Nutter, 2013). The city also launched a website, phone app, and social media campaign targeting youth to promote the Freedom Condoms (www.takecontrolphilly.org). This website includes information about HIV and STIs, as well as locations to pick up free condoms and the option to have condoms mailed directly to teens(“Take Control Philly,” 2013).

This project also prompted the Philadelphia AIDS Activities Coordinating Office to integrate a geographic focus into its Enhanced Comprehensive HIV Prevention Planning and Implementation for Metropolitan Statistical Areas Most Affected by HIV/AIDS planning (ECHHP) proposal. The city's ECHHP programs have also redoubled the city's efforts to address the needs of youth, especially in highly-affected areas (PPG, 2011).

The findings of this CBPR project also informed the *Do One Thing* HIV testing, treatment and retention in care program in Southwest Philadelphia (http://1nething.com/). This geographically oriented testing, treatment and care program aims to respond to unmet need for testing and treatment in the most heavily impacted neighborhood of Philadelphia. In response to the aforementioned policy recommendations, the campaign combines community mobilization, clinical and non-clinical testing, and a massive media campaign in the most highly impacted zipcode of Philadelphia, which also has the most limited HIV testing, treatment and care services. The project aims to dramatically stimulate and then

provide more HIV testing and treatment services, and has tested over 7,000 individuals to date, with high rates of linkage and retention in care (Nunn A, 2013; Trooskin, Feller, et al., 2012; Trooskin, Yolken, et al., 2012).

Additionally, in 2010, a group of African American clergy members who participated in many of these focus groups launched a citywide HIV testing and awareness campaign that included HIV testing, billboards and sermons in over 40 congregations across the city (Avril, 2010; Jones, 2010; Nunn et al., 2012; Nunn, Cornwall, Thomas, Waller, et al., 2013). Those efforts have been sustained by a coalition of African American clergy committed to eradicating Philadelphia's AIDS epidemic called *Philly Faith in Action* (www.phillyfaithinaction.org). In 2012, *Philly Faith in Action*, in partnership with the Kaiser Family Foundation's *Greater than AIDS* program, launched a citywide media campaign profiling African American clergy that promotes HIV testing ("Faith in Action in Philadelphia," 2012). This campaign profiled local faith leaders promoting HIV testing and includes billboards, radio ads, video clips, and social media platforms.

While these efforts cannot be attributed solely to the outcomes of this case study, the City Council resolution, associated media coverage and community mobilization surrounding this initiative likely contributed in important ways to ongoing efforts to reduce racial and geographic disparities in Philadelphia.

Conclusion

Greater efforts are needed to engage African American community leaders in designing culturally appropriate, locally tailored HIV prevention interventions to reduce racial disparities in HIV infection. This CBPR project investigated community leaders' suggestions for addressing disparities in HIV infection, which culminated in City Council hearings in 2010 and informed several HIV prevention programs and media campaigns launched after City Council hearings. This CBPR approach that focuses on research, community mobilization and policy change has helped inform and advance HIV prevention policy and intervention development in the city of Philadelphia. This approach with diverse stakeholders has helped promote public policy action and new interventions addressing the aforementioned policy recommendations. CBPR can be a catalyst for social and political change to address racial and geographic disparities in HIV infection.

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Table 1

Community Leaders Policy Recommendations for Reducing Racial Disparities in HIV Infection in Philadelphia

Theme	Challenge	Specific Recommendations
There is a general lack of awareness about the gravity of Philadelphia's HIV/AIDS epidemic	In spite of high infection rates, there is generally low perceived risk about HIV/AIDS Philadelphia. Many people mistakenly believe that HIV is a gay disease, even though Philadelphia has a largely heterosexual HIV/AIDS epidemic.	The city should declare a public health emergency about HIV/AIDS. Philadelphia should sponsor age- and gender-specific media campaigns about HIV/AIDS.
	Young people are increasingly at risk for HIV/AIDS in Philadelphia and do not always fully appreciate their HIV risks.	The city should Implement and finance robust HIV Prevention programs in public schools, starting in junior high and middle schools. These curricula should include: **a.** Integrate comprehensive, compulsory HIV education programs into school curricula. **b.** Require basic training for teachers, administrators, other educators and even parents about HIV/AIDS. **c.** Offer HIV testing in junior and senior high schools.
	There is little media coverage, public leadership and public awareness about HIV/AIDS in Philadelphia.	City Council, the Health Commissioner, the Mayor, and other public sector leaders should speak out publicly about HIV/AIDS to draw attention to the local issue.
HIV prevention interventions should address social and structural factors rather than focus exclusively on mode of HIV transmission	Incarceration raises women's HIV risks by removing too many African American men from the community. This has important impacts on sexual networks, which raise women's HIV risks.	City Council should endorse prison reform, including reducing drug-related sentencing, sentencing for non-violent crimes, and reducing time to sentencing and trial. Lower rates of incarceration would reduce communal HIV risks.
	Complex social and economic factors such as high rates of incarceration and poverty contribute to the community's HIV risks equally as much, or more than, traditional risk factors like condom use rates, numbers of sexual partners, and drug use.	When allocating resources, the Philadelphia Department of Public Health should focus less on modes of HIV transmission (drug use, heterosexual, homosexual) and more on sexual networks and geographic disparities in HIV infection and care.
Greater prevention resources should be distributed to Philadelphia, and particularly the most highly impacted neighborhoods of the city	Several communities with largely African American populations have high HIV infection rates and too few HIV testing and treatment services.	The Philadelphia Department of Public Health should: **a.** Direct more HIV prevention, treatment and care funds to the most heavily impacted and often underserved neighborhoods of the city. **b.** Offer HIV testing services at other public assistance programs (in welfare and Medicaid offices, among other places). **c.** Funding and even earmarking funds for organizations that specifically reach out to African Americans as a core function of their mission. **d.** Requiring or providing AIDS Service Organizations with financial incentives to provide services to underserved communities, and to women in particular. **e.** Offering more technical and financial assistance to local start-up groups and community-based organizations whose mission is to address the health needs of African Americans.
	Community leaders who implement HIV prevention programs feel that many of the HIV prevention interventions endorsed by CDC are not appropriate for their clients, do	Permit local groups to implement and tailor interventions to their client populations.

Theme	Challenge	Specific Recommendations
	not address the drivers of the AIDS epidemic, or are outdated.	
	Too few Pennsylvania and federal HIV/AIDS resources are transferred to Philadelphia.	Advocate in state Congress for greater resources to be directed to Philadelphia.
	State-level budget cuts have had very detrimental impacts on HIV/AIDS prevention in Philadelphia.	City Council should encourage state representatives and senators to reinstate HIV prevention funds in the next budget.
Faith institutions play a critical role in HIV testing and prevention efforts	Local faith leaders and clergy have not responded sufficiently to the local epidemic.	African American clergy should promote HIV testing, awareness and treatment in houses of worship, including in sermons and health ministries. Greater local, state and federal resources should be allocated to faith institutions for HIV testing, awareness and treatment programs.