VIEWS FROM THE FIELD
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GRANT MAKERS IN HEALTH

HIV/AIDS and Women of Color: Changing the Conversation

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WHERE IS THE OUTRAGE?

For the past decade, HIV/AIDS-related conditions have been the leading cause of death for African-American women ages 25-34 in the United States (CDC 1999). Over the past two decades, our local foundation has seen this national epidemic take root in our local community in Washington, DC, where we now have *10 times* the rate of HIV/AIDS per capita compared to the rest of the country. Its impact is disproportionately felt in communities of color in our city, where nearly 7 percent of black men and almost 3 percent of black women are living with AIDS compared to about 3 percent for white men and *less* than 1 percent for white women. Black women now make up 90 percent of women living with AIDS (District of Columbia Department of Health 2009).

At the same time the city's health department was first releasing comprehensive statistics about HIV/AIDS, the Consumer Health Foundation was reassessing its funding strategy and response to the epidemic. For one of our trustees, the data represented more than numbers. It was a wake-up call. As a longtime, passionate advocate for women's health, she wanted to know, "Where was the outrage in our local community about what was happening to women of color?" Despite good intentions and the expenditure of millions of dollars from both public and private funders, it was clear that existing strategies were having little or no impact on the rising rates of HIV/AIDS infection among these women.

She asked our board and staff if we were asking the right questions.

Her question was the right question.

SHIFTING THE PARADIGM

Our community had an intractable problem that could not be solved using the prevailing prevention framework that focused on increasing access to screenings and changing personal behavior. We needed to take a broader approach, and we needed to start by asking different questions.

So we invited Pat Nalls, the leader of The Women's Collective, a local nonprofit organization led by women with HIV and their allies/advocates, to meet with our foundation's board and staff members. We asked her to tell us about the lived experiences of women living with and at risk of HIV/AIDS. Based on the stories she shared, it seemed clear that there was not one cause or one solution to what was happening – no magic bullets. There were a number of complex, interwoven, and powerful forces putting women at risk – poverty; racism; isolation; stigma; and the stress of meeting daily needs and responsibilities, including taking care of children. These social conditions shaped women's life options and choices, and therefore, personal behavior. For communities of color, there was the added burden of structural racism.

Seeing HIV/AIDS as a symptom of these larger social conditions made sense, in part because our foundation had been questioning its strategy and approach to eliminating health disparities. We were broadening our theory of change to include improving equitable access to health care *AND* creating health justice (such as addressing the social determinants of health equity or SDOHE). We had just completed a racial justice assessment of our work conducted by the Applied Research Center and the Philanthropic Initiative for Racial Equity. Applying an equity lens had shifted our understanding of community and individual health. We needed to move from an illness to a wellness perspective.

The convergence of the SDOHE approach and the emerging insights into the HIV/AIDS epidemic among women of color presented us the opportunity to "change the conversation." We gave a grant to Grantmakers In Health (GIH) to work with us to better understand HIV/AIDS prevention among women of color within the SDOHE context and to begin exploring new and effective prevention strategies.

CHANGING THE CONVERSATION

We worked with GIH over several months to design and convene an invitational meeting of HIV/AIDS service

providers and activists (including women of color living with the disease) from the DC metropolitan area and from nearby southern states where HIV/AIDS rates among African-American women are especially high and where resources to address the epidemic are scant. Also included in the conversation were research experts from academia and government whose work focuses on racial and ethnic health inequities using the social determinants framework. Local and national funders were also at the table. Entitled *Changing the Conversation: Taking a Social Determinants of Health Approach to Addressing HIV/AIDS Among Women of Color*, the meeting was kept small in order to provide a safe and intimate environment and the time needed to enable everyone to listen, learn, process, and reflect.

We also viewed the meeting as an opportunity to challenge our thinking and change the language related to HIV/AIDS. Having included SDOHE in the theory of change, we wanted to look closely at the extent to which women of color possess resources needed to achieve their aspirations, satisfy their needs, and cope with their environment.

Although we are still in the process of figuring out next steps, some of the highlights of what we have learned include:

- ***Racial inequity across social and health indicators stems from a history of people of color not being highly valued in American society.*** At the roots is structural racism, which limits the opportunity for self-determination (for example, having the power to decide on, act in relation to, and control resources in one's community) and leads to disproportionate levels of poverty, incarceration, and other conditions that put communities of color at higher risk. We need to change structures, policies, practices, norms, and to invest in families and communities as a whole.
- ***HIV/AIDS disparities parallel all other large racial disparities.*** Residential segregation by race is a fundamental source of inequality as it impacts school quality, access to employment opportunities, healthy foods, quality of available medical care, and other health-promoting resources. Investing in and creating communities of opportunity that improve economic circumstances for people of color can eliminate health inequities.
- ***When talking about working upstream and operationalizing an SDOHE approach***, it is important not to create a false dichotomy between current prevention strategies and working to create the underlying conditions needed for individuals and communities to achieve good health. We must do "both/and" NOT "either/or."

  Emerging SDOHE-focused strategies and approaches that appear to be effective (see recommended reading) include developing microenterprise and cooperative ventures where women have shared ownership and decisionmaking power, and which use culturally based principles. With such opportunities, low-income women learn that they have something to offer and gain concrete benefits from producing for themselves and their families.
- ***Engage communities in determining the most effective interventions in addressing the epidemic.*** Instead of letting academic and government researchers lead the way in setting the criteria for what works in communities of which they are not a part, allow community-based organizations (CBOs) to help determine what works and to formally document their effectiveness and designate *that* work as an evidence-based practice.
- ***Foundations have an important role in this paradigm shift.*** Foundations should adopt multiyear funding and other strategies that enable CBOs to institutionalize their work to address SDOHE as they relate to stemming the tide of HIV/AIDS among women of color.

Given the magnitude and complexity of the challenge, we realize that shifting the prevention paradigm requires the collective will and vision of all stakeholders. We also recognize that identifying and/or developing effective program ideas and funding strategies requires deeply listening to people and communities most affected by the disease and then working with them to develop appropriate solutions. We also know that this kind of work requires a sustained commitment. Our pledge has been to move from passion and theory to effective practice. We invite our colleagues to join us.

RECOMMENDED READING

Marshall, Khiya, Cynthia Prather, Kim Williams, et al., Prevention Research Branch, Division of HIV/AIDS Prevention, Centers for Disease Control and Prevention, *It's All About ME: Using Micro-Enterprise as an HIV Prevention Intervention for Impoverished Women*, poster session, American Public Health Association annual meeting, October 27, 2008.

Sherman, S.G., D. German, Y. Cheng, et al., "The Evaluation of the JEWEL Project: An Innovative Economic Enhancement and HIV Prevention Intervention Study Targeting Drug Using Women Involved in Prostitution," *AIDS Care*, 18(1):1-11, January 2006.

Stratford, Dale, Yuko Mizuno, Kim Williams, et al., "Addressing Poverty as Risk for Disease: Recommendations from CDC's Consultation on Microenterprise as HIV Prevention," *Public Health Reports* 123:9-20, January/February 2008.

SOURCES

Centers for Disease Control and Prevention (CDC), "Leading Causes of Death by Age Group, Black, Females, United States – 1999," <http://www.cdc.gov/women/lcod/99black.pdf>, 1999.

District of Columbia Department of Health, *District of Columbia HIV/AIDS Epidemiology Update, 2008* (Washington, DC: February 2009).

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