



HARVARD JOURNAL
OF
AFRICAN AMERICAN
PUBLIC POLICY



John F. Kennedy School of Government, Harvard University

INVISIBLE
HIV/AIDS in the African American Community

Featuring...

Lorraine Cole, Black Women's Health Imperative
Deborah Prothrow-Stith, Harvard School of Public Health
Robin G. Steinberg, Bronx Defenders

Eleni Andreadis
Sara Bleich and Kalahn Taylor-Clark
Cathy J. Cohen
Robert E. Fullilove and Mindy Thompson Fullilove
Avis A. Jones-DeWeever
Pernessa Seele

Volume XI • Summer 2005

HARVARD JOURNAL OF AFRICAN AMERICAN PUBLIC POLICY

JOHN F. KENNEDY SCHOOL OF GOVERNMENT
HARVARD UNIVERSITY

Summer 2005
Cambridge, Massachusetts

The Harvard Journal of African American Public Policy (ISSN# 1081-0463) is published annually at the John F. Kennedy School of Government at Harvard University. An annual subscription is \$10 for students, \$20 for individuals and \$40 for libraries and institutions. Subscriptions will be automatically renewed unless notice to the contrary is received at the office. Additional copies of volumes 1-10 may be available for \$10 each from the Subscriptions Department, Harvard Journal of African American Public Policy, 79 JFK Street, Cambridge, MA 02138.

DONATIONS: Donations provided in support of the Harvard Journal of African American Public Policy are tax deductible as a non-profit gift under the John F. Kennedy School of Government at Harvard University's IRS 501(c)(3) status. Please specify intent.

POSTMASTER: Send address changes to Harvard Journal of African American Public Policy, 79 JFK Street, Cambridge, MA 02138, or e-mail hjaap@ksg.harvard.edu.

COPYRIGHT © 2005 BY THE PRESIDENT AND FELLOWS OF
HARVARD COLLEGE.

ALL RIGHTS RESERVED

The Harvard Journal of African American Public Policy does not accept responsibility for the views expressed by individual authors. No part of the publication may be reproduced or transmitted in any form without the expressed written consent of the editors of the Harvard Journal of African American Public Policy.

CALL FOR PAPERS

The *Harvard Journal of African American Public Policy* accepts unsolicited articles year round and is currently accepting submissions for Volume XII to be published summer 2006.

The *Harvard Journal of African American Public Policy* is an annual, nonpartisan scholarly review published by the John F. Kennedy School of Government at Harvard University. Our mission is to educate and provide leadership that improves the quality of public policies affecting the African American community. In so doing, we hope to further the economic, social, and political empowerment of African Americans.

We are interested in manuscripts that emphasize the relationship between policy making and the political, social, and economic environments affecting African Americans in the United States.

SUBMISSION GUIDELINES

To be eligible for the editorial review:

- Articles must be original and unpublished
- Articles should be 5-30 double-spaced pages
- Articles should be formatted on any version of Microsoft Word
- References and endnotes should be formatted according to the guidelines and author-date system of the *Chicago Manual of Style*. Footnotes are not accepted. All figures, tables, and charts should be submitted as entirely separate files.

In addition, we request that all authors submit the following:

- A cover page with the submission title, author's name, mailing address, e-mail address, daytime telephone number, and a brief biography
- Five hard copies of the article
- An electronic copy of the article on a 3.5" IBM diskette or formatted CD
- A 100-word abstract

Authors are required to cooperate with editing and fact checking.

The deadline is November 1, 2005.

MAIL ENTRIES TO:

Harvard Journal of African American Public Policy
John F. Kennedy School of Government
Harvard University
79 John F. Kennedy Street
Cambridge, MA 02138

PLEASE CONTACT US WITH ANY QUESTIONS AT:

Tel: 617-496-0517

Fax: 617-384-9555

Email: hjaap@ksg.harvard.edu

Website: <http://www.ksg.harvard.edu/HJAAP>

**HARVARD JOURNAL
OF AFRICAN AMERICAN
PUBLIC POLICY**

**JOHN F. KENNEDY SCHOOL OF GOVERNMENT
HARVARD UNIVERSITY**

Summer 2005
Cambridge, Massachusetts

The editorial board of the *Harvard Journal of African American Public Policy* would like to thank the following individuals and organizations for their generous support and contributions to the publication of this issue:

John F. Kennedy School of Government

Dean Joseph McCarthy

Helaine Daniels

Kennedy School Student Government

Richard Parker

Christine Connare

HARVARD JOURNAL OF AFRICAN AMERICAN PUBLIC POLICY

2004-2005 EDITORIAL BOARD

EDITORIAL BOARD

GERALYN RICHARD

Editor-in-Chief

ERICA L. MCKNIGHT

Managing Editor of Operations

FELECIA MCCRAY

Managing Editor of Publication

BRIA GILLUM

Associate Publisher of Finance

ASHLEY STEWART

Associate Publisher of Subscriptions

BRANDON HUDSPETH

Associate Publisher of Advertising

QUEEN NWORISARA-QUINN

Associate Publisher of Community Relations

CHRISTOPHER CARTER

Associate Publisher of Web Development

DOMINICA HENDERSON

Grant Writer

CHRISTINE CONNARE

Publisher

RICHARD PARKER

Faculty Advisor

EDITORS

QUENTIN BARBER

MARK CANAVERA

CHRISTOPHER CARTER

JOHNSON ELUGBADEBO

TREINA FABRE

BRIA GILLUM

ELLEN KNEBEL

JAMES KU

ERICA L. MCKNIGHT

TUMELO MOLOKO

FOLAKE OGUNTEBI

RACHELLE PIERRE

SAMUEL ROE

ALEXANDRA ZUBER

GUEST EDITOR

MICHAELJULIUS IDANI

Oxford University

EXECUTIVE ADVISORY BOARD

LERONE BENNETT, JR.

Ebony Magazine

FRANCES BRISBANE

State University of New York

HENRY LOUIS GATES, JR.

Harvard University

DOROTHY GILLIAM

The Washington Post

ROBERT HOLLAND

WorkPlace Integrators

JAMES LLORENS

Southern University

DAVID THOMAS

Harvard University

CORNEL WEST

Princeton University

WILLIAM JULIUS WILSON

Harvard University

HARVARD JOURNAL OF AFRICAN AMERICAN PUBLIC POLICY

TABLE OF CONTENTS

EDITORS' NOTE11

ARTICLES

Black Men on the "Down-Low" and the HIV Epidemic:
The Need for Research and Intervention Strategies
Sara Bleich and Kalahn Taylor-Clark13

HIV/AIDS: Leadership Challenges in Africa and in the African Diaspora
Deborah Prothrow-Stith21

HIV/AIDS in the African American Community: The Legacy of Urban
Abandonment
Robert E. Fullilove and Mindy Thompson Fullilove33

Unprotected: HIV Prison Policy and the Deadly Politics of Denial
Robin G. Steinberg43

The Politics of HIV Prevention and Black Women
Lorraine Cole51

INTERVIEWS

Power, Politics, and HIV/AIDS: An Interview with Cathy J. Cohen
Mark Canavera63

Restoring Our Faith: HIV/AIDS and Black Faith Communities
An Interview with Pernessa Seele
Erica L. McKnight71

COMMENTARY

Saving Ourselves: African American Women and the HIV/AIDS Crisis
Avis A. Jones-DeWeever79

FILM REVIEW

The Lost Generation: A Documentary Film Review of *A Closer Walk*
Eleni Andreadis85

Editors' Note

Geralyn Richard

Felecia McCray

It is difficult to ignore the escalating rate of HIV/AIDS within the African American community. Regional statistics for infection rates among African Americans rival those in other countries whose national identities have become indistinguishable from this global pandemic. Unfortunately, many in the United States continue to examine this issue through the very narrow lens of health care. However, no place else in the world is HIV/AIDS a health care issue alone, and many rarely consider the ways in which this epidemic is sweeping through Black communities. The lack of attention paid to the looming crisis of HIV/AIDS in the African American community often conjures the renowned line Ralph Ellison penned in his classic *Invisible Man*: "I am invisible, understand, simply because people refuse to see me." It is within this context that we have chosen to dedicate the eleventh volume of the *Harvard Journal of African American Public Policy* to the exploration of HIV/AIDS within the African American community.

Entitled *Invisible: HIV/AIDS in the African American Community*, Volume XI aims to capture the current state of this growing epidemic and reveal the far-reaching implications of HIV/AIDS for Black communities. We also hope to broaden the scope of this topic to reveal how its complexities manifest in various contexts, including but not limited to community and national leadership, housing policies, and the current U.S. prison system.

This volume reflects the diversity of perspectives regarding HIV/AIDS in the African American community and seeks to engage readers by highlighting the dense reality of this crisis.

Sara Bleich and Kalahn Taylor-Clark, Ph.D. candidates at the Harvard School of Public Health, introduce *Invisible* by exploring the "down-low" phenomenon that has recently been popularized by the media. Emphasizing the need for more substantive research to legitimate the relevance of the "down-low" as a contributing factor to increased infection within Black communities, Bleich and Taylor-Clark also recommend intervention strategies that address the heightened susceptibility to infection associated with this trend.

An examination of HIV/AIDS in the African American community would be incomplete without understanding the function of leadership in any crisis. Deborah Prothrow-Stith, associate dean of the Harvard School of Public Health, outlines the challenges that leaders face in the age of HIV/AIDS, detailing the instrumental role of leadership and governance in effectively responding to public health crises both domestically and abroad. To illustrate, Prothrow-Stith imparts four important components that potentially define the success or failure of policymakers' responses to the impending HIV/AIDS crisis in the African American community and the African Diaspora.

With reference to HIV/AIDS in the African American community, the quality and significance of leadership and governance is not isolated to the public health arena. Robert E. Fullilove and Mindy Thompson Fullilove, both of the Mailman

School of Public Health at Columbia University, seamlessly illustrate how the development and execution of urban renewal programs between 1950 and 1970 weakened the social networks and cohesion of Black neighborhoods and precipitated the HIV/AIDS crisis that the African American community faces today. This legacy of urban abandonment assesses the enduring effects of past policy decisions — a lesson for current and future policy makers — while bringing into focus the various social factors that enabled HIV/AIDS to evolve and weave itself through Black communities. Moreover, Robin G. Steinberg, executive director of the Bronx Defenders, discusses policymakers' refusal to acknowledge and address HIV/AIDS as a crisis in the U.S. prison system and examines how the deadly politics of denial advance the virus and disease as a public health crisis by failing to protect populations both within and outside prison walls.

Valiant efforts are being made to address this problem within the African American community, and *Invisible* aims to encourage both discourse and action. Lorraine Cole, president and CEO of the Black Women's Health Imperative, analyzes the disproportionate rates of infection among Black women and identifies a comprehensive strategy to protect women. Such policy would include the development of microbicides to protect women against HIV infection, universal quality health care, vaccine research, enhanced sex education, and the empowerment of women to assume personal responsibility for their health and well-being.

An interview with Cathy J. Cohen, director of the Center for the Study of Race, Politics, and Culture at the University of Chicago, illumines the need for social and empirical research as a requisite to understanding the systemic and structural conditions that advance HIV infection in the African American community. And in an interview with Pernessa Seele, executive director of The Balm In Gilead, the role of Black faith communities as the foundation and mobilizing force of Black political and social movements is revisited. Seele shares the work her organization is doing to destroy the perpetual stigma surrounding HIV/AIDS within Black faith communities while simultaneously building their capacity to create HIV/AIDS ministries to address the needs of the communities they serve. Looking ahead, Avis A. Jones-DeWeever of the Institute for Women's Policy Research offers a commentary about how the linked-fate of Black men and women contributes to the feminization of HIV/AIDS in Black communities and will ultimately inform any effective measures against one of the greatest challenges our community has faced. Finally, a review of director Robert Bilheimer's documentary *A Closer Walk* reminds us that the plight of Black communities is the plight of the world as we collectively endeavor to fight this global pandemic.

It is our hope that *Invisible* will inspire our readers to, as Pernessa Seele pleads, *do something* so that our collective efforts as a community and a nation might enable others to see HIV/AIDS in the African American community for the crisis that it is.

Black Men on the “Down-Low” and the HIV Epidemic: The Need for Research and Intervention Strategies

Sara Bleich and Kalahn Taylor-Clark

ABSTRACT

HIV remains a critical health issue in the Black community. Black men who have sex with men and women (BMSM/W) — also known as men on the “down-low” (or “DL”) — are disproportionately affected by HIV/AIDS and have recently become the focus of scholarly and media attention. This paper synthesizes the existing empirical literature on HIV prevalence and risk factors in the BMSM/W population, discusses the shortcomings of available research, proposes recommendations for future studies, and assesses the strengths and weaknesses of existing intervention strategies for this subgroup.

INTRODUCTION

Black men who have sex with men and women (BMSM/W) — also known as men on the “down-low” (or “DL”) — have recently become the focus of scholarly and media attention.¹ MSM/W are defined as men who consider themselves heterosexual but engage in homosexual behaviors, which are typically not openly discussed or acknowledged.²

The goal of this paper is three-fold. First, we synthesize the existing empirical literature on HIV prevalence and risk factors within the Black community, in general, and within the BMSM/W population, in particular. Next, we discuss the shortcomings of research in this area and propose several recommendations for future studies. Finally, we conclude with an assessment of the strengths and weaknesses of proposed and existing intervention strategies to deal with HIV prevention and care in the BMSM/W population.

Sara Bleich is a Ph.D. candidate in health policy at Harvard University and a research assistant at the Harvard Initiative for Global Health. Her dissertation focuses on the determinants of obesity in Mexico. She is also interested in disparities underlying differential access to health care. In 2000, she graduated from Columbia University with a bachelor of arts degree in psychology. Kalahn Taylor-Clark, M.P.H., is a Ph.D. candidate in health policy at Harvard University and a W.K. Kellogg Fellow in health policy research. Her dissertation focuses on government, the public, and health policy.

RESEARCH ON HIV PREVALENCE AND RISK FACTORS IN AFRICAN AMERICANS: WHAT WE KNOW

Blacks compose approximately 13 percent of the U.S. population, yet they account for 39 percent of AIDS cases diagnosed since the beginning of the epidemic and over half of HIV diagnoses in 2002 (Denizet-Lewis 2003). The number of HIV/AIDS cases reported among Blacks is greater than any other racial or ethnic group (CDC 2001b, 6). In 2000, HIV was the leading cause of death for Black males aged 25 to 44 compared to the fifth leading cause of death for White males in the same age group (Anderson 2002, 21–28).

Although Black men account for most of the new HIV infections among African Americans, Black women compose a growing share. In 1991, Black women represented 22 percent of new HIV/AIDS cases reported among African Americans. By 2001, Black women represented more than one-third (CDC 2001b, 32). Empirical evidence indicates that 62 percent of HIV infections among Black women are the result of heterosexual contact (CDC 2002, 20).

Nascent literature on HIV risk among men who sleep with men (MSM) and MSM/W suggests that increased attention on the BMSM/W population is appropriate. First, research indicates that there are racial disparities in HIV infection between MSM/W populations. BMSM/W have 4.4 times higher odds of HIV infection compared to their White counterparts (CDC 2001c, 440). Second, within the Black community, the BMSM/W population has disproportionately higher rates of HIV infection compared to other Black men. In Los Angeles, one study estimates that BMSM/W are 30 times more likely to be infected with HIV than Blacks who engage only in heterosexual behavior and 13 times more likely than Black homosexuals (LACDHS 2000). Third, 64 percent of women infected with HIV are African American, and the leading cause of HIV infection among Black women is heterosexual contact (CDC 2002, 18). Popular media coverage of men on the “DL” suggests that increased infection in African American women may be linked to the BMSM/W population, yet no empirical research has been conducted to make this connection (Denizet-Lewis 2003).

A myriad of risk factors may contribute to the rising HIV rates within the BMSM/W population. Although more than a third of Blacks say HIV/AIDS is the most urgent health problem facing the nation, Blacks are much less likely than Whites to say that they are personally concerned about becoming infected (*Washington Post/KFF* 2002). According to the CDC, 90 percent of young Black men who sleep with men do not know they are HIV positive (CDC 2003a, 83–84). We have identified two potential reasons for BMSM’s lack of knowledge about their HIV status. First, saturation of HIV/AIDS prevention measures and long-term efforts to maintain safer sex practices has led to what some researchers are calling “AIDS burnout,” which refers to the difficulty of sustaining behavior change over a lifetime. A four-city study indicates that AIDS burnout is an independent predictor of unprotected anal intercourse among HIV-seropositive MSM (Ostrow et al. 2002). In addition, some researchers speculate that pharmaceutical advertisements that minimize the negative aspects of HIV infection and highly active anti-retroviral therapy (HAART), coupled with unrealistically upbeat portrayals of HIV-seroposi-

tive persons, may also lead to increased risk behavior (Dilley, Woods, and McFarland 1997; Remien et al. 1998). To date, no studies have measured the effects of AIDS burnout on increased HIV risk among potential BMSM/W populations.

Also, some research suggests that race compounded with the sexual behaviors of BMSM/W may increase stigmatization or discrimination by medical personnel (CDC 2001c, 440). This, in turn, can reduce the willingness of the BMSM/W population to undergo HIV testing, return for test results, or adhere to medication regimes (Malebranche 2003). It may also exacerbate client distrust in health care providers and lead to a decrease in knowledge of their HIV status (Jordon, Vaughan, and Hood 2004; Blair, Fleming, and Karon 2002). Certainly, delays in HIV diagnosis and treatment can lead to more rapid progression of the disease as well as increased risk among sexual networks of BMSM/W.

Another factor that complicates prevention and treatment efforts is how BMSM/W self-identify. Popular media coverage, such as that in the June 6, 2001 *Village Voice*, suggests that the evolution of "DL" culture may be largely associated with the stigmatization of homosexuality by the larger Black community or may be a response to the desire of BMSM/W to avoid stereotypes of gay, White male culture in an effort preserve their masculinity. BMSM are much more likely than WMSM to self-classify as heterosexual. A CDC-sponsored survey of 8,780 infected MSM found that 24 percent of African American men identified as heterosexual, compared with 6 percent of White men (CDC 2001a, 10–11). How this group characterizes their sexual identity may lead health care workers to misclassify risk behaviors within this population. This may reduce the efficacy of prevention and treatment efforts by health care workers and may be particularly problematic for those persons with other STDs.

The presence of STDs can increase chances of contracting or transmitting HIV. African Americans have the highest STD rates in the United States. For example, compared to Whites, Blacks are 24 times more likely to have gonorrhea and 8 times more likely to have syphilis (CDC 2003b, 104). Moreover, STDs can facilitate transmission of HIV by increasing infectiousness or susceptibility. In other words, a person who is co-infected with HIV and another STD has higher chance of spreading HIV to others, and a person with an STD has a higher chance of contracting HIV (Fleming and Wasserheit 1999). If BMSM/W are disproportionately affected by other STDs, they may have an increased risk of contracting HIV. To date, no quantitative research has explored this relationship in BMSM/W populations.

WHAT KIND OF RESEARCH NEEDS TO BE DONE?

There are currently no scientific studies looking exclusively at HIV and BMSM/W. The absence of an empirical knowledge base makes it difficult to fully understand the problem and subsequently offer useful solutions. Moreover, what is available has been conducted in major cities and is often not generalizable to the larger population. Broader research focused on the BMSM/W population will allow us to better understand HIV trends and risk factors as they pertain to this subgroup in the United States. It may also shed light on whether there is a link between the behaviors of BMSM/W and rising HIV infection among African American women. As a com-

plement to quantitative survey research, it will also be important to conduct qualitative studies to gain an in-depth understanding of sexual identity, perceived risk, and needed interventions targeted to the BMSM/W population. Some possible directions for future research are discussed below.

Examine the Role of Media in Influencing Health-Seeking Behavior of Black Men

As is highlighted above, AIDS burnout seems to affect a broad population of people. For example, research has shown that MSM may be returning to riskier sexual practices that were given up earlier in the epidemic (Dilley, Woods, and McFarland 1997). The extent to which this phenomenon occurs within the BMSM/W population will matter most to those who are crafting messages and interventions targeted at this group. More research on the media's influence on BMSM/W is essential to developing effective prevention messages.

Explore Co-Infection Rates of HIV and STDs

Given that the presence of STDs may facilitate HIV transmission, it is necessary to understand the prevalence of STDs among Black men who have sex with men and women. This area of research will be particularly important since African Americans have the highest rate of STD infection in the United States.

Conduct Empirical Research on the Relationship between HIV Infection in Black Women and BMSM/W

To date, there exists no empirical evidence to support popular media claims that HIV in Black women may be linked to BMSM/W. More research in this area will improve our understanding of the epidemiology of HIV in Black women and help health care workers better target prevention and treatment efforts.

Conduct Qualitative Research to Better Understand the Identity Construction of BMSM/W

Given the existing literature, which suggests that BMSM/W are more likely to self-identify as heterosexual, understanding this sexual identity construction will be important. For example, it is possible that perceived discrimination or stigma might contribute to non-disclosure of BMSM/W's sexual behavior. A better understanding of this identity formation will be important for both their sexual partners and health care providers, among others. It may also add clarity to the media's current presentation of this group.

Explore the Role of Spirituality and the Black Church

Black ministers have one of the most influential bully pulpits in the Black community. Their decisions to confront or ignore BMSM/W may have significant consequences for HIV infection rates in the African American community. There

still lacks a productive body of qualitative research that explores the impact of religion and spirituality on BMSM/W behaviors. Findings from this research may allow Black ministries and other faith-based organizations to more effectively provide needed HIV prevention and support services.

Challenges to Conducting Research in this Population

Researchers who engage this field of study have the potential to make profound contributions to an area of investigation about which little is known or understood. However, it is important to be cognizant of the challenges involved in studying this population. For example, that BMSM/W often self-classify as heterosexual can make it difficult to recruit study participants. Therefore, research designs that do not account for the construction of Black male sexual identity are likely to yield inadequate response rates from the target population. In addition, given the stigma and discrimination associated with Black men who have sex with men and women, confidentiality and careful dissemination of findings will be critical (Wheeler 2003).

RECOMMENDATIONS FOR FUTURE INTERVENTIONS

Although HIV/AIDS has had a tragic impact on the BMSM/W population and African Americans more generally, there is reason for hope. A few programs have been relatively successful in reducing the spread of HIV in the Black community, including, but not limited to People of Color in Crisis (POCC), the Critical Thinking and Cultural Affirmation (CTCA) model, the Down Low Barbershop Project, and The Balm In Gilead, which provides capacity building to churches and pastors and has created a venue for discussing issues of sexuality and HIV in the Black faith-based community (Wheeler 2004).

The development and implementation of successful intervention strategies requires the consideration of a potentially unique epidemiological and social profile of HIV within the BMSM/W population. Black men who sleep with men and women are not immune to HIV prevention and treatment efforts; more effective services need to be made available. This review has identified a number of key components that may be successful at preventing and treating HIV infection in the BMSM/W population.

Provide Culturally Competent HIV Prevention and Treatment Services

A review of the research in this area finds that the actions of health care providers and staff may exacerbate the problem of HIV in BMSM/W populations (CDC, 2003a). The goal of culturally competent services with respect to this population is to increase client trust in health care providers, to raise BMSM/W's awareness of their HIV status, and to target risk factors associated with their behaviors.

To do this, organizations must train staff to diminish "shaming and blaming" the individual. This means that providers must be given the tools to make a client feel safe in his interaction with the provider without making him feel ashamed about his behavior or identity. Organizations should provide *all* staff and clinicians with strategies to ask questions that are clear of judgment so that they can learn more

about the Black man's perspective of his own sexual identity and behaviors (Gallant 2004). This knowledge should allow staff and clinicians to more effectively deliver interventions.

Of note, demographic matching does not necessarily mean that staff and clinicians are culturally competent. In other words, being Black and caring for Black clients does not guarantee effective delivery of services just as being White and caring for Black clients does not ensure ineffectual care.

Design Intervention Strategies with the Target Population in Mind

Available knowledge of HIV prevalence, risk factors, and sociocultural factors affecting the BMSM/W population necessitate appropriately tailored interventions. Interventions that work effectively to reduce HIV infection in the gay White male population, for example, are unlikely to be as effective in BMSM/W populations (Fitzpatrick et al. 2002). Moreover, given that BMSM/W are significantly more likely than their White counterparts to describe themselves as heterosexual, intervention strategies designed to specifically target Black gay or bisexual men may leave out large portions of the BMSM/W population (Wheeler 2003). Successful intervention plans should consider the nuances in this identity formation.

In the short term, encouraging HIV testing — preferably using tests that do not require follow-up visits — will be critical since an overwhelming majority of HIV-positive BMSM are unaware of their status.

In the long term, distrust in the medical care system makes a focus on community clinics and other support services another key area of attention.³ Designing and implementing HIV programs with members of the community will be an important component of successful prevention and treatment efforts. However, as long as stigma and discrimination exist both within and outside of the Black community, Black men who have sex with men and women may continue to conceal their sexual behaviors. Therefore, intervention programs should be developed to encourage honest disclosure of sexual activity from BMSM/W.

CONCLUSION

Unfortunately, the end of the HIV epidemic is not in sight. Yet, with increased research and intervention efforts targeted to BMSM and BMSM/W, HIV/AIDS rates may be significantly reduced within the African American population. To that end, sustained attention from within and outside of the Black community is necessary. A research agenda that targets BMSM/W will require both qualitative and quantitative studies, which specifically consider the effects of sexual identity, race, and discrimination on HIV risk and health-seeking behaviors. From this work, it will be possible to design and implement more effective intervention programs. Going forward, an important consideration for policy makers should be the development of evidence-based policies that will help to reduce transmission, raise awareness, and increase access to prevention and treatment programs for the BMSM/W population.

REFERENCES

- Anderson, Robert N. 2002. Leading Causes of Death for 2000. NCHS *National Vital Statistics Report* 50(16). www.cdc.gov/nchs/data/nvsr/nvsr50/nvsr50_16.pdf.
- Blair, Janet M., Patricia L. Fleming, and John M. Karon. 2002. Trends in AIDS Incidence and Survival among Racial/Ethnic Minority Men Who Have Sex with Men, United States, 1990–1999. *Journal of Acquired Immune Deficiency Syndromes* 31(3): 339–347.
- Centers for Disease Control and Prevention (CDC). 2001a. HIV/AIDS among Racial/Ethnic Minority Men Who Have Sex with Men—United States, 1989–1998. *MMWR* 40(1): 4–11. www.cdc.gov/mmwr/preview/mmwrhtml/mm4901a2.htm.
- . 2001b. *HIV/AIDS Surveillance Report* 13(2). Atlanta, GA: U.S. Department of Health and Human Services, CDC. www.cdc.gov/hiv/stats/hasr1302.pdf.
- . 2001c. HIV Incidence among Young Men Who Have Sex with Men - Seven U.S. Cities, 1994–2000. *MMWR* 50(21): 440–444. www.cdc.gov/mmwr/preview/mmwrhtml/mm5021a4.htm.
- . 2002. *HIV/AIDS Surveillance Report* 14(2). Atlanta, GA: U.S. Department of Health and Human Services, CDC. www.cdc.gov/hiv/stats/hasr1402/2002SurveillanceReport.pdf.
- . 2003a. HIV/STD Risks in Young Men Who Have Sex with Men Who Do Not Disclose Their Sexual Orientation—Six U.S. Cities, 1994–2000. *MMWR* 52(5): 81–85. www.cdc.gov/mmwr/PDF/wk/mm5205.pdf.
- . 2003b. *Sexually Transmitted Disease Surveillance, 2002*. Prepared by the U.S. Department of Health and Human Services, Centers for Disease Control. www.cdc.gov/std/stats02/toc2002.htm.
- Denizet-Lewis, B. 2003. Double Lives on the Down Low. *New York Times Magazine*, August 3.
- Dilley, James W., William J. Woods, and William McFarland. 1997. Are Advances in Treatment Changing Views about High Risk Sex? *New England Journal of Medicine* 337(7): 501–502.
- Fitzpatrick, L., et al. 2002. *HIV Prevention Strategies in Communities of Color: Effective Behavioral Intervention Programs for African Americans*. San Francisco: The Cochrane Collaboration and UCSF AIDS Research Institute.
- Fleming, Douglas T., and Judith N. Wasserheit. 1999. From Epidemiological Synergy to Public Health Policy and Practice: The Contribution of Other Sexually Transmitted Diseases to Sexual Transmission of HIV Infection. *Sexually Transmitted Infections* 75(1): 3–17.
- Gallant, Joel E. 2004. HIV Counseling, Testing, and Referral. *American Family Physician* 70(2): 295–303.
- Hagen, K.S. 2005. Bad Blood: The Tuskegee Syphilis Study and Legacy Recruitment for Experimental AIDS Vaccines. *New Directions for Adult and Continuing Education* 105(Spring): 31–41.
- Jordan W.C., A.C. Vaughn, and R.G. Hood. 2004. African Americans and HIV/AIDS: Cultural Concerns." *AIDS Read* 14(10 Supplement): S22–S25.
- Los Angeles County Department of Health Services (LACDHS). 2000. *HIV Prevention Plan 2000*. Los Angeles, CA: Office of AIDS Programs and Policy, LACDHS.
- Malebranche, David J. 2003. Black Men Who Have Sex with Men and the HIV Epidemic: Next Steps for Public Health. *American Journal of Public Health* 93(6): 862–865.
- Ostrow, D.G., K. J. Fox, J. S. Chmiel, A. Silvestre, B. R. Visscher, P. A. Vanable, L. P. Jacobson, and S. A. Strathdee. 2002. Attitudes Towards Highly Active Antiretroviral Therapy Are Associated With Sexual Risk-Taking Among HIV-Infected and Uninfected Homosexual Men. *AIDS* 16(5): 775–780.

Remien, R.H., G. Wagner, A. Carballo-Diequez, and C. Dolezal. 1998. Who May Be Engaging in High-Risk Sex Due to Medical Treatment Advances? *AIDS* 12(12): 1560–1561.

Washington Post/Kaiser Family Foundation (KFF). 2002. National Survey of the Public Attitudes Towards HIV/AIDS in the U.S. and the World, July 6–7.

Wheeler, Darrell P. 2003. Methodological Issues in Conducting Community-Based Health and Social Services Research among Urban Black and African American LGB Populations. *Journal of Gay and Lesbian Social Services* 15(1/2): 65–78.

———. 2004. *Fact Sheet #54E: What Are Black Men's HIV Prevention Needs?* San Francisco, CA: Center for AIDS Prevention Studies, University of California at San Francisco.

ENDNOTES

1 In this paper, the terms Black and African American will be used interchangeably.

2 While men on the “DL” is a relatively recent term, it is not a new practice.

3 Research suggests that Black distrust of the medical care system largely grew out of the Tuskegee syphilis study, conducted from 1932 to 1972, where the federal government withheld medical treatment from syphilis-infected Black men in Alabama in order to study the natural progression of the disease (Hagen 2005, 32).

HIV/AIDS: Leadership Challenges in Africa and in the African Diaspora

Deborah Prothrow-Stith

ABSTRACT

The HIV/AIDS pandemic has confirmed the unmistakable: leadership in a public health crisis is crucial. Millions of lives and trillions of dollars are at stake. In Africa and the African Diaspora, the epidemic has disproportionately disastrous consequences with corresponding challenges to leadership and governance. This article explores four such challenges: 1) getting out of the gate — acknowledging the problem; 2) understanding and handling mistrust; 3) building public health infrastructure; and 4) confronting poverty — the greatest threat to health. The lessons gleaned from leaders and their responses to these challenges can be used to chart the way forward and set standards for responses to future epidemics.

THE HIV/AIDS BURDEN IN AFRICA AND THE DIASPORA

The numbers are staggering and the tragedy unimaginable. Nearly a quarter of a century into this global pandemic, the good news is scarce. HIV/AIDS has taken a tremendous toll on health and economies throughout the world. The disproportionate impact on poor people, Africans, and people of the African Diaspora is predictable because epidemics and disasters tend to have a greater impact on those already at a disadvantage. Oppression, economic despair, a history of abuse and discrimination, imbalances in power, and multiple existing health problems are fertile ground for an epidemic. In these circumstances, disproportionate impact is predictable, but nonetheless tragic.

This disparate burden on Africans and people of color in the United States is evident in the worldwide statistics on HIV/AIDS that are available from the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the United States Centers for Disease Control and Prevention (UNAIDS/WHO 2004; CDC 2005). Of the 39.4 million people now estimated to be living with HIV/AIDS, 25.4 million (64 percent) are in sub-Saharan Africa. Of the 4.9 million people who were infected in 2004, 3.1 million (63 percent) are in sub-Saharan Africa, where an estimated 20 million peo-

*Deborah Prothrow-Stith, M.D., is associate dean, professor, and founder of the Division of Practice at the Harvard School of Public Health. Appointed in 1987 as the first woman and youngest-ever Commissioner of Public Health for the Commonwealth of Massachusetts, she expanded treatment programs for AIDS, as well as substance abuse services. Co-author of *Murder Is No Accident*, Dr. Prothrow-Stith is nationally recognized for her leadership in addressing violence as a public health problem.*

ple have died from HIV/AIDS since 1981. While the global adult infection rate is 1.1 percent, in sub-Saharan Africa it is 7.4 percent.

In the United States, African Americans are 12.3 percent of the population according to the U.S. census, but they account for 40 percent of all the U.S. HIV/AIDS cases ever diagnosed. African Americans make up 49 percent of those cases diagnosed in 2003, and African American women make up 67 percent of women diagnosed in 2003. Tragically, African American children share a disproportionate burden as well, making up 68 percent of U.S. children younger than thirteen with a new AIDS diagnosis (CDC 2005). This disproportionate burden reflects a similar set of preexisting conditions that represent a fertile ground for an epidemic. Poor people, the descendants of slaves, and those victimized by discrimination and oppression are at greater risk, and the associated challenges to leadership and governance require particular attention.

In Africa and the African Diaspora, HIV/AIDS takes a greater toll on life and health regardless of the variables measured or the assessment methods. In addition to the tragic loss of life, the economic burden of HIV/AIDS in sub-Saharan Africa is considered a major threat to life and health. The loss of trained members of the young adult professional and working classes has blunted economic development and growth. The death of even a few bankers and teachers can devastate a developing country that already has too few members of the professional classes.

Addressing this disproportionate burden — a virtually unmanageable task — requires strong leadership from elected officials, as well as the principals of grassroots and non-governmental organizations and people living with HIV/AIDS. Examples of leadership from elected officials are found in the heads of state of sub-Saharan African countries and African American elected officials in the United States. With HIV/AIDS, there is evidence that leadership and governance have an impact on incidence rates and prevalence. While the impact is not well delineated and the relationship should be explored further, it is sobering to realize that the number of people who die in this epidemic is determined, in part, by the leader and the governance structure.

LEADERSHIP IN PUBLIC HEALTH

Public health as a profession is distinguished from health care delivery in several important ways (Fineberg n.d.). Rather than focus on treating diseases in individual patients, public health focuses on prevention within a group of people (residents of a geographical area, a particular age group, people exposed to a toxin, etc.). Public health uses tools such as epidemiology, economics, and political and behavioral sciences to understand, maintain, and promote the health of a given population. Surveillance, the ongoing measurement of causes of morbidity and mortality, is a basic strategy of public health. The earlier an outbreak or increase in illness or death is detected, the sooner a response can be designed and implemented. The internationally coordinated response to the SARs threat is an example of an early response that seems to have dampened potential devastation. On the other hand, the response to HIV/AIDS was delayed, both within the United States and internationally where, until very recently, leaders in developing countries struggling with life-threatening

poverty, famine, malaria, emerging democracies, histories of oppression and colonialism, and many other trials were expected to step up to the plate and handle this pandemic as well (Shilts 1987).

In 1987, when I was interviewed for my position as public health commissioner of the Commonwealth of Massachusetts, I was told that the administration didn't want surprises and asked what I would do to avoid surprising the administration. I responded with the obvious ways that I intended to keep everyone aware of the issues and informed about our strategies for addressing them. However, I also added that it was unrealistic to expect no surprises. Public health is full of surprises; the next epidemic or crisis was always looming around the corner. I could promise to organize a concerted, competent, and best effort in responding to the Commonwealth's public health problems, but I could not prevent surprises. They are in the nature of public health. The role of leadership is to acknowledge the crisis early, gear up with a response based on available knowledge, and harness the funds that tend to flow in a crisis. Funds must be used to strengthen the public health infrastructure, improve basic health status, and prepare to respond to future crises.

Politicians hate surprises and problems — unless they are the problems of their opponents. But more than just problems, politicians hate problems without solutions, and public health is full of surprise problems without solutions. "Surprise" problems with HIV/AIDS in the Black community in the United States have emerged consistently around clinical trials and demands for inclusion, concerns about ethical issues and access to care, needle-exchange debates, and insurance and disability claims, to name a few. Examples in other communities and countries, including South Africa, are similar. Commissioners of health, ministers of health, and health directors are engaged in activities daily to strike the appropriate balance between politics and science and handle these problems. There is irony in the predictable nature of the problems, yet they surprise elected officials when they receive media coverage, which can be provoked by many erratic factors.

Effective public health policy requires the merger of science and politics. Thus, leadership in both sectors is necessary. Generally, leaders in these two sectors are from two different worlds. Scientists and politicians operate out of a different fund of knowledge, speak different languages, have different skills, and respond to different incentives and values. Scientists are often narrow, focused, precise, and slow. Politicians are broad, operating at the 30,000-foot level, responsive, pragmatic, and require a timely response. Occasionally, there is overlap between the two sectors, with scientists or health leaders becoming involved in politics by running for office. For example, U.S. Senator Bill Frist (R-Tennessee) is also a physician. When this overlap occurs, there is the possibility of improved public policy on health and science issues because of greater understanding. But this overlap is unusual. On the other hand, appointed health officials such as ministers of health, commissioners of health, and local health directors constantly negotiate a balance between the worlds of politics and science, and are prepared and trained to lead and manage during an epidemic. However, their influence and potential pales next to that of elected officials who must provide life-saving leadership in times of public health catastrophes.

The HIV epidemic has presented one of the most significant challenges in the history of public health. Across the globe, public health leadership at all levels

(local, state, federal) is involved in managing the HIV epidemic. Along with the obvious and much discussed list of public concerns — stigma, resources, inaccurate information in the media, slow science, and many others — is the opportunity within the HIV epidemic to address fundamental public health concerns. It is a chance to address public health infrastructure, basic services like maternal and natal care, and lack of funds or professional capacity to immunize all children. Building a public health infrastructure where there is none or a very weak one in the time of an epidemic is a challenge — to put it mildly. But it is the basic challenge facing public health leaders and elected officials. About the only time the public or elected officials pay attention to public health prevention goals and infrastructure is during an epidemic. Using the increased attention and flow of resources that occur during a crisis to build a prevention system and infrastructure is an ever present task.

FOUR LEADERSHIP CHALLENGES IN A PUBLIC HEALTH CRISIS

When I was commissioner during the first decade of the HIV/AIDS epidemic, the need for leadership across the federal government and the fifty-two state and territorial health departments was quite evident. Responding to activists and protestors in a way that created a partnership, being passionate towards individuals while taking the larger population needs into account, and looking forward so that allies stayed involved and committed were some of the challenges. One of the most difficult challenges was sustaining investment in the basic public health services and infrastructure while attending to the epidemic. I had to strike the balance between funding HIV/AIDS research and prevention (treatment was only available in experimental settings at that time) and funding for the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), an effective program that provides nutrition and food coupons for pregnant or nursing women, infants, and children. When there is a crisis in public health, particularly when it affects middle and upper classes, funds and political attention are diverted appropriately. In a public health crisis, there are four challenges to leadership, regardless of location and circumstance.

Getting out of the Gate: Acknowledging the Problem

Getting out of the gate is not easy. It requires foresight as well as a willingness to be distracted from an already urgent and important set of public policy issues. In the midst of efforts to fulfill promises, live up to expectations, and deal with numerous severe problems, it is hard to step up to the plate on yet another issue.

And the Band Played On (Shilts 1987) is a heartbreaking description of the lack of leadership within President Reagan's administration in the United States during the early years of the HIV/AIDS epidemic. Whether because of frank disdain for homosexuals and what appeared to be a "gay disease" or a shortsighted ignorance of public health, science and the potential for this epidemic, U.S. leaders did very little to prevent HIV/AIDS from spreading.

His Excellency President Yoweri Museveni of Uganda provides an impressive example of effective "getting out of the gate." In 1986, he spearheaded a mass cam-

campaign against HIV/AIDS after his minister of health announced the existence of the virus and disease in Uganda at the UN World Assembly in Geneva. In 1988, a national sero-survey indicated that the average prevalence rate was at 9 percent with peak rates of 30 percent indicated in 1992. But shortly thereafter, the prevalence rates began to decline and have continued to decline ever since. In 1995, the prevalence was estimated at 18.5 percent. This declined to 14.7 percent in 1997, then to 9.5 percent in 1998, and to 8.3 percent at the end of 1999 (Ugandan AIDS Commission Secretariat 2001).

On President Museveni's accomplishments, BBC reporter Joanna Buchan wrote on July 8, 2002, "There have been success stories of course, and Uganda is the most notable. There the political will existed early, and at the very highest levels. The result of a sustained campaign of education and prevention has been that infection rates dropped there in the 1990s, the opposite of what was happening everywhere else, and they are still dropping." President Museveni's quote, "when a lion comes to your village, you must raise the alarm loudly," captures his administration's response to the HIV/AIDS epidemic (Jimoh 2001). And this response has made a difference.

Getting out of the gate on an epidemic requires acknowledging the crisis, facing the challenge, shaping public opinion, garnering the resources, and planning and implementing both harm reduction and prevention strategies. The Ugandan experience seems to indicate that in the case of HIV/AIDS, this kind of out-of-the-gate strategy can make a huge difference.

Understanding and Handling Mistrust

Africans and members of the "colored" African Diaspora have substantial and historic reasons to mistrust science and scientists. Scholars have documented a "legacy of harm" associated with Western medicine and science that can be dated back to the days of antiquity (Bernal 1987; Byrd and Clayton 2002, 158–163). This represents a horrific legacy that metastasized during the eighteenth and nineteenth centuries among European scientists (Prothrow-Stith and Whitaker 1995; Bernal 1987). The mistrust African Americans have of medical research and the U.S. health care system has clear roots in slavery and the use of slaves for medical experimentation. Some of the "great" scientists and contributors to medical knowledge abused slaves in the name of health care (Byrd and Clayton 2002, 194–201). J. Marion Sims, recognized as a founder of modern obstetrics and gynecology, was notorious for his experimentation on slave women, who served as surgical guinea pigs for him. There is an infamous portrait of him, surrounded by other White male medical staff, preparing to conduct an investigation on a slave woman (Byrd and Clayton 2002, 194–201). Documented, contemporary examples of mistreatment of African Americans such as the Tuskegee syphilis experiments exacerbate the historic problems with trust, and the informal stories told from personal experience often add fuel to the fire. Practicing physicians who serve African Americans deal with the skepticism and mistrust of reluctant patients on a daily basis (Smedley, Stith, and Nelson 2002).

The same kind of documentation of abuses in the name of science has been uncovered in South Africa where, during apartheid, horrific accounts of death have been uncovered. Dr. Wouter Basson of South Africa, often referred to as “Dr. Death,” was the supervisor of Johan Theron, who confessed to nearly a decade (1979–1987) of executions of South African prisoners. The murders, of varied methods, were part of Theron’s job, and Dr. Death provided the supplies and materials when chemicals and toxins were used. Dr. Death was director of South Africa’s chemical and biological warfare program at the time and, according to Theron, was responsible for the strategy behind three particularly gruesome murders. Theron was instructed to tie three prisoners up to a tree and smear a jelly-like mixture of chemicals all over their bodies. The aim was to see if the toxins could kill. When the men survived the night and the next day, Theron used his more common mechanism for disposing of bodies by throwing them out of an airplane 100 miles off the coast after injecting them with a muscle relaxant. The aforementioned abuse and malfeasance against Blacks in both South Africa and the United States are examples of the horror that resulted in both historic and contemporary mistrust of science and health care.

Thabo Mbeki’s Comments

In 2000, His Excellency President Thabo Mbeki of the Republic of South Africa questioned the role of the HIV virus in causing the AIDS disease, despite fairly widespread knowledge and documentation to the contrary. His comments received worldwide condemnation from mainstream public health researchers and practitioners. What is often ignored in the discussions that followed is that President Mbeki had a group of radical scientists around him when he questioned the role of the virus, emphasizing instead the role of poverty and tuberculosis. While radical in their ideology, these were not just any scientists. They include professors from respected institutions, molecular biologists, and a Nobel Prize laureate whom I have personally challenged on this very subject. A partial listing of the antiviral etiology of AIDS advisors to President Mbeki can be found in Table 1. These scientists are ideologues who seem to have axes to grind, particularly with the economics of the medical and pharmaceutical industries.

What would cause an astute, forward-thinking, highly respected, and effective leader like President Thabo Mbeki — who was re-elected with 69 percent of the vote with an administration that has shown remarkable progress — to listen to such a fringe group of scientists spouting antiestablishment theories? When the question is examined with respect to the history of science, the answer becomes clear. Apartheid science laid fertile ground for a skeptical, even disdainful, view of science — an inevitable consequence of discrimination, unethical practices, baseless theories for political and economic gain, and horrific acts like those of Dr. Death and Mr. Theron.

Many responded to President Mbeki’s statements on HIV and AIDS with disbelief and disgust, failing to understand why a man who had witnessed so much “state-sponsored” destruction and damage would not believe the world’s mainstream scientists. In these types of circumstances, public health leaders must refrain from

assuming that their good intentions will be trusted and recognized. Rather than questioning the motives and intelligence of a leader like President Mbeki — a typical response — public health researchers and practitioners who must convey the viral causality of AIDS should have understood the history and avoided the blanket, absolute “just trust us” response. In light of the history of science and the serious questions raised recently and reported in the December 14, 2004 *Indianapolis Star* about the ethical conduct of researchers and the United States federal government during the clinical trials of the antiviral agent Nevirapine to prevent mother-to-fetus transmission of HIV during gestation in Uganda, President Mbeki was justified in questioning science, raising the importance of poverty, and demanding a more holistic and accurate approach to AIDS.

He seems to have understood the response to him as an attempt to silence him and have him follow others blindly. At the 13th International AIDS Conference in Durban, in his opening session speech, Mbeki (2000) stated, “Some in our common world consider the questions I and the rest of our government have raised around the HIV/AIDS issue, the subject of the conference you are attending, as akin to grave criminal and genocidal misconduct. What I hear being said repeatedly, stridently, angrily, is — do not ask any questions!”

In order for the correct transfer of information to result in effective public policy, scientists and political leaders must communicate with each other (Thomas, Fine, and Ibrahim 2004). Effective public policy with respect to HIV/AIDS requires cultural competency and communication skills. Cultural competency requires more than knowing the culture of a population. It requires the knowledge and skill set to build trust and operate effectively within the culture. The need for black South African scientists from the south with resources, information, and professional status was clearly illustrated in this scenario with President Mbeki. Currently, the South African government’s approach to HIV/AIDS is widely acclaimed and includes both prevention and substantial investments in antiviral therapy.

Whether it’s the medical experimentation that occurred in the Tuskegee syphilis experiments or the current trials of Dr. Death in South Africa, the negative impact that such malfeasance has on trust is a measurable consequence that public health leaders must consider and address.

Building the Public Health Infrastructure

In an epidemic, resources must be allocated to screening, prevention, and treatment. At the same time, the basic public health infrastructure must be maintained or, as is the case in many developing countries, even created. The balance is not easy to strike. In debt-ridden poor countries, funds are often diverted from essential and basic services, and the practical, ethical, and long-term considerations are huge.

Using a public health crisis to build the basic infrastructure serving a population is a fairly common challenge for public health leaders. There are numerous examples of the role basic health systems and sturdy infrastructure play in effectively responding to major public health crisis. The recent SARS epidemic is an example. Occurring after the U.S. anthrax scare and the HIV pandemic, the U.S. and international responses to SARS took advantage of newly formed worldwide

communications linkages and a fragile, but nevertheless in place, public health infrastructure that was not there at the start of the HIV epidemic.

Maintaining a focus on those not directly affected by the epidemic but in need of basic health and human services is difficult, particularly when there is substantial media attention to a high-profile epidemic. For example, those working to reduce infant mortality, discourage smoking, or immunize children often find it difficult to focus resources and the public's attention during an event like the West Nile virus scare in the United States. Michael Caldwell, health commissioner for Dutchess County, New York, describes a relatively large flow of dollars during the time of widespread media attention about the threat of a West Nile virus outbreak, which has not infected or killed anyone in his county, when compared to funds for the prevention of smoking, a leading cause of death. His challenge was to use the public's and elected officials' interest in West Nile to build the public health infrastructure. With the new funds allocated to his department, he hired an epidemiologist who is now providing much-needed basic surveillance for the county while addressing the potential for West Nile.

The more these basic things are in place, the easier, less expensive, and more effective dispensation will be. A strong public health infrastructure is an essential foundation—so essential that when responding to epidemics, leaders are “positively distracted” by the need to build a foundation. Whether it's trying to prevent infant mortality without dealing with the basic health and nutritional status of young women, or recognizing and responding to an epidemic without a surveillance or health care delivery system, when the basics are not in place, the response to an epidemic is weakened. These basics (water and sewer systems, hygienic practices, nutrition, immunizations, access to care, adequate number of providers of care, etc.) must be the focus of the public health system in every setting. The list is different in rural South Africa than it is in urban Boston. The resources and infrastructure are not comparable; however, in both settings, building and maintaining the basics, especially during an epidemic, is a challenge that confronts the public health officials.

During my tenure as health commissioner, a major challenge was increasing the number of substance abuse treatment slots to reduce an eight-week waiting list. Drug treatment was only indirectly related to HIV/AIDS in the minds of many, and needle exchange was more compelling for some who had a narrow focus on the epidemic. An argument for needle exchange was that it could get people into treatment—a weak argument in the face of this waiting list. There were people who wanted treatment, but there weren't enough slots. Using federal resources and HIV/AIDS dollars, we were able to substantially increase the number of slots. We never had enough slots, and HIV/AIDS continued to spread. I think we might have come close, but I still wonder what would have been the perfect balance in that scenario.

Effective public health leaders understand and embrace this challenge and use the resources and public attention that come with a crisis to build infrastructure. The dilemmas facing Dr. Caldwell with West Nile virus or me with substance abuse treatment slots pale in comparison to those facing health leaders in developing countries.

In the global context, whether in the United States or sub-Saharan Africa, maintaining a focus on those not directly affected by the epidemic, but who are in need of health and human services, is crucial.

Responding to Poverty — the Greatest Threat to Health

Despite its best efforts, public health as a discipline has a bias toward working on the problems of the middle and upper classes. Exceptions are often in the area of communicable diseases that might threaten the middle and upper classes. In the environmental health movement, the example of lead poisoning stands out. Many more relative dollars have been spent on exposures to nuclear sites and parts-per-million-level pesticide contaminations in food, leaving the noncommunicable and much more pervasive and devastating problem of lead poisoning among poor urban children as a second-class issue that receives second-rate attention. Another example is in the issue of violence prevention. Suicide, almost exclusively a middle and upper-middle class problem until recently, has been considered a preventable health problem for far longer than homicide. When the problem spread to suburban schools, homicide gained significant national attention, though concern is still quite limited. Often funding and attention is rooted in the larger society and affects public health professionals, public policy, and funding.

Worldwide, the role of poverty as the major threat to health and the bilateral relationship between poverty and health have been emphasized.¹ An outstanding example of the struggle to incorporate the relationship between health and poverty generally and HIV/AIDS specifically can be found in the Millennium Development Goals (MDG). The MDGs were fashioned during the Millennium Summit, held in September of 2000 in New York City. Representatives from 189 countries, including 147 heads of state, gathered to address a wide range of development issues and recommend roles and responsibilities for both developing and wealthier countries in seven areas: 1) peace, security, and disarmament; 2) development and poverty eradication; 3) protecting our environment; 4) human rights, democracy, and good governance; 5) protecting the vulnerable; 6) meeting the special needs of Africa; and 7) strengthening the United Nations (UN n.d.). The MDGs address development and poverty eradication and were further refined at an international conference in Monterrey, Mexico, and the World Summit on Sustainable Development in Johannesburg, South Africa, both held in 2002.

The MDGs illustrate the two-way relationship between poverty and health. The goals are broad and far-reaching and set a very high bar in most instances. The poverty eradication goal is to achieve a 50 percent reduction in income poverty by 2015 (UN 2001). The vast health inequities in the world were highlighted with particular attention to the significant role HIV/AIDS plays in creating and sustaining inequities. There was clear recognition that many of the sub-Saharan African countries are not on track to meet the MDGs. Coupled with current trends, the poverty target will not be met for 40 years, and, even more troubling, the poverty target for children less than five years old will not be met for 60 years. The overall trends are somewhat positive because of the economic progress in China and India; however,

sub-Saharan Africa is fairing much less well. It was also recognized that rich countries had not met the MDG obligations.

An effective response to HIV/AIDS requires attention to the difficult issues surrounding poverty. Services and attention given in South Africa to women who are HIV positive are flush when compared to homelessness, starvation, and the disregard faced by many desperately poor women who are not positive. Without a balanced approach, perverse incentives can be created and perpetuate the very problem that HIV/AIDS presents. Leaders must create comprehensive systems that somehow provide the basics as a prevention strategy and particular intervention where needed.

If public health practitioners are concerned about HIV prevention, then they must also be concerned about basic access to health. The *2004 State of Africa Report* issued by the Boston University African Presidential Archives and Research Center (APARC) is the third compilation of major addresses from current heads of state. The report contains the following quote by His Excellency President Festus G. Mogae of the Republic of Botswana that illustrates the relationship between poverty and HIV/AIDS in concrete terms that extends across geographic boundaries and easily applies to the challenge the United States also faces with respect to the growing epidemic within African American communities:

Without victory over HIV/AIDS, we cannot hope to defeat poverty through productivity. While the absence of HIV itself is not a guarantee of prosperity, we can be sure that if unchecked, the spread of HIV will condemn us to stagnation and decline (2004, 21).

Of the fourteen countries tracked by APARC, eleven heads of state mention the HIV/AIDS pandemic in their major addresses. The leadership provided by each of these leaders has resulted in remarkably comprehensive national HIV/AIDS prevention and treatment plans in almost every country, despite insufficient funds for implementation. South Africa, Zambia, Mozambique, Botswana, and Uganda are among the countries heralded for their efforts. **Poverty is a risk factor for HIV/AIDS, and HIV/AIDS is a risk factor for individual and national poverty.** Many African heads of state understand this bilateral relationship — a lesson that should not be allowed to escape leadership in the United States.

CONCLUSIONS AND THE WAY FORWARD

In an epidemic, both because of the precise nature and limitations of science, political and lay leadership are crucial. Leaders cannot expect to be perfect and will inevitably make mistakes. However, recovery from mistakes and the capacity to move forward are essential to saving lives and money. Despite the slow start out of the gate, President Thabo Mbeki has put South African money and infrastructure behind treatment and prevention and has fully embraced the 3-by-5 World Health Organization initiative, an international effort to have 3 million people on antiretroviral treatment (ART) by 2005. As a democracy, South Africa was able to debate the policies, the nongovernmental sector was able to step up to the plate to offer treat-

ment services, and the government has changed its policy to reflect current knowledge and standards of care.

The way forward has been made clear by those leaders who have set the example and raised HIV/AIDS to the level of a serious national concern. Several recommendations and observations can be made.

1. Getting out of the gate by acknowledging a public health crisis early can save lives and money.
2. Acknowledging and addressing the deep mistrust Africans and the African Diaspora have because of the horrific race-based history of science can go a long way toward creating an understanding between science and politics and can rebuild trust.
3. Focusing on the basic public health infrastructure in developing countries is essential to improving the response to future epidemics and reducing the health threats to all.
4. There is an intimate relationship between poverty and health, and the HIV/AIDS epidemic has taught the world that lesson. Hopefully it will be remembered for many, many years to come.

REFERENCES

- Bernal, Martin. 1987. *Black Athena*. New Brunswick, NJ: Rutgers University Press.
- Byrd, Michael, and Linda Clayton. 2002. *The American Health Dilemma: A Medical History of African Americans and the Problem of Race, Beginnings to 1900*. New York: Rutledge Press, 2002.
- Centers for Disease Control and Prevention (CDC). 2005. *Fact Sheet: HIV/AIDS Among African Americans Surveillance*. Atlanta, GA: U.S. Department of Health and Human Services, CDC. www.cdc.gov/hiv/pubs/facts/afam.htm.
- Fineberg, Harvey. n.d. *Chart of Distinctions Between Public Health vs. Medicine*. Washington, DC: Association of Schools of Public Health. www.asph.org/document.cfm?page=724.
- Jimoh, Akim. 2001. Raise the Alarm Loudly: Africa Confronts the AIDS Pandemic. *Dollars & Sense: The Magazine of Economic Justice* 235: 16–19. <http://www.dollarsandsense.org/archives/2001/0501jinoh.html>.
- Mbeki, Thabo. 2000. Speech given at the opening session of the 13th International AIDS Conference, July 9–14, at Durban, South Africa. Issued by the South African Office of the Presidency, July 9. www.virusmyth.net/aids/news/durbspmbeki.htm
- Mogae, Festus G. 2004. State of the Nation Address: “Renewed Responsibility” by His Excellency Festus G. Mogae, President of the Republic of Botswana, for the First Session of the Ninth Parliament, November 8, 2004. Gaborone, Botswana. *African Leaders State of Africa Report 2004*. Boston, MA: African Presidential Archives and Research Center at Boston University.
- Prothrow-Stith, Deborah, and Eric Whitaker. 1995. Can the Health Needs of African American Men Be Met Through Public Health Empowerment Strategies? *Trotter Review: Public Health and Communities of Color: Challenges and Strategies* 9(1): 20–22.
- Shilts, Randy. 1987. *And the Band Played On: Politics, People, and the AIDS Epidemic*. New York: St. Martin's Press.

Smedley, Brian D., Adrienne Y. Stith, and Alan R. Nelson, eds. 2002. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Washington, DC: The National Academies Press.

Thomas, Stephen B., Michael J. Fine, and Said A. Ibrahim. 2004. Health Disparities: The Importance of Culture and Health Communication. *American Journal of Public Health* 94(12):2050.

Ugandan AIDS Commission Secretariat. 2001. *Twenty Years of HIV/AIDS in the World: Evolution of the Epidemic and Response in Uganda*. Kampala, Uganda: Ugandan AIDS Commission Secretariat.

Joint United Nations Programme on HIV/AIDS/World Health Organization (UNAIDS/WHO). 2004. *AIDS Epidemic Update*. Geneva, Switzerland: UNAIDS/WHO. www.unaids.org/wad2004/EPI_1204_pdf_en/EpiUpdate04_en.pdf.

United Nations (UN). 2001. Road Map Towards the Implementation of the United Nations Millennium Declaration. *Report of the Secretary General A/56/326*, September 6. daccessdds.un.org/doc/UNDOC/GEN/N01/526/07/PDF/N0152607.pdf?OpenElement.

———. n.d. United Nations Millennium Development Goals (UNMDG). New York: UN. www.un.org/millenniumgoals/.

ENDNOTES

1 The United Nations has emphasized poverty as threat to health.

TABLE 1: PARTIAL LIST OF PRESIDENT MBEKI'S ADVISORS WHO ADVOCATED THE NON-VIRAL CAUSATION OF HIV/AIDS

Sam Mhlongo, M.B., B.S.	Professor of Medicine, MEDUNSA, Johannesburg, South Africa
Etienne de Harven, M.D.	Emeritus Professor of Pathology, University of Toronto, Canada
Christian Fiala, M.D.	Obstetrician, Vienna, Austria
Claus Kohnlein, M.D.	Physician, Städtisches Krankenhaus, Kiel, Germany
Andrew Herxheimer, M.D.	Pharmacologist, London, United Kingdom
Peter Duesberg, Ph.D.	Professor of Molecular Biology, University of California, Berkeley, United States
David Rasnick, Ph.D.	Research Fellow, Dept of Molecular Biology, University of California at Berkeley, United States
Roberto Giraldo, M.D.	Physician, New York City
Manu Kothari, M.D.	Pathologist, Seth GS Medical College, Bombay, India
Harvey Bialy, Ph.D.	Research Scholar, National University, Mexico City, Mexico
Charles Geshekter, Ph.D.	Professor of African Studies, California State University, Chico, United States
Kary B. Mullis, Ph.D.*	1993 Nobel Prize in Chemistry

* Not an official member of the panel, but an informal advisor to Mbeki, a proponent of the non-viral theory of AIDS transmission and a supporter of the work of Duesberg.

HIV/AIDS in the African American Community: The Legacy of Urban Abandonment

Robert E. Fullilove and Mindy Thompson Fullilove

ABSTRACT

In this paper, we argue that a disproportionate concentration of HIV/AIDS cases in many African American communities signals a significant collapse in the social structure of those affected communities. Specifically, the open, extensive sale and use of illicit drugs and high rates of unprotected sex — all of which serve as the foundation for HIV infection — are the “symptoms” of the loss of important social controls within affected communities. The solution to this set of problems requires more than interventions tailored to individuals at risk. The structural problems that created the epidemic must be addressed with equal, if not greater, vigor.

INTRODUCTION

AIDS represents the end stage of HIV disease or, more commonly, HIV/AIDS. An AIDS diagnosis signals a significant level of deterioration of an individual's immune system and an increased likelihood that a variety of potentially fatal conditions will ensue. In this paper, we argue that a disproportionate concentration of HIV/AIDS cases in many African American communities signals, analogously, a significant collapse in the social structure of those affected communities. Specifically, the open, extensive sale and use of illicit drugs and high rates of unprotected sex — all of which serve as the foundation for HIV infection — are the “symptoms” of the loss of important social controls within affected communities. We also argue that public health interventions designed to change individual risk behaviors or to promote large-scale testing and treatment programs for individuals at risk will not suffice to decrease HIV infection rates in such communities. If further destruction is to be prevented, programs and policies designed to reverse the community decline that facilitates exposure to HIV/AIDS must be implemented as well. Changing the “structure of risk” — the goal of what are termed “structural

Robert E. Fullilove, Ed.D., and Mindy Thompson Fullilove, M.D., have been doing research on HIV/AIDS and minority health since 1986 as members of the Center for AIDS Prevention Studies at the University of California. Currently, they are professors at the Mailman School of Public Health at Columbia University, where they co-direct the Community Research Group.

interventions” — must become a priority for those in government who are charged with the responsibility of leading HIV prevention efforts (Sumartojo 2000).

Understanding the historical factors that transformed African American neighborhoods that once boasted of considerable social cohesiveness into HIV-risk environments is also critical. We suggest that one policy — a government-initiated structural intervention — that had drastic negative consequences in poor communities of color was the implementation of approximately 1,600 urban renewal projects in African American communities between 1950 and 1970 (Fullilove 2004). We argue that the long-term social and economic consequences of these programs resulted in a process of deterioration that ultimately affected the health of individual residents by destroying their neighborhoods and weakening the social networks that connected them to their families and to their neighbors.

HIV PREVENTION CIRCA 2005

The public health approach to AIDS is significantly influenced by what we will term the medical approach to HIV prevention and treatment. This approach focuses on the individual as the target of prevention campaigns as well as the target of medical treatments. The logic of such an approach is evident. It is the individual who becomes HIV infected, and the infection must be treated by tailoring medical interventions to all of the particular manifestations of HIV disease in each patient. Hence, many of the HIV prevention interventions in the United States are increasingly similar to the approaches we use to treat individual cases of many illnesses; namely, we test and we treat. Analogously, testing and treatment have been the leading themes in the efforts of the U.S. Public Health Service to prevent and treat HIV/AIDS here in the United States since the year 2000.

Specifically, in 2003, the U.S. Centers for Disease Control and Prevention (CDC) initiated a program entitled Advancing HIV Prevention (CDC 2003). Advancing HIV Prevention seeks to make HIV testing a routine part of medical care and implement new models for diagnosing HIV infections outside of traditional medical settings. Moreover, in collaboration with the Health Resources and Services Administration, Advancing HIV Prevention also calls for getting those who are tested positive for an HIV infection into treatment.

Special emphasis is placed on identifying those individuals who are both HIV infected and unaware of their infection status. Large-scale testing campaigns have been launched under the slogan “Know your status.” Additionally, to prevent new HIV infections among the partners of those who are found to be HIV positive, partner counseling and testing programs have been implemented under the Advancing HIV Prevention banner. Those whose tests are negative but who reveal in pre-test counseling that they engage in one or more HIV-risk behaviors are counseled to practice safe sex and/or safe drug-using practices. This focus on testing was initiated because estimates hold “that as many as two-thirds of the estimated 40,000 new HIV infections each year occur through transmission from persons who are unaware of their HIV-positive status” (CDC 2003, 2).

One significant critique of this approach is that, if Advancing HIV Prevention is successful, there will not be enough treatment slots for those who are newly identi-

fied as HIV positive. The lack of available treatment slots is particularly acute in poor communities of color, which have never had the same access to health care as other Americans. Moreover, in many states in 2003, the AIDS Drug Assistance Program, a federally-sponsored program to assist those who are unable to pay for their HIV medications, was unable to meet the demands for its services (Davis et al. 2004). Thus, while Advancing HIV Prevention is a logical extension of modern methods for managing individual illness, the growing, disproportionate number of HIV/AIDS cases in poor communities of color suggests that the demand for drugs and treatment slots has already exceeded the available supply. In other words, the United States is at the limit of its resources for managing an effective medical approach to this epidemic.

THE ECOLOGICAL APPROACH TO UNDERSTANDING HIV/AIDS

Our own work has consistently criticized HIV prevention campaigns that fail to account for a variety of community environmental conditions that frame individual HIV-risk behaviors. These conditions might be described as the community risk ecology (Fullilove and Fullilove 1999). We have pointed out that the unequal distribution of HIV/AIDS cases by state and metropolitan area in the United States is evidence that where one lives is as important a factor in understanding the HIV epidemic as one's racial or ethnic identity.

For example, three states — California, Florida, and New York — accounted for 43 percent of the cumulative AIDS cases in the United States reported to the CDC in 2003 (a count which excludes those who are HIV infected but do not have a diagnosis of AIDS). More importantly, three cities in the New York metropolitan area — New York City; Newark, New Jersey; and Jersey City, New Jersey — accounted for 18 percent of all cumulative cases of AIDS in the United States in 2003. The rates per one hundred thousand of AIDS cases in these three cities differed dramatically from those reported in 2003 from Chicago, Illinois, and Detroit, Michigan (CDC 2004). As demonstrated in Table 1, although these cities have significant concentrations of people of African descent, they do not, as one might expect, have similar rates of AIDS cases. These data suggest that HIV/AIDS is as much a condition of communities as it is of the behavioral and cultural characteristics — including race and ethnicity — of individuals who are HIV infected. An analysis of the distribution of HIV/AIDS in New York City provides support for this assertion.

In a 2004 report from the New York City Department of Health and Mental Hygiene, *Health Disparities in New York City*, Black New Yorkers had higher rates of newly diagnosed HIV infections than Whites or Latinos, even when controlling for neighborhood income. Black neighborhoods with “very low neighborhood income levels” had rates of new diagnoses that were 3 times those of comparable White neighborhoods and twice those of Latino neighborhoods. Overall, rates of newly diagnosed HIV infection varied from 2 per 100,000 to 10 per 100,000 among White neighborhoods in the city, while comparable rates among Black neighborhoods varied from 16 per 100,000 to 32 per 100,000 (Karpati et al. 2004).

THE ROOTS OF URBAN DECAY AND THE LONG DESCENT INTO HIV/AIDS

Lost in the intricacies of the discourse about the causes of the disproportionate rates of HIV infection among African Americans is the fact that Black communities in this country have undergone tremendous changes during the course of the twentieth century. The most dramatic occurred following World War II with the passage of the *Housing Act of 1949*. This act of the U.S. Congress was designed to spark a postwar era of prosperity and progress by renewing the core of American cities. Cities were able to use the right of eminent domain to seize “blighted” areas for redevelopment. Highways, offices, buildings of all shapes, sizes, and descriptions were to be constructed on the land that had been seized and cleared (Fullilove 2004).

Typically, the areas that were designated as blighted were those in the nation’s inner-city ghettos, neighborhoods that served as the home for wave after wave of Black immigrants from the deep South from the beginning of the twentieth century until the 1970s. These communities had, in many cities, housed earlier immigrants from Europe who spent a generation or two seeking the American dream before departing for the suburbs. Blacks took over housing in these neighborhoods that was often dilapidated and in ill repair. Despite the poor quality of their homes and high levels of poverty, residents in many communities managed to create thriving, vibrant neighborhoods.

Urban renewal changed the character of many of those neighborhoods. Between 1949 and 1973, approximately 2,553 urban renewal projects were funded under the *Housing Act of 1949* and its subsequent revisions. Approximately 1,600 of these projects were in largely African American communities. Put in other terms, a group that comprised 12 percent of the U.S. general population was the target for roughly two-thirds of the urban renewal projects undertaken during that period. One summation of this twenty-four-year program noted:

Urban renewal agencies in many cities demolished whole communities inhabited by low income people in order to provide land for private development of office buildings, sports arenas, hotels, trade centers, and high income luxury buildings.... As of June 30, 1967, 400,000 residential units had been demolished in urban renewal areas, while only 10,760 low rent public housing units had been built on these sites (Weiss 1985, 253–254).

In addition to a loss of housing, many intact communities had been razed. Although these neighborhoods were housing significant numbers of people in poverty, they exhibited a high level of social cohesion. At the beginning of the twenty-first century, that sense of cohesion had all but disappeared from many of these neighborhoods. In a series of studies conducted by our research group between 1990 and 2002, we interviewed hundreds of residents of these communities who recalled the dramatic differences between the pre- and post-urban renewal era (Fullilove, Green, and Fullilove 1999; Fullilove 2004). One of the most eloquent recollections of this period was offered by Sala Udin, a councilman in the Hill District of

Pittsburgh, Pennsylvania at the time of our interview, who provided this description of life in that famous community:

The sense of community and the buildings are related in an old area. The buildings were old, the streets were cobblestone and old, there were many small alleyways, and people lived in those alleyways. The houses were very close together. There were small walkways that ran in between the alleyways that [were] really a playground. So the physical condition of the buildings helped to create a sense of community. We all lived in similar conditions and had similar complaints about the wind whipping through the gaps between the frame and the window and the holes in the walls and the leaking and the toilet fixtures that work sometimes and don't work sometimes. But that common condition bound us together more as a community. I knew everybody on my block, and they knew me. They knew me on sight, and they knew all the children on sight, and my behavior changed when I entered the block (Fullilove 2004, 61).

Udin echoes a theme that we heard repeatedly from our interviewees, namely that despite the poverty and the poor quality of the housing stock, residents experienced themselves as belonging to a community. Respondents agreed that during their childhood, the knowledge that they were known to their neighbors and were under their observation — if not their direct supervision — exerted significant controls on their behavior. Finally, many reported feeling that their neighbors had as much influence on their growth and development as their parents.

As urban renewal was demolishing neighborhoods and scattering their residents, another process was also contributing to the woes of African Americans: deindustrialization (Wilson 1987). Poverty without neighbors and without jobs is a very different kind of poverty from that of earlier times when African Americans of varied socioeconomic status lived together in racially segregated communities. These processes of abandonment and decay also tended to hyper-segregate poor African Americans. In *American Apartheid*, Massey and Denton (1993) observed that the intensification of segregation and racial isolation has exacerbated the impact of poverty on community residents. That these communities are marked by, among others, high rates of crime and high rates of morbidity and mortality from a variety of preventable health conditions follows from the fact that they have lost the links to neighbors, work, and the larger society that served as an effective buffer against the effects of poverty and racism. The hypersegregated poor Black community of the 1980s and 1990s was geographically marginalized, socially disrupted, and economically abandoned.

It is worthwhile to draw the links between the inherently social processes of marginalization, disruption, and abandonment and the health outcomes of HIV/AIDS or other diseases. The evidence is quite clear that the confluence of these social processes increases vulnerability to disease. However, the specific diseases that will emerge depend upon the interaction of host, agent, and disease. The efficient propagation of the AIDS epidemic depends upon infected bodily fluids passing from one person to another. Absent places where high levels of such exchanges can occur —

the bathhouse, crack house, shooting gallery, or tattoo parlor, to name a few — AIDS cannot spread. Hence, despite the general processes of exclusion, which have operated on all African American communities, it is only some cities that have massive epidemics of HIV/AIDS, as we noted earlier (see Table 1).

Wallace (1988), in a series of studies of the propagation of HIV/AIDS in the South Bronx of New York City, has provided one of the most dramatic examples of a place-based epidemic. He studied the policy of “planned shrinkage,” which closed fire stations in neighborhoods deemed redundant. The lack of adequate fire extinguishment permitted fires to destroy buildings and led to the loss of 55 to 81 percent of the occupied housing units in the South Bronx, New York during the 1970s. This massive destruction of housing dispersed the residents and destroyed the social fabric that held this largely Black and Hispanic community together. Poor people were forced to move from neighborhoods that had been hollowed out by this massive, fire-induced loss of housing to neighboring poor communities that, in their turn, quickly became overcrowded. Well-established social and family networks were destroyed by this migration, and the character of neighborhood life changed dramatically. He noted:

In such times, the social controls that permit large numbers of people to live together in densely packed neighborhoods are greatly disrupted. Behaviors, most notably violent and criminal activities, which would not have been tolerated by residents in a previous period, are more likely to appear as the preventive influence of social and family networks and associated economic opportunities disappear (Wallace, Fullilove, and Wallace 1992, 948).

One immediate, dramatic consequence of the loss of social cohesion was the loss of control of the streets. When the twin epidemics of heroin and cocaine use followed, the closely knit neighborhoods of the 1950s had largely disappeared. Two twists of fate intervened at this point. First, HIV was established among intravenous drug users in the South Bronx in the 1970s. When the neighborhoods were dispersed, the drug users were dispersed. HIV, Wallace found, was “shotgunned” around the borough. Second, the burning out of large apartment buildings often left large, uninhabited hulks looming over the landscape. Drug users occupied these derelict buildings and used them for shooting galleries. Hundreds of people might move through a single shooting gallery in the course of a day, thereby creating a highly efficient mechanism for the transmission of HIV.

Planned shrinkage created both drug epidemics and derelict buildings, which, in turn, became sites for the transmission of HIV. However, the War on Drugs responded to the crisis of place by creating another place destined to augment the harms of disinvestment: the prison system. At one point in the 1990s, seven Black and/or Latino neighborhoods in New York City — all victims of planned shrinkage in the 1970s — accounted for more than 70 percent of the prison population in New York state (Fullilove and Fullilove 1999). These neighborhoods are precisely those which report some of the highest rates of HIV/AIDS in the United States, a fact which partially explains why New York state prisons in 2001 housed approximately 25 percent of all HIV/AIDS cases among prison inmates in the United States (Maruschak

2004). As we have argued elsewhere (Fullilove and Fullilove 1999), the cycling of inmates in and out of prison and in and out of their home communities is one of the most significant engines maintaining a reservoir of HIV infection in poor communities of color both in New York and throughout the United States.

This complex scenario which relates neighborhood destruction to the spread of AIDS links a widespread process of marginalization to a very specific set of circumstances in which the agent (HIV) and the environment (abandoned buildings and prisons) lead to a massive epidemic. It is important to point out that the processes of geographic marginalization, social disruption, and economic abandonment uniformly lead to one or more negative consequences for any affected population (see Figure 1). But affected populations, because of unique circumstances, will not experience the same harms. The devil — or, one might say, the disease — is in the details.

CONCLUSION

Examining the model we have presented here suggests numerous points of intervention. However, after examining all of the alternatives, we argue that a narrow focus on individual behavior — the use of condoms or clean needles — lacks the power to counter the social forces that fuel the epidemic, specifically the exclusion of some citizens from the economic and social life of the nation. The real power to create health and control disease lies in the stabilization of and reinvestment in marginalized neighborhoods. Stabilizing housing is an important first step. Stable housing creates stable neighborhoods. Stable neighborhoods are a cornerstone of a healthy community.

Such a policy is of particular importance in the early years of the twenty-first century. Housing shortages in many major urban centers and the gentrification of existing urban Black communities are increasingly evident trends in many American communities. One consequence of these trends is a shifting of the population at risk for HIV infection from the inner city to surrounding suburbs. The destabilization of urban communities that began with urban renewal in the 1950s is continuing into the twenty-first century.

The conclusions we draw from these observations are clear: if the United States fails to intervene to stabilize housing, increase educational opportunities, and reform policies that continue to send individuals at risk for HIV infection to prison, the standard prevention interventions that are directed at changing the HIV risk behaviors of individuals will fall short of their mark. Changes in the structure of urban life in the twentieth century are at the heart of the current HIV/AIDS pandemic in the Black community. Only structural interventions — specifically those that change the risk structure of the urban environment — stand a chance of averting sure disaster.

REFERENCES

- Centers for Disease Control (CDC). 2003. *Advancing HIV Prevention: Interim Technical Guidance for Selected Interventions*. Atlanta, GA: U.S. Department of Health and Human Services. www.cdc.gov/hiv/partners/AHP/AHPIntGuidfinal.pdf.

———. 2004. *HIV/AIDS Surveillance Report* 15. www.cdc.gov/hiv/stats/2003SurveillanceReport.pdf.

Davis, M. Danielle, Chris Aldridge, Murray Penner, Jennifer Kates, Lei Chou, and Daniel Kubert. 2004. *National ADAP Monitoring Project: Annual Report*. Washington, DC: Henry J. Kaiser Family Foundation.

www.nastad.org/documents/public/pub_careandtreatment/2004519TheNationalADAPMonitoringProjectAnnualReport.pdf

Fullilove, Mindy Thompson. 2004. *Root Shock: How Tearing up City Neighborhoods Hurts America and What We Can Do about It*. New York, NY: Ballantine.

Fullilove, Mindy Thompson, Lesley Green, and Robert E. Fullilove. 1999. Building Momentum: An Ethnographic Study of Inner-City Redevelopment. *American Journal of Public Health* 89(6):840–844.

Fullilove, Robert E., and Mindy Thompson Fullilove. 1999. HIV Prevention and Intervention in the African American Community. In *The AIDS Knowledge Base*. 3rd. ed. Edited by P. T. Cohen, Merle A. Sande, and Paul A. Volberding. Philadelphia, PA: Lippincott Williams and Wilkins.

Maruschak, Laura M. 2004. HIV in Prisons, 2001. *Bureau of Justice Statistics Bulletin*. Washington, DC: Department of Justice. www.ojp.usdoj.gov/bjs/pub/pdf/hivp01.pdf.

Massey, Douglas S., and Nancy A. Denton. 1993. *American Apartheid: Segregation and the Making of the American Underclass*. Cambridge, MA: Harvard University Press.

Karpati, A., B. Kerker, F. Mostashari, T. Singh, A. Hajat, L. Thorpe, M. Bassett, K. Henning, and T. Frieden. 2004. *Health Disparities in New York City*. New York, NY: New York City Department of Health and Mental Hygiene.

Sumartojo, Esther. 2000. Structural and Environmental Factors in HIV Prevention: Concepts, Examples, and Implications for Research. *AIDS* 14(suppl 1): S3–S10.

Wallace, R. 1988. A Synergism of Plagues: “Planned Shrinkage,” Contagious Housing Destruction and AIDS in the Bronx. *Environmental Research* 47(1): 1–33.

Wallace, R., Mindy Thompson Fullilove, and D. Wallace. 1992. Family Systems and Deurbanization: Implications for Substance Abuse. In *Substance Abuse: A Comprehensive Textbook*. 2nd ed. Edited by Joyce H. Lowinson, Pedro Ruiz, and Robert B. Milman. Baltimore, MD: Williams and Wilkins.

Weiss, Marc A. 1985. The Origins and Legacy of Urban Renewal. In *Federal Housing Policy and Programs: Past and Present*. Edited by Paul Mitchell. New Brunswick, NJ: Rutgers University Press.

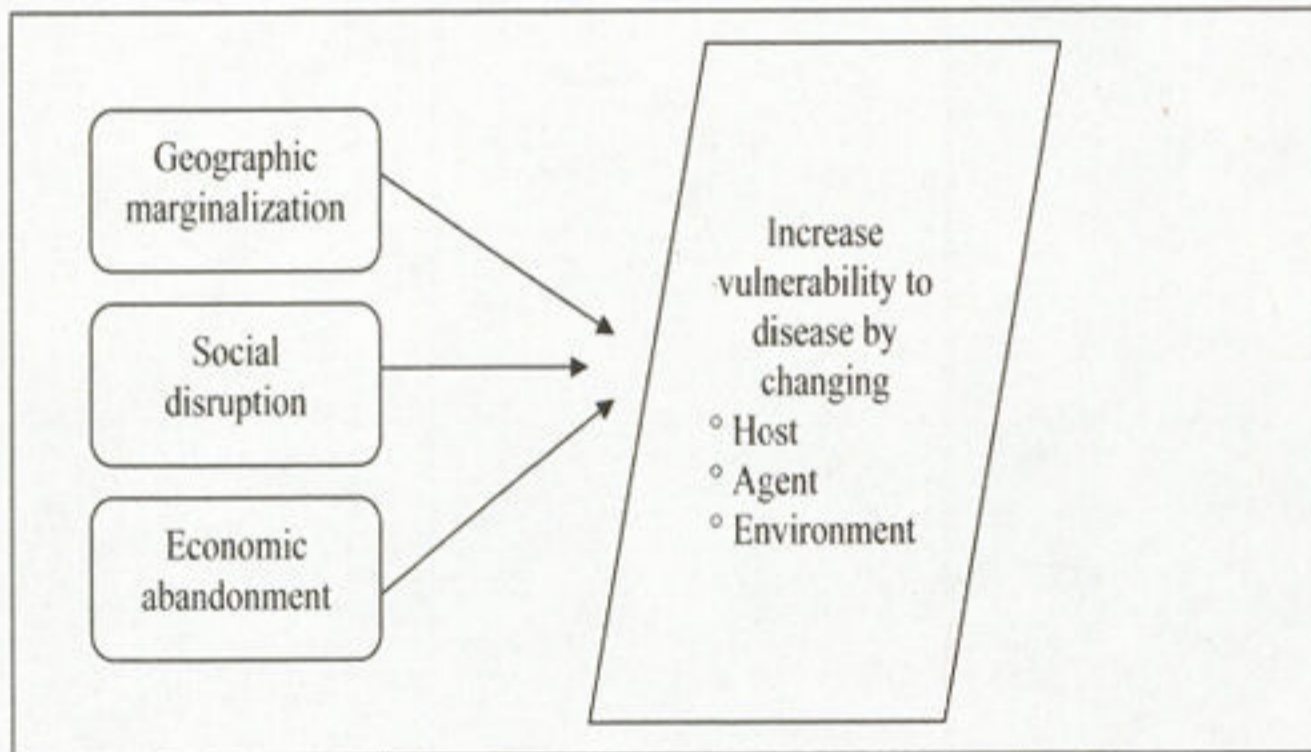
Wilson, William Julius. 1987. *The Truly Disadvantaged*. Chicago, IL: University of Chicago Press.

TABLE 1: REPORTED AIDS CASES, CUMULATIVE THROUGH 2003, FOR SELECTED CITIES IN THE UNITED STATES

<u>CITY</u>	<u>RATES/100,000</u>	<u>CUMULATIVE AIDS CASES</u>
Chicago	18.0	26,057
Detroit	10.8	9,250
Jersey City	28.3	7,217
New York City	59.2	137,178
Newark	25.8	18,848

SOURCE: CDC 2004.

FIGURE 1: SOCIAL PROCESSES SHIFT RISK ECOLOGY



Unprotected: HIV Prison Policy and the Deadly Politics of Denial

Robin G. Steinberg

ABSTRACT

HIV/AIDS is reaching epidemic proportions in U.S. prisons and in prison populations worldwide. The United States trails Canada, Australia, and much of Europe in responding to the crisis. What is more disturbing is that the United States does not respond to the prevalence of HIV/AIDS in prisons because policy makers refuse to acknowledge the crisis as worthy of intervention. Across the United States, policy conversations about HIV/AIDS are riddled with judgments about what prisoners do not deserve. However, while these conversations and excuses take place, people are becoming infected and dying in prison and outside of prison. Our refusal to address this issue wholeheartedly and aggressively has effects that stretch farther than prison walls—they reach into poor communities across the country.

In July 2004, at the 25th International AIDS Conference in Bangkok, Thailand, a worldwide panel of experts openly discussed the HIV/AIDS epidemic in prisons across the globe. It appears that everywhere in the world, prisons present a higher rate of infection than in the general population, with rates ranging from 10 percent to 25 percent (Jürgens 2004). What was particularly disturbing about the discussions and outcomes of this conference was the extent to which the United States trails other developed countries on this issue.

Wardens, legislators, and prison administrators in the United States do not seem to care about HIV in prison and have been overwhelmingly opposed to the distribution of condoms or clean needles to prevent sexually transmitted diseases. In 1999, under much fire from the Bush administration, only a handful of penal systems participated in condom distribution programs, including New York City, Philadelphia, San Francisco, Washington, D.C., and state prisons in Vermont and Mississippi (Hammett, Harmon, and Maruschak, 49). The root of the problem lies in the fallacy that denying the existence of sex or drug use in prisons will mean that prisons are, in fact, drug- and sex-free. Nothing could be farther from the truth. Some wardens have spoken against condoning undesirable or illegal behavior in prisons while others have been concerned about security risks. But whatever the proffered excuse,

Robin G. Steinberg is the executive director of the Bronx Defenders, a nonprofit public defender office in the South Bronx offering holistic criminal defense services to indigent clients. Ms. Steinberg was a 2002-2003 Wasserstein Public Interest Fellow at Harvard Law School and a participant in the Executive Session on Public Defense, a joint program with the Kennedy School of Government and Harvard Law School.

it appears that the United States has, to its great detriment, sat idly by while many other countries have taken steps to address the rampant spread of AIDS in prisons.

Findings presented in Bangkok included the following: in 1991, almost half of the European prison systems surveyed distributed condoms to prisoners. Many prisons in Australia, most in Canada, and a small but growing number in the United States have also adopted this policy. When evaluated, this policy exhibits no negative consequences, and systems that have adopted the policy have not had to reverse it (Harding and Schaller 1992).

In the same report, 16 out of 52 prison systems surveyed in Europe made bleach available to prisoners to clean their needles. Again, bleach is also available in most Canadian prisons and in many prisons in Australia. And again, no system that has adopted this policy has reversed it. A major recommendation of this conference was the adoption of needle exchange programs in prisons, which have been demonstrated to be quite effective in other areas outside of prisons. Switzerland, Germany, Spain, and several countries in Eastern Europe have already adopted this policy. And all evaluations of needle exchange programs in prisons have shown positive health effects and no negative consequences (Harding and Schaller 1992).

Yet both problem and solutions seem to escape the attention of our policy makers. On October 5, during the 2004 vice presidential debate at Case Western Reserve, Vice President Dick Cheney was asked about the HIV/AIDS epidemic among African American women in the United States. His response speaks legions about the continued invisibility of the problem in America: "I have not heard those numbers..." Cheney murmured. "I was not aware..." (Commission on Presidential Debates 2004).

Senator John Edwards also seemed unable to answer the question, quickly turning to a discussion of the AIDS epidemic in Africa (Commission on Presidential Debates 2004). Despite all of the media campaigns, all of the lobbying, and all of the ways HIV/AIDS has touched the lives of nearly every resident of the United States, HIV/AIDS remains a topic few are willing to touch.

When it comes to HIV among African American women, the epidemic nature of the problem among this population of women is, at best, on the back burner. But even more in the shadows, more hidden from the attention of policy makers, is the epidemic of HIV/AIDS and other diseases in this country's prison system. In our prisons live the people who few want to acknowledge, few want to support, and few want to help. But add the stigma of being incarcerated to the stigma associated with HIV/AIDS, and infected prisoners often become completely invisible to policy makers, despite the reality that HIV and AIDS are very much a part of American prison life.

The HIV/AIDS epidemic in U.S. prisons exists and continues to persist not because we do not know how to deal with the public health issues. In fact, we do. We know exactly what works in prisons. We can look to many successful models in this country and abroad. Thus, the question is not whether there is an epidemic, nor even how to deal with the epidemic. The question is why we are not doing what needs to be done.

Policy makers are reluctant or unwilling to acknowledge and address the HIV problem in prisons because they are stalled by questions of merit, denial, and equi-

ty. Prisoners do not deserve better health care. Sex and drug use does not happen or is not supposed to happen in prison. Prisoners should not be getting good health care if every person outside of prison is not getting good health care first. The invisibility of prisoners in this country stems directly from these issues and these judgments.

Unfortunately, our policy makers are mistaken and misguided. A failure to address HIV/AIDS in prisons affects everyone in this society. To not respond says something far more damaging about our society and its brutality and indifference. To not respond is actively killing entire communities inside and outside of prison.

THE SCOPE OF THE PROBLEM

HIV/AIDS is already at epidemic levels in our penal system. Exacerbated by denial, the spread of HIV has continued unchecked among the incarcerated populations of American jails and prisons. Indeed, HIV is now the second largest cause of death in the U.S. penal system (Hammett, Harmon, and Maruschak 1999, 11). The prevalence of AIDS is, in large measure, due to the fact that the American prison population is disproportionately poor, minority, and drug addicted — a mirror of high-risk groups on the outside. As a consequence, a significant number of inmates are engaged in high-risk behaviors before they enter the prison system, and many come into the prison system already infected with HIV. Once inside, HIV/AIDS spreads through consensual sex, intravenous drug use, rape, and the sharing of needles for tattooing and/or body piercing (Hammett, Harmon, and Maruschak 1999, 47-51). These methods of transmission are real and well documented, and yet American prison officials persist in denying that prison sex, rape, and drug use even occur. The consequences of this willful ignorance are dire and deadly and drive a number of America's failing prison policies.

Because prison officials barely acknowledge that prison sex and rape exist, they fail to provide prisoners with resources to protect themselves (condoms, lubricants). Because prison officials deny that intravenous drug use happens inside prisons, they fail to provide clean needles or bleach for needle sterilization. Because they do not want to examine the problem, they fail to provide culturally and contextually appropriate education to prisoners. And because they refuse to accept the continuing spread of the virus through the incarcerated population, they fail to provide prisoners with opportunities to learn and practice skills that they need to protect themselves inside and outside prison.

As a result, the rate of HIV/AIDS infection in prisons over the past decade has continued to outstrip the incidence in the general population. The Academy for Educational Development (2003) reported that HIV rates are 14 times higher in the prison population than in the general U.S. population. Furthermore, 17 percent of people with AIDS in 1996 had been incarcerated at some time, and 13 percent of people with HIV had been previously incarcerated (AED 2002). If you have AIDS in prison, you are twice as likely as a free person to die from it (Maruschak 2004, 7).

Mirroring the general population, women are at a much greater risk of infection than men in prison. New York was the only state where more than 5 percent of the male inmates were known to be HIV positive, whereas at the end of 2001 in nine

states, more than 5 percent of all female inmates were HIV positive (Maruschak 2004, 3). It is important to remember that this seemingly small percentage represents thousands of HIV-positive people. Even more frightening, because prisoners do not often have regular access to medical care or to confidential HIV screenings, the reported figures are likely to be low.

And HIV/AIDS in prisons is not only a problem for prisoners. The epidemic behind prison walls has real and measurable effects on those of us who live on the outside — especially those who live in poor communities of color.

In 1991, state prisons admitted and released nearly 600,000 people (Petersilia 2000, 1). This revolving door to and from a place in which the incidence of HIV/AIDS and other diseases such as hepatitis and tuberculosis (TB) is so high puts entire communities at risk. In New York City, 80 percent of the TB outbreak cases in 1989 traced back to jails and prisons. By 1991, New York's Rikers Island jail had one of the highest TB rates in the country (Petersilia 2000, 4). The introduction and reintroduction of HIV/AIDS into our communities and into prisons presents no less a threat and no less a public health challenge.

Prisons are filled with people from poor and disenfranchised communities, many of whom are already poorly educated and already suffer from limited access to health care and social services. Continuing that trend in prisons exacerbates the HIV epidemic in prisons and spreads it to poor communities. This problem can be solved. By establishing aggressive intervention and protracted after-care, as several jurisdictions in the United States have (Massachusetts and Rhode Island), high-risk behavior can be reduced and the degenerative effects of the virus can be controlled (Watson & Riceberg 2002; Wright 2004).

RESPONSES TO THE PROBLEM

As the Bangkok conference demonstrated, the challenge of responding to the public health crisis of HIV/AIDS continues to exist throughout the world, in both free and incarcerated populations. And while the United States has not been alone in avoiding the issues created by a burgeoning HIV/AIDS crisis in prisons, continued avoidance will not only exacerbate the problem, but will also allow us to fall farther and farther behind in the global effort to contain the disease.

We can learn from Canada. The Canadian government has made great advances in the fight against HIV in prisons. They distribute condoms and clean needles, they have called for enhanced access and opportunities for confidential testing and counseling, and they have improved public health education for people in prison and for prison personnel while seeking greater resources for drug treatment and other alternatives to incarceration for people struggling with addiction (Jürgens 2004; Jürgens 1996, 97–121).

Many of these advances have been echoed in the recommendations of advocacy organizations in the United States. Sadly, they have been met with only limited success. In 2004, the New York AIDS (NYAIDS) Coalition testified before the New York State Assembly calling for many of the Canadian policies to be implemented in New York state prisons. The NYAIDS Coalition also urged the state to improve

health care facilities in prisons and to address more adequately the substantial needs of prisoners living with HIV and AIDS (Pressley 2004).

WHY DO WE DO NOTHING?

In testimony before the New York State Assembly, Joey Pressley, executive director of the NYAIDS Coalition, stated, "Sadly, there are those who would say that prisoners do not deserve health care. They would say it is unfair to provide care to inmates when there are so many people outside of prisons who cannot afford to seek medical attention" (Pressley 2004, 3). Sadly, he is right. Even more sadly, "those people" who have these opinions seem to be the ones making policy in the United States today.

One of the findings of the Bangkok conference was that creating policies to contain and reduce the spread of HIV/AIDS in prisons is impeded primarily by the denial of prison systems and governments that sex and drug use happen in prisons, not by a lack of evidence that interventions work (Jürgens 2004).

In 2002, Mike Long, head of the New York State Conservative Party, spoke out against a bill that would have allowed state prisons to distribute condoms, saying, "Taxpayer money shouldn't be spent on condoms so inmates can do whatever they want, whenever they want. Prisons should not be hotels" (KFF 2002). Mr. Long was not alone. In 2004, Margot Bach, a spokesperson for the California State Corrections Department, stated that condoms are not permitted in California prisons because sex between inmates is illegal (KFF 2004).

These absurd excuses do nothing to move AIDS policy forward. Despite the testimony of countless incarcerated people and prison personnel and despite the experiences and policy interventions of prison systems throughout the world, many policy makers in the United States continue to deny that sex and drug use run rampant in our prisons. Equally disturbing are those who simply say that the behavior is illegal as an excuse for lack of action. Yes, illegal drug use should not happen in prisons. And yes, as a society, we should take steps to curb or eliminate drug use in the most just and humane ways possible. But until then, we must also deal with the true consequences of its existence. Simply because sex between inmates is illegal does not mean that it does not happen and that we do not have a social responsibility to deal with some of the negative consequences that arise from it.

Many would argue on the grounds of equity that, all things being equal, people outside prisons deserve better health care and more resources than people in prison. However, prison is no paradise. There is no comparison between living in even the poorest community and having the freedom to walk outside and speak to whomever you want and dictate your schedule. Prisons are designed to punish and strip people of their dignity in ways that often cross into the inhumane and unjust. Adding adequate medical care facilities, training for the incarcerated as well as prison personnel, and even distributing condoms will not singly or in concert transform prisons into "hotels" or even decent places to spend a few years. But these interventions will make a difference in the battle against HIV/AIDS inside and outside of prisons. Everyone deserves excellent medical care. Everyone deserves to live a disease-free life. To victimize people living in prisons by depriving them of medical

care and the tools they need to prevent the spread of HIV/AIDS, not to mention hepatitis and tuberculosis, is to add insult to injury. It is reflective of an ignorance of the realities of our society where there is a steady stream of 600,000 people from poor communities coming in and out of prisons every year. To not address a major public health epidemic in prison is to not address it outside of prison.

CONCLUSION

Our refusal to acknowledge the problem of HIV/AIDS in prison has only made it worse — ending the lives of many inmates and endangering the lives of many more both inside prisons and in the communities to which they return. Rather than view incarcerated populations as an opportunity to leverage change in free communities, the U.S. prison system has opted to turn a blind eye. Instead of declaring the problem illusory, we should institutionalize explicit talk and education about sexual contact and drug use in prisons and establish specific skills training, such as demonstrations on how to use condoms, lubricants, and clean needles. Instead of driving the problem ever further underground, we should use inmates' prison time to train them to be leaders in groups who will teach and provide skills training on the outside. It is precisely because this population will be returning to their underresourced and poor communities that we must educate them about prevention to, in effect, seed the incarcerated population with information, knowledge, and protection that will be extended to the community upon release, staunching the spread of HIV/AIDS not only inside the prison system, but outside as well.

HIV/AIDS in U.S. prisons is at epidemic proportions — a reality shared by countries across the globe. But what is more disturbing is that, with few exceptions in the United States, policy makers and heads of prison systems turn away from the problem, despite a massive and growing base of evidence for what works in prisons and what effective interventions are available to address this public health challenge. Only in places where advocates have been able to move policy makers away from their denial about the frequency of drug use and sex in prisons and their misguided conceptions of merit and equity have we begun to see continuums of care set up between prisons and the communities to which many prisoners will return. More policy makers must take a lesson from the strides made by some prisons in the United States and by many more throughout the world and as close as Canada in addressing this public health problem. The well-being of all of us is at stake, and our sense of humanity and justice as a society is no less at risk.

Many thanks to Franklin A. Cruz for his research. Without him, this paper would not have been written. Mr. Cruz is the director of strategy and evaluation at the Bronx Defenders and a graduate of the Goldman School of Public Policy at the University of California, Berkeley.

Thanks to Dixon Valderruten, director of prison education and outreach at the Osborne Association, and Romeo Sanchez, director of the Prison Project at the Latino Commission on AIDS, for further informing us about these important issues.

REFERENCES

- Academy for Educational Development Center for Community-Based Health Strategies (AED). 2002. *Improved Community Health Through Better Correctional Health Care*. Washington, DC: Academy for Educational Development.
- . 2003. *HIV Prevention Community Planning Groups and Correctional Institutions: A Collaboration for All*. Washington, DC: Academy for Educational Development.
- Commission on Presidential Debates. 2004. Transcript of the Cheney-Edwards Vice Presidential Debate, October 5. www.debates.org/pages/trans2004b.html.
- Hammett, Theodore M., Patricia Harmon, and Laura M. Maruschak. 1999. 1996-1997 Update: HIV/AIDS, STDs, and TB in Correctional Facilities. *Issues and Practices in Criminal Justice Series*. Washington, DC: National Institute of Justice, Office of Justice Programs, U.S. Department of Justice.
- Harding, T. W. and G. Schaller. 1992. *HIV/AIDS and Prisons: Updating and Policy Review*. Geneva, Switzerland: University Institute of Legal Medicine for the WHO Global Programme on AIDS.
- Jürgens, Ralf. 1996. *HIV/AIDS in Prisons: Final Report*. Ottawa, Ontario: Canadian HIV/AIDS Legal Network & Canadian AIDS Society.
- . 2004. Is the World Finally Waking up to HIV/AIDS in Prisons? A Report from the 25th International AIDS Conference, July 11–16, in Bangkok, Thailand.
- Henry J. Kaiser Family Foundation (KFF). 2002. Politics & Policy: New York Lawmakers Propose Distribution of Condoms in Prisons to Slow Transmission of HIV. *Daily HIV/AIDS Report*, April 30. www.kaisernet.org/daily_reports/rep_index.cfm?hint=1&DR_ID=10874.
- . 2004. Across the Nation: Contra Costa Times Examines Spread of HIV/AIDS Among California Prison Inmates. *Daily HIV/AIDS Report*, August 23. www.kaisernet.org/daily_reports/rep_index.cfm?hint=1&DR_ID=25374.
- Maruschak, Laura. 2004. HIV in Prisons, 2001. *Bureau of Justice Statistics Bulletin*, January.
- Petersilia, Joan. 2000. When Prisoners Return to the Community: Political, Economic, and Social Consequences. *Sentencing & Corrections: Issues for the 21st Century* (9).
- Pressley, Joey. 2004. Testimony before New York State Assembly on Behalf of New York AIDS Coalition, April 30. www.nyaidscoalition.org/binary-data/NYAC_ARTICLE/pdf_file/616-1.pdf.
- Watson, Rita A., and Jessica L. Riceberg. 2002. A Dangerous Gap in AIDS Care in Prison. *Boston Globe*, July 13. Cited in CDC. 2002. HIV/AIDS, Sexually Transmitted Diseases, and Tuberculosis Prevention News Update. *CDC News Updates*, July 18.
- Wright, Lester. 2004. Letter from the Editor. *HIV Education Prison Project Report* 7(7/8).

The Politics of HIV Prevention and Black Women

Lorraine Cole

ABSTRACT

Since the beginning of the HIV/AIDS epidemic in the United States, the burden of the disease has been steadily shifting from White males, predominantly in the gay community, to Black females. Because the root causes of the HIV/AIDS epidemic among Black women are multifactorial, approaches to ending the rampant spread of HIV must be multifaceted. There must be a method of HIV protection that women can control, universal access to quality health for early diagnosis and treatment, comprehensive sex education and empowerment programs, and a mass public education campaign about HIV/AIDS, as well as a safe, effective, and affordable preventative HIV vaccine.

The room erupted with enthusiastic outbursts of approval at our debate watch party in reaction to moderator Gwen Ifill's question about AIDS and Black women. Her question was quite specific: "I want to talk to you about AIDS, and not about AIDS in China or Africa, but AIDS right here in this country, where Black women between the ages of 25 and 45 are 13 times more likely to die of the disease than their counterparts" (Commission on Presidential Debates 2004). Momentarily motionless, hardly breathing, we awaited the responses from the two 2004 vice presidential candidates, only to have our half-hopeful anticipation turn to exasperation. Both Richard Cheney and John Edwards responded in Media Training 101 style, using the opportunity to reiterate other platform messages and avoid the direct question. At the end of his response, incumbent Vice President Cheney returned to the original question with an open admission that he had "not heard those numbers with respect to African American women" (Commission on Presidential Debates 2004). That moment in history was probably the most profound confirmation of what Black health advocates had previously known — the health of Black women does not rank with any priority on the national agenda.

In describing the impact of HIV/AIDS on Black women, it can be said definitively that it is a *disease of mass destruction*. Since the beginning of the HIV/AIDS epidemic in this country over two decades ago, the disease burden has been steady-

Lorraine Cole, Ph.D., is president and chief executive officer of the Black Women's Health Imperative (formerly the National Black Women's Health Project). Located in Washington D.C., the Black Women's Health Imperative is a leading national educational, advocacy, research, and leadership development organization dedicated solely to ensuring optimum health for Black women across the life span.

ly shifting from White males, predominantly in the gay community, to Black females. AIDS is the number one cause of death for African American women in their prime childbearing years, ages 25 to 34 (NCHS 2003). Thus, two generations are being impacted simultaneously. It is among the top four causes of death for African American women aged 20 to 54 years (Anderson and Smith 2003). According to the National Institute of Aging, the number of new AIDS cases is growing faster in women over age 40 than in those under 40. And more than half of the new cases of HIV infection in women over 50 are African American (AA 2005). In absolute numbers, more Black men have AIDS than Black women. But the absolute numbers for Black women are rising at a staggering rate. Black women are the fastest-growing population of new cases, accounting for two-thirds (67 percent) of new AIDS cases among women. The rate of AIDS diagnoses for African American women is 25 times the rate for White women. By contrast, the rate of AIDS diagnoses for African American men is 8 times the rate of White men (CDC 2004c).

In the introduction to the *Surgeon General's Call to Action to Promote Sexual Health and Responsible Sexual Behavior*, then-Surgeon General David Satcher stressed that the enemy in this epidemic is the virus, not those who are infected with it (OSG 2001). In the absence of a cure for HIV/AIDS, prevention is our greatest weapon against this enemy. The ABC trilogy of HIV prevention has been the recent mantra of the U.S. government for legislation and programs, domestically and internationally (particularly, the A and the B). A refers to abstinence (or delayed sexual initiation among youth), B stands for being faithful (or reduction in the number of sexual partners), and C is for correct and consistent condom use, especially for casual sexual activity and other high risk situations (USAID 2004). Reduction in the AIDS epidemic in Uganda from 15 percent to 5 percent between 1991 and 2001 has been attributed to the use of the ABC approach as a national policy (Singh, Darroch, and Bankole 2003, 9). This approach has led to fewer Ugandans having sex at young ages, increased levels of monogamy, and a steady rise in condom use among unmarried, sexually active men and women.

There can be no argument that abstinence is the only guaranteed method for prevention of pregnancy and sexually transmitted diseases, including the sexual transmission of HIV. Abstinence and delayed onset of first sexual encounter among youth have been cultural values and societal expectations throughout most of the history of the Western world. However, abstinence within marriage is not a reasonable prospect.

Being faithful in a mutually monogamous relationship with an uninfected partner is also in the "undisputable" category of HIV-prevention approaches. The promotion of values that uphold committed, enduring, and mutually monogamous relationships is an important societal tenet to be embraced and pursued. Being faithful is basic to religious, moral, and even legal principles of the marriage contract. Unfortunately, the current high rate of divorce, deferral of marriage to pursue education and careers, low male-to-female ratios within certain societal contexts, and the ever-evolving notions about dating have led to a culture in the United States in which serial monogamy and concurrent relationships have become normative.

Within the ABC context, the C is regarded as the fail-safe method when factors encumber the ability to practice A or B. But correct and consistent condom use is reliant on shared agreement. Furthermore, there are certain negative social realities that can pose real obstructions to complete condom compliance with every sexual encounter. There is a societal blind eye to pervasive issues such as infidelity, rape, incest, intimate partner violence, custodial sexual abuse, the so-called "down low" lifestyle of secret bisexuality, sex trades, drug- or alcohol-impaired judgment, and fear of rejection or loneliness.

The most fundamental basis of the sexual experience is the desire and need for procreation. But, in addition to reproduction, human sexuality has come to serve many other functions. Sexual need involves a complex interaction of psychological and physiological responses that are influenced by a complex interaction of learning, culture and genetic factors, all with considerable individual variations. These complexities are not clearly understood scientifically or easily quantifiable. The crux of the ABC approach is the control of this very complex human phenomenon by changing individual attitudes, values, and behaviors. As a national health policy strategy to avert the potential devastation of HIV infection, ABC alone is not enough. There are additional consonants and vowels that must be added to this HIV prevention "alphabet" — at minimum, the letters M, U, V, and E.

M—MICROBICIDES

In its *Position Statement on Condoms and HIV Prevention*, the Joint United Nations Programme on HIV/AIDS (2004) indicated that the male latex condom is the single, most efficient, available technology to reduce the sexual transmission of HIV and other sexually transmitted infections. Although condoms will remain the key preventive tool for many years to come, there is a need for a method of HIV protection that women can control. Condom use, though effective in preventing the transmission of HIV, is a decision often controlled by the male. For some women, social, cultural, psychological, and economic barriers limit their ability to insist on condom use.

There is research currently underway to develop such a method, known as microbicides, which would give women the control to protect themselves, as well as their partners. Similar to spermicides in application, microbicides are odorless, tasteless, unobtrusive creams, gels, films, or suppositories that could be used intravaginally or intrarectally. Therefore, it could potentially be more accepting to a partner who is unwilling to use a condom. Furthermore, women could use it discretely and undetected by their sexual partner. Thus, microbicides could offer a feasible alternative to condom use for HIV protection.

Unlike the name implies, microbicides may not necessarily work by killing microbes, such as HIV, but by providing a mucosal barrier that the virus could not penetrate or creating a hostile environment that would not be conducive to the survival of the virus. Unlike spermicides, microbicides may not be contraceptive. Similar to spermicides, microbicides would not be as effective as a condom, but certainly could be more effective at risk reduction than using nothing at all. Even with

less than optimum effectiveness, microbicides could be valuable in slowing the pace of HIV/AIDS throughout the world.

Microbicides are not currently available and are projected to be at least 2 to 7 years away. The ideal product would be one that would be safe, effective, widely accessible, affordable, available with and without contraceptive properties, as well as stable in tropical climates. Federal funding for microbicide research has been relatively small, representing just over 2 percent of the National Institutes of Health funding for AIDS research across the institutes (AMD 2004). This represents the largest share of federal funding for microbicide research, with other financial support allocated from the U.S. Agency for International Development (USAID) and the Centers for Disease Control and Prevention (CDC). Pharmaceutical companies have been reluctant to invest in microbicide development for a variety of reasons, such as uncertain profitability, demand, liability, and effectiveness. Microbicide researchers are largely dependent on donations from private philanthropy, such as the Bill and Melinda Gates, Hewlett, and Rockefeller Foundations.

U—UNIVERSAL ACCESS TO QUALITY HEALTH CARE

Universal access to quality health care is an important key to prevention and curbing the spread of HIV among Black women. However, about one out of every three Black women has no health insurance. Contrary to the stereotype, most uninsured Black women are employed. But, unlike most Americans who depend on their employers to offer health insurance coverage, most uninsured Black women have either part-time or low-paying jobs with no job-based insurance coverage.

Without health insurance, women do not get routine primary care to identify sexually transmitted diseases (STDs) that make them more susceptible to HIV infection or gynecological conditions that could signal co-morbidity with HIV/AIDS. Studies in both the United States and abroad have demonstrated that sexually transmitted infections, particularly infections that cause ulcerations of the vagina such as genital herpes, syphilis, and chancroid, greatly increase a woman's risk of becoming infected with HIV (NIH 2004). Women and men typically suffer from the same complications of AIDS, but women can experience gender-specific manifestations, such as recurrent vaginal yeast infections and severe pelvic inflammatory disease, which increase the risk of cervical cancer.

Without health insurance, women who are HIV-positive or have AIDS may experience delayed diagnosis and delayed treatment and lack continuity of care. The Centers for Disease Control and Prevention estimates that nearly one-third of people who are HIV positive do not know it (CDC 2004a). Compared to White men, Black women typically have higher viral loads and lower CD4, or T-cell, counts upon initiation of treatment and are often symptomatic upon initiation of antiviral therapy (Perry 2003).

In addition, the majority of pregnant women without health insurance do not receive prenatal care in their first trimester. Pregnant women who are HIV positive are at risk of perinatal transmission of the virus to the child. Prenatal HIV testing and early antiretroviral treatment has been credited for the tremendous progress that has been made in reducing the risk of mother to child transmission of HIV during

pregnancy from 25 percent to between 1 and 3 percent. Despite the dramatic reduction, the majority of babies that reportedly have HIV/AIDS are born to African American women. In 2003, 62 of the 90 reported infants diagnosed with HIV/AIDS were African American (CDC 2004c).

It is important to note that prenatal HIV testing of pregnant women is not always routine, with variations across states. In some states, in order to receive HIV tests, pregnant women must "opt in" by specifically responding affirmatively when an HIV test is offered. In other states, prenatal HIV testing is routine, given to every pregnant woman, except those who exercise the right of refusal or "opt out" when notified that it would be administered. It has been shown that opt-out policies and practices can increase the HIV testing rate to as high as 98 percent in contrast to states with opt-in approaches with testing rates that range from 25 percent to 69 percent (CDC 2004d). Therefore, opt-out policies for pregnant women should be uniformly implemented across all states.

African American women who are poor enough can qualify for health care coverage through Medicaid. It has been shown that there is a vast difference in the quality of care received by women who are HIV positive on Medicaid compared to those who are privately insured. Those who rely on Medicaid to access services were less likely to receive prophylaxis for opportunistic diseases and had a significantly shorter survival rate than those who were privately insured. Poor women are more likely to be treated by less experienced physicians. It has also been shown that Black women often receive less aggressive care than White male counterparts (Perry 2003).

Currently, most individuals who receive HIV care through Medicaid qualify because they meet two criteria: their income is below a certain level of poverty and their condition has progressed to a diagnosis of AIDS, which makes them categorically eligible as disabled. Expansion of Medicaid to include people with an HIV diagnosis, as AIDS activists have proposed repeatedly, would allow individuals to be covered at stages with a higher prognosis for success and when treatment is less costly. But changes in Medicaid appear to be moving in the opposite direction, with severe cuts being proposed in this administration's FY 2006 budget that would extend for ten years. Furthermore, with changes to Medicare, poor individuals who are dually eligible for Medicare and Medicaid may lose prescription drug coverage under Medicaid, will likely incur higher copayments for drugs, and will have fewer HIV/AIDS drugs covered under the new Medicare prescription drug programs.

Even if an African American woman with HIV/AIDS is able to access private health insurance, she may not be able to access HIV/AIDS treatment because many insurance companies impose policies that restrict the coverage of HIV and AIDS as pre-existing conditions (Stein 1998). With the annual cost of AIDS treatment at about \$20,000, African American women and others who may be financially able to access private health insurance are often forced to turn to the public sector to gain access to care.

Lack of health insurance limits access to treatment for drug addiction, particularly among intravenous drug users who are at the greatest risk of contracting HIV. In 2003, the second most common route of HIV transmission among African American women — accounting for 16.2 percent — was intravenous drug use (CDC

2004b). Cumulatively, since the beginning of the epidemic through 2003, 50 percent of the AIDS cases among Black women were the result of contaminated needles used to inject illicit intravenous drugs, either through needle sharing or having unprotected sex with a man who has used a contaminated needle (CDC 2004c). This means that if contaminated needles could have been eliminated, theoretically, the epidemic among Black women would be half of the current rate. Although not a substitute for drug treatment for addiction, needle-exchange programs have been demonstrated to be an effective HIV prevention strategy, as well as the least expensive. But needle exchange has been the subject of longstanding resistance because of concerns that such programs encourage or legitimize illicit drug use. The Black AIDS Institute profiled eight government-funded studies from 1991 to 2001 that concluded that needle-exchange programs reduce HIV-infection rates without increasing drug use (Wright 2005). Despite the strong evidence of the benefits, a 1989 ban on federal funding for needle-exchange programs imposed by Congress has never been lifted.

V—VACCINE RESEARCH

Perhaps the world's best hope for stopping the spread of HIV and eliminating the disease outright is a safe, effective, and affordable vaccine. Historically, preventive vaccines have effectively controlled serious worldwide epidemics, such as polio and smallpox. There have been dramatic drops in the occurrence of various diseases after a vaccine was discovered. HIV would be no different. There currently is no such vaccine, but there are numerous federal and private vaccine studies underway worldwide.

In May 1997, President Clinton issued a challenge to develop an AIDS vaccine by 2007. We now know it was an ambitious deadline that will not be met. Currently, it is projected that it will take at least 10 more years for a vaccine to be developed, tested through the various stages of clinical trials, and approved for market. Vaccine development is by nature a long and complicated process. For instance, it took 30 years from the time that the cause of measles was discovered to the development of the measles vaccine. It took 47 years to find a vaccine to stop polio. Researchers already have been working on an HIV vaccine for approximately 22 years. While many of those involved in HIV research are committed to finding a vaccine as quickly as possible, there is still a great deal of complex and challenging work to be done. HIV has proven to be a highly mutative virus that has confounded some of the best researchers in the world so far. However, if we hope to live in a world without AIDS, then more energy and resources must be focused on HIV vaccine research.

Currently, among the most affected by this disease, participation of African American women in vaccine development research has been very limited. And understandably so, given well-founded historical reasons for mistrust of medical science. Targeted public education and outreach to African American women is necessary to increase awareness of the impact of HIV on Black women and the need for a vaccine. Further, increased awareness is needed about the numerous safeguards of clinical trials in general and the processes of HIV vaccine trials specifically.

E—EDUCATION AND EMPOWERMENT

There is a great irony when it comes to passing on knowledge about one of the most natural human behaviors — sex. It is essential for the perpetuation of the human race. But there is tremendous trepidation, angst, and controversy about it. It is one of the few, if not the only subject, in which there are societally imposed boundaries placed on the acquisition of knowledge. In the era of the HIV pandemic, the code of silence about sexual knowledge can have deadly consequences.

The current sex education controversy consists of two opposing camps: abstinence-only-until-marriage education on one side and comprehensive sex education on the other. Evident from the title, abstinence-only programs stress virginity until marriage as the only option—solely the A of the ABC approach. It relies on shame and fear to control behavior. Because, the word “no” is considered the only inoculation needed to prevent pregnancy and sexually transmitted diseases, proponents of abstinence-only programs believe that instruction on contraceptives and condom use is unnecessary. Furthermore, such instruction is viewed as legitimizing promiscuity and having a disinhibiting effect on sexual behavior. If condom use is discussed in some abstinence-only programs, it is only in terms of failure rates and the information is often exaggerated. On the other side, comprehensive sex education programs also stress abstinence as the most effective way to prevent pregnancy and STDs, including HIV. In addition, comprehensive sex education curricula teach that the proper use of latex condoms can significantly reduce, but not eliminate, the risk of unintended pregnancy and of infection with STDs, including HIV.

Proponents in each camp tout both empirical and non-empirical reasoning to justify the merits of their respective positions (Bearman and Bruckner 2001; Kirby 2001, Kirby 2002; Rector 2002). But the most compelling reasoning in support of an age-appropriate, comprehensive approach to sex education is the ever-increasing devastation that HIV/AIDS is raging. In 2002, African American teens, ages 13 to 19, accounted for 65 percent of the new AIDS cases among teens. The ranking of AIDS as the top killer of Black women aged 25 to 34, coupled with the ten-year latency that can occur between HIV infection and progression to AIDS, indicates that the infection for many women occur in their teen years. It is evident that the collective level of knowledge about the impact, risk factors, modes of transmission, and prevention of HIV infection is woefully inadequate. Thus, any pedagogy that purports to bring about individual behavior change by perpetuating significant knowledge gaps is far too risky. Under the current administration, however, the promotion of abstinence-only-until-marriage programs has been stepped up. At the same time, federal support for comprehensive sex education programs has screeched to a halt, and many effective programs have been terminated.

The need for comprehensive sex education is not confined to adolescents. Programs that provide comprehensive, culturally relevant, gender-specific, and woman-friendly sex education or empowerment are critical for adult Black women. In 2003, the most common route of infection among African American women, accounting for 81.1 percent of the AIDS diagnoses, was heterosexual transmission (CDC 2004b). Women are more susceptible to contracting HIV through heterosexual contact because of biological and anatomical differences between women and

men. Semen can carry a higher viral load than female genital secretions. During sexual intercourse, women have a greater area of mucosal exposure through which the virus can be readily transmitted. As a result male-to-female transmission is about double the rate of female-to-male transmission (Biddlecom, Fredrick, and Singh 2004).

Most women are unaware that their male partners have placed them at possible risk of HIV infection, through such actions as having unprotected sex with multiple partners, engaging in bisexual behavior, or injecting drugs (Hader et al. 2001). For instance, in a study of HIV-infected persons, only 6 percent of African American women reported having had sex with a bisexual man, while 34 percent of African American men who had sex with men reported also having sex with women (Montgomery et al. 2003). Clearly, the vast majority of women in sexual relationships with bisexual men do not know it. This is also true of older women, whose most prevalent mode of transmission of HIV is also through sexual intercourse. New treatments, such as Viagra, have served to increase sexual activity among older individuals and consequently increase risk of HIV exposure. Because condom use is primarily viewed as a contraceptive device by older individuals, the importance of consistent and correct use for STD or HIV risk reduction is not always considered.

A gender-specific HIV/AIDS curriculum designed for Black women should encompass at least four areas. The first area should convey the sheer gravity of the epidemic, such as the basic differences between HIV and AIDS and their manifestations, myths about the origins and transmission of the disease, the seriousness of the health consequences of the disease, the rampant spread of the disease within all segments and age groups within Black America, particularly among Black women, and the various modes of transmission of the disease.

The second area should be aimed at personal behavior and responsibility, such as the role of abstinence and alternative expressions of intimacy, risk implications of multiple sexual partners, HIV testing, and correct use of a condom. The discussion of condom use should not be simply instructive, but comprehensive, encompassing issues such as latex versus animal skin, female condoms, latex allergy and prevention of allergic reactions, and the use of latex gloves, dental dams, and plastic wrap. Also, information on the future prospects of a microbicide and a preventive HIV vaccine should be addressed.

The third area should explore personal empowerment, such as building self-esteem, the roles within male/female relationships, intimate partner violence, techniques for negotiating condom use and HIV testing; addressing expressions of hurt, insult, anger, and suspicion; identifying signs of the "down-low" lifestyle; and addressing issues specifically relevant to women of various age groups and marital status.

Finally, the fourth area should involve HIV/AIDS advocacy. Community apathy about HIV/AIDS can be as deleterious as the virus itself. It was proactive, grassroots community education and activism that drove the rates of HIV down in the gay White community. Black women trained as HIV/AIDS activists can be a powerful force toward the realization of a policy-oriented agenda, working as individual citizens through social service organizations and faith institutions and as part of national campaigns. Finally, because the high rate of HIV affects so many African

Americans, advocacy training that includes social support and care giving for family members, intimate partners, and friends who are HIV infected is important.

In addition to youth-oriented, adult-oriented, and gender-oriented sexual education programs to curb the spread of HIV, mass public education is warranted. Commenting on the successful implementation of the ABC policy in Uganda, Harvard medical anthropologist Edward Green noted that the approach went well beyond the promotion of individual behavior change. He described the importance of mass public education that is focused on “reducing stigma, bringing discussion of sexual behavior out in the open, involving HIV-infected people in public education, persuading individuals to be tested and counseled, improving the status of women, involving religious organizations, enlisting traditional healers and much more” (Cohen 2003, 2).

Other governments have recognized the need to be straightforward, creatively clever, and bold in their approaches to educating the mass public about sexually transmitted diseases. One case in point is the National Health Service (NHS) of the United Kingdom, analogous to the U.S. Department of Health and Human Services. Seizing the power of the Internet in a public education campaign, the NHS created a humorous, animated e-card about sexually transmitted diseases with lyrics to the tune of “The Twelve Days of Christmas” (Block 2004, 85–91). The e-card directed people to a Web site that provided straightforward comprehensive sex education information. Such efforts underscore the fact that, when it comes to mass public health risks, being coquettish about prevention is an unaffordable luxury.

Mass media also can be implicated as part of the problem of this epidemic, but it can be transformed into a powerful vehicle toward a solution. All forms of media are saturated with images and messages that distort male/female relationships as being solely sexual encounters and objectify women as solely sexual instruments. Therefore, effective counter-messages that promote responsible sexual behaviors and serve to counterbalance, if not denounce, such distortions must be equally omnipresent throughout all forms of mass media.

Finally, despite the fact that HIV/AIDS has no socioeconomic, sociocultural, or sociopolitical boundaries, poverty as a root cause of the epidemic cannot be ignored. A study of HIV transmission among African American women in North Carolina found that women with HIV infection were more likely than noninfected women to be unemployed, receive public assistance, have had 20 or more lifetime sexual partners, have a lifetime history of genital herpes infection, have used crack or cocaine, or have traded sex for drugs, money, or shelter (CDC 2005). Aptly, former surgeon general David Satcher adds another element to the ABC prevention scenario – hope. He stated that “any domestic version of an ABC approach must be expanded to also address the sense of hopelessness that too often leads many people to engage in high risk sexual behavior” (KFF 2004). Therefore, personal, social, and economic empowerment must be at the very core of ending this epidemic.

CONCLUSION

If I could rewind the tape on the 2004 vice presidential debate and rewrite the transcript in response to Ifill’s question, a sweeping agenda of health policy and research

would have been articulated to dramatically alter the path of this disease for Black women. One candidate would have expressed the need for a method of HIV protection that women can control, such as microbicides, and called for a sizable increase in the National Institutes of Health AIDS research funding directed toward microbicide development. The other candidate would have noted that 1 out of every 3 Black women has no health insurance and stated that universal access to quality health care is key to the identification of risk factors, prevention, early diagnosis, and treatment of HIV/AIDS. One candidate would have praised President Clinton for having thrown down the gauntlet for an HIV vaccine by 2007, noting that it is no longer a realistic deadline, yet promising to throw down a new gauntlet for 2014 with adequate research support. Then, he would have asked all Americans to wear a red AIDS ribbon upside down, which is the symbol for HIV vaccine awareness. His opponent would have called for a repeal of abstinence-only-until-marriage sex education legislation, replacing it with stepped-up federal support for comprehensive sex education for youth, empowerment programs for adults, especially women, and a mass public education campaign about HIV/AIDS.

Although such a verbal exchange during the 2004 presidential campaign seems far-fetched, African Americans cannot afford to expect or accept anything less from national leaders. Because the root causes of the HIV/AIDS epidemic among Black women are multifactorial, approaches to ending the rampant spread of HIV must be multifaceted, multidimensional, far-reaching, and aggressive. The fact that a comprehensive national HIV prevention agenda for African American women has not been forthcoming underscores the need for a groundswell of outrage and urgency emanating from all African American institutions and sectors. We are, indeed, at war — with an enemy we cannot see, without the body armor and ammunition we need, and without the financial commitment necessary to envision an end. Winning will require serious political will, meaningful public and private investment, as well as personal responsibility. The war against the AIDS virus is one that African American women and men must not lose.

REFERENCES

- Administration on Aging (AA), Department of Health and Human Services (DHHS). 2005. *Promoting Healthy Lifestyles*. Washington, DC: U.S. Department of Health and Human Services. aoa.dhhs.gov/eldfam/healthy_lifestyles/hiv/hiv_pf.asp.
- Alliance for Microbicide Development (AMD). 2004. *Microbicide Legislation*. Silver Spring, MD: AMD. www.microbicide.com/microbicideinfo/legislation.shtml.
- Anderson, R. N., and B. L. Smith. 2003. Deaths: Leading Causes for 2001. *National Vital Statistics Reports* 52(9): 27–33. www.cdc.gov/nchs/data/nvsr/.
- Bearman, Peter S., and Hannah Bruckner. 2001. Promising the Future: Virginity Pledges and First Intercourse. *American Journal of Sociology* 106(4): 859–912. www.journals.uchicago.edu/AJS/journal/issues/v106n4/040236/040236.web.pdf.
- Biddlecom, Ann E., B. Fredrick, and S. Singh. 2004. Women, Gender and HIV/AIDS. In *Countdown 2015: Sexual and Reproductive Health & Rights for All*. New York: Family Care International. www.countdown2015.org.

Block, Jennifer. 2004. Sex, Lies and Abstinence. In *The W Effect: Bush's War on Women*. Edited by Laura Flanders. New York: The Feminist Press at the City University of New York.

Centers for Disease Control and Prevention (CDC). 2004a. *Advancing HIV Prevention Initiative*. Atlanta, GA: U.S. Department of Health and Human Services, CDC. www.cdc.gov/programs/hiv01.pdf.

———. 2004b. Diagnoses of HIV/AIDS—32 states, 2000–2003. *MMWR* 53(47):1106–1110.

———. 2004c. *HIV/AIDS Surveillance Report* 15:1–46. <http://cdc.gov/hiv/stats/2003surveillancereport.pdf>.

———. 2004d. *Routine Prenatal Testing the Opt-Out Approach*. Atlanta, GA: U.S. Department of Health and Human Services, CDC. www.cdc.gov/hiv/projects/perinatal/materials/OptOutNews3-2.htm.

———. 2005. HIV Transmission Among Black Women—North Carolina, 2005. *MMWR* 54(4): 89–94.

Cohen, Susan A. 2003. Beyond Slogans: Lessons from Uganda's ABC Experience. *Issues in Brief* 6(5): 1–3. www.guttmacher.org/pubs/ib2004no2.html.

Commission on Presidential Debates. 2004. Transcript of the Cheney-Edwards Vice Presidential Debate, October 5. www.debates.org/pages/trans2004b.html.

Hader, S., D. Smith, J. Moore, and S. Holmberg. 2001. HIV Infection in Women in the United States: Status at the Millennium. *JAMA* 285(9): 1186–1192.

Henry J. Kaiser Family Foundation (KFF). 2004. Former Surgeon General David Satcher Calls for "ABC+ Hope" Approach to HIV Prevention in the United States. *Daily HIV/AIDS Report*, May 27. www.kaisernetwork.org/daily_reports/rep_index.cfm?hint_1&DR_ID=23931.

Kirby, Douglas. 2001. *Emerging Answers: Research Findings on Programs to Reduce Teen Pregnancy*. Washington, DC: National Campaign to Prevent Teen Pregnancy. www.teenpregnancy.org/resources/data/pdf/emersumsum.pdf.

Kirby, Douglas. 2002. *Do Abstinence-Only Programs Delay the Initiation of Sex Among Young People and Reduce Teen Pregnancy?* Washington, DC: National Campaign to Prevent Teen Pregnancy. www.teenpregnancy.org/resources/data/pdf/abstinence_eval.pdf.

Montgomery, J. P., E. D. Mokotoff, A. C. Gentry, and J. M. Blair. 2003. The Extent of Bisexual Behavior in HIV-Infected Men and Implications for Transmission to Their Female Sex Partners. *AIDS Care* 15(6): 829–837.

National Center for Health Statistics (NCHS). 2003. *National Vital Statistics Report* 52(9).

National Institutes of Health (NIH), National Institute of Allergy and Infectious Disease (NIAID). 2004. *HIV Infection in Women: NIAID Fact Sheet*. Washington, DC: U.S. Department of Health and Human Services. www.niaid.nih.gov/factsheets/womenhiv.htm.

Office of the Surgeon General (OSG). 2001. *The Surgeon General's Call to Action to Promote Sexual Health and Responsible Sexual Behavior*. Washington, DC: U.S. Department of Health and Human Services. www.surgeongeneral.gov/library/sexualhealth/call.htm.

Perry, Toya. 2003. HIV/AIDS Policy and African American Women. In *African American Women and AIDS: Critical Responses*. Edited by D. J. Gilbert and E. M. Wright. Westport, CT: Praeger Publishers.

Rector, Robert E. 2002. *The Effectiveness of Abstinence Education Programs in Reducing Sexual Activity Among Youth*. Backgrounder no. 1533. Washington, DC: Heritage Foundation. www.heritage.org/Research/Family/BG1533.cfm.

Singh, Susheela, J. E. Darroch, and A. Bankole. 2003. A, B and C in Uganda: The Roles of Abstinence, Monogamy and Condom Use in HIV Decline. *Occasional Report* no. 9. New York: The Alan Guttmacher Institute. www.guttmacher.org/pubs/or_abc03.pdf.

Stein, T. J. 1998. *The Social Welfare of Women and Children with HIV and AIDS: Legal Protections, Policy, and Programs*. New York: Oxford University Press.

Joint United Nations Programme on HIV/AIDS (UNAIDS). 2004. *Position Statement on Condoms and HIV Prevention*. Geneva, Switzerland: UNAIDS. www.unaids.org.

U.S. Agency for International Development (USAID). 2004. *The ABCs of HIV Prevention*. Washington, DC: USAID. www.usaid.gov/our_work/global_health/aids/News/abcjan04.pdf.

Wright, Kai. 2005. *The Time Is Now! The State of AIDS in Black America*. Los Angeles, CA: Black AIDS Institute.

Power, Politics, and HIV/AIDS: An Interview with Cathy J. Cohen

Interview conducted by Mark Canavera

*Cathy J. Cohen, Ph.D., is professor of political science at the University of Chicago and director of the Center for the Study of Race, Politics, and Culture. She is the author of *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics* (University of Chicago Press, 1999) and the co-editor of *Women Transforming Politics: An Alternative Reader* (New York University Press, 1997). Dr. Cohen is currently conducting a research project through the Center entitled "African American Youth and Their Empowerment: Sex, Politics, and Culture," which will include a new national survey of young people ages fifteen to twenty-five, culminating into a multifaceted public education campaign.*

Mark Canavera of the Harvard Journal of African American Public Policy interviewed Cathy J. Cohen on 29 January 2005 at the University of Chicago in Chicago, Ill.

HJAAP

Thank you so much for meeting with me. I wanted to start with a question about *The Boundaries of Blackness*.¹ What's changed since you published it? Has there been a rise in the visibility of the problem of HIV/AIDS in the African American community? Have the political responses changed?

COHEN

There's no doubt that there's greater visibility in African American communities in particular around HIV and AIDS and the threat that the pandemic poses to Black and, I would argue, Latino communities. For example, BET's "Rap It Up" public education campaign has been incredibly successful. Evaluations of that program suggest that young people know the words "rap it up," and they have a sense of what it means. The question is, are they wrapping it up, and are they wrapping it up consistently in a way that will provide them with ongoing protection?

Mark Canavera is a master in public policy candidate at the John F. Kennedy School of Government at Harvard University. After a three-year tour as a Peace Corps volunteer in Burkina Faso, where he worked on HIV-prevention and girls' education, Mark completed a master of arts degree in peace studies at the University of Notre Dame.

On a different note, we have any number of television shows and talk shows that have taken up the issue of the “down-low,” the idea that there’s some phenomenon unique to African American communities — which I would dispute — where men sleep with men but don’t identify as being gay or bisexual. These men also have female partners and are thought to put women at risk because they have sex with these women without telling them that they’re also having unprotected sex with men. I’m not suggesting that the phenomenon doesn’t exist. We don’t know how systemic or how significant it is. The truth is we don’t have good data on this issue. The willingness to label this trend the “down-low” and to make it something specific to Black communities really speaks to a history of understanding Black people to have marginal and abnormal sexual appetites and behaviors. So there’s an ease almost in attributing this undisciplined sexual behavior to Black communities without the corresponding data that we would expect if we were talking about, for example, White men and their sexual behaviors.

We have, in fact, seen more discussion of HIV and AIDS in Black communities, and that, I think, is a positive thing. The question becomes, What type of response is it eliciting? Are we talking about HIV and AIDS in a manner that is librating? Are we honestly and accurately talking about sex and the behaviors in which people engage? Are we talking about the differences in power that inform sexual decision making [and] sexual behavior, and exist within any community? While there’s greater visibility and at some levels greater mobilization — in particular, from community groups — and while there’s more willingness for some Black elected officials to talk about HIV and AIDS both here and in Africa, I’m still not sure we’re seeing the most progressive analysis of HIV and AIDS or an understanding of the centrality of HIV and AIDS as a political issue for African American communities. But that just means we have more work to do.

HJAAP

Why do you think there’s so much more attention to HIV/AIDS in Africa than in the African American community in the United States?

COHEN

Many have argued that, because HIV and AIDS seems to be more rooted in African American communities — and clearly African Americans now make up the majority of new cases — it’s predictable that the government, the press, and in some cases foundations are less interested in the issue because they are, in fact, less interested in Black people in this country. And so, for many of us, it’s not a surprise.

Another way of explaining the focus on Africa is just the substantial numbers we’re talking about. In sub-Saharan Africa, we’re talking 20 or 30 percent of the population being HIV positive. So in terms of the sheer magnitude of the pandemic, it’s hard to argue with paying attention to what’s happening in Africa and the Caribbean.

Also, in terms of political expediency, we have a president who has billed himself as a “compassionate conservative,” and his attention to HIV and AIDS in Africa

and the Caribbean is an attempt to reconstitute the compassionate part of his image. It's hard to talk about compassion when we're bombing Afghanistan, invading Iraq, and making threats around the world. So there's a way in which Africa is currently being utilized as an example of what good things the U.S. can do.

A fourth explanation is just the nature of reporting. Twenty years into a story, reporters are looking for something different and dramatic. Clearly, HIV and AIDS in Africa [are] not different, but, again, the substantial numbers make it more dramatic. The fight over the distribution of drugs that can save lives make it more dramatic, even though many of those same fights happen in the U.S.

I don't think the right way to think about this is to say we should be doing [fewer stories] on Africa and more stories on HIV and AIDS in the African American community. We have to understand the significance and the reach of this epidemic — this pandemic — across the world, especially in marginal communities in the U.S. There are people *here* who don't have access to drugs. There are people *here* who don't have access to health care. There are people *here* who still lose their jobs and lose their housing because of HIV and AIDS. There are people *here* who still depend on the support of their families to survive. So we have to also pay attention to the evolution of HIV and AIDS here in the U.S., and that means paying attention to African communities in total.

HJAAP

You make it very explicit that *The Boundaries of Blackness* is engaged political science, that you want it to have a direct impact. You also suggest that you encounter some skepticism in the halls of academia with engaged political science. Having come to the University of Chicago to run the Center for Race, Politics, and Culture, do you still feel that you're facing resistance to engaged, direct political science?

COHEN

That's a great question. One of the things I really love about the Center for the Study of Race, Politics, and Culture is that we have a group of about twenty-five faculty members affiliated with the Center who are really working hard and struggling to figure out how we can promote and implement the idea of engaged scholarship. For us, the idea is to produce scholarship that holds to the rigor expected within universities, but also has relevance and is accessible to the communities that surround universities. Communities that are comprised of folks of color, people with fewer resources who might in fact be poor or working class, and people who will never have the chance to send their children to the universities where they work and clean and empty garbage cans or take phone calls as administrative staff.

We have to remember that we learn lots of things about how to formulate research questions and research designs by working with folks who don't necessarily have [doctorates], but have a clear understanding of their communities and the issues that they confront. Often people living and working just outside the university have been dealing with these issues far longer than we have. I think at times we

have lost our connection to really significant constituencies that don't necessarily reside within universities.

Let me say one last thing about doing what you call "engaged political science," specifically on the topic of HIV and AIDS. First, the good news is that there are lots of faculty members who are also struggling with the issue of how to make our work in political science engaged and relevant. And secondly, as HIV and AIDS has become such a significant political issue, it's hard now for my colleagues to suggest that it's not central to the study of political science. When I first wrote the dissertation on HIV and AIDS, I think there were still any number of people who just didn't understand what this had to do with political science. For them it was public health — it was about social behavior — but it had nothing to do with political science. Now I think that's probably an indicator of how out of touch the discipline of political science can be at times. I'm happy to say that that question is rarely raised anymore. Usually the question is, What are the other things that people in political science are doing to think about HIV and AIDS as a central political issue?

HJAAP

In 2002, you contributed to the National Gay and Lesbian Task Force seminal survey, *Say It Loud: I'm Black and I'm Proud*.²

COHEN

I'm very proud of that.

HJAAP

It is a very important document.

COHEN

We think it's an important document. And I think everyone associated with the document feels very proud about being a part of that project — it almost goes back to engaged scholarship — not only for the scholarship it produced, but also for the experience. I can't tell you what it felt like to be in a city and to ask Black gay, lesbian, bisexual, transgender, and queer folks to fill out a survey. Many just couldn't believe that somebody wanted to hear what they had to say. It was empowering to have that experience and to say, "Yes, we do. We want to hear what you have to say about what are the priorities and what are the challenges you face and what are the strategies that you utilize not only for survival, but progress." And so, while I think we're all very proud of the document, we were all enriched substantially by those interactions.

HJAAP

How did that study inform your thought and research on HIV/AIDS?

COHEN

The Boundaries of Blackness, I would argue — and other people have also — is much more of an elite study in the sense that I'm looking at Black elected officials and traditional Black leaders and organizations. I'm looking at Black ministers. I'm interested in how Black newspapers cover HIV and AIDS in Black communities as well as how traditional media sources like the *New York Times* and the television evening news cover this phenomenon. It's not a mass-based study.

With *Say It Loud*, we had a chance to look at the complexity of Black gay and lesbian, bisexual, transgender, and queer folks — the ways that they relate to each other, the ways that they constitute family, their religious practice and ideology, the resources on which they exist. Do they rent, do they own? Where do they work? Do they work? So there's a kind of complexity to Black queer people that you find in *Say It Loud* that I never attempted to approach in *The Boundaries of Blackness*.

Now it's not that I didn't want to pay much closer attention, for example, to the mobilization on the part of Black lesbian and gay people. I do think you get a picture of Black gay people in *Say It Loud: I'm Black and I'm Proud* that we haven't seen in the past. It's not just an imagined complexity. It's based on the numbers, as good social science often is.

HJAAP

You mentioned you were interested in looking at mobilization. Why has the White gay HIV/AIDS mobilization movement been so White?

COHEN

Let's not discount the mobilization that's happening in communities of color. There were people of color caucuses within ACT UP, and there were *small* groups of people doing work around HIV and AIDS in Black communities and Latino communities since the mid-eighties. And there were early conferences on HIV and AIDS in Black communities and other people of color communities. I don't want to make that invisible. There's been work going on for twenty [or] thirty years. We need to recognize that and be thankful for that work. But we can always ask the question of why haven't we seen more, which is basically a question in *The Boundaries of Blackness*. And I think even within predominantly White organizations and networks of mobilization, there are always progressive White folks who struggle around why they don't have more folks of color. I don't want to present this homogenous picture of there being only White people mobilizing and none of them pay attention to race with the other side being that there are no Black people mobilizing. There *are* Black people mobilizing, and there are White people struggling with the question of race. Too often, however, even those predominately White organizations with the best intentions remain predominantly White.

I would argue that part of the reason those organizations have remained primarily White is because quite often what they want is Black participants or Latino participants or Asian American participants or Native American participants to join them on their terms without soul-searching and redefinition and sacrifice. I remem-

ber an ACT UP meeting — I was living in New York in the early 1990s and going to ACT UP meetings both for my activism and part of my research — where a White man stood up and said, “I’m tired of those people coming down here from Harlem to join our organization because they want the money that we secure and the power that we have.”

It’s very difficult to have a sustained multiracial organization because it means that you really have to confront privilege and resources and power. If part of the mobilization for White gay men was based on the fact that, for the first time, they perceived themselves as marginal — their government wouldn’t respond — it becomes very difficult to then incorporate an understanding of their own power. Your government won’t respond to you, but you really *do* have more access than most folks of color, and you really *do* have more health care options, and you really *do* have insurance. It becomes very difficult for people who believe themselves at one moment to be marginal as a way of mobilizing themselves to then complicate that understanding with a sense of their power. And it becomes very hard for folks of color to be in an organization with White people when they’re not willing to recognize how much power and access and privilege they have. For sustained multiracial organizing, it doesn’t just mean coming together and marching together. It means a real struggle around who we are, our social and political identity, how we relate to the state in very different ways, how our communities are very differently situated, and what it means in terms of going forward. That’s a lot of work to do when you’re trying to fight what you consider to be the enemy or the target or the state. So I think that’s part of the reason why we don’t see more multiracial organizations.

HJAAP

The Boundaries of Blackness is a superb diagnosis, and we can look at this issue historically. But in some ways it makes the prospects for these doubly marginalized or triply marginalized communities seem quite bleak. What is the hope?

COHEN

I don’t see it as bleak actually. Beyond HIV and AIDS, if you look at folks of color and their willingness to sacrifice and struggle to make things better, that is a glorious history. If you read Robin Kelley’s *Freedom Dreams* or if you look on the ground at the Black AIDS Institute headed by Phill Wilson and the work that they’re doing, I’m always hopeful that not only are there individuals who will mobilize in terms of leaders, but there are always other individuals whose names we don’t know who see a problem or see a systemic issue and work within their communities to talk to people, to force their church to react. I’m probably more hopeful about individual indignation and the willingness to mobilize and change institutions than I am about institutions and organizations that aren’t necessarily going to do that. That said, there’s still an incredible amount of work for us to do, and some of the work we call mobilization is really a struggle around understanding and reconceptualizing sexuality in all communities. But I’m most concerned with how we deal with

questions of sex and lesbian, gay, bisexual, transgender, and queer identities within Black communities.

We will never really see progressive movement around the issue of HIV and AIDS until we fundamentally struggle around the issue of sex and sexuality. That's a much more difficult discussion to have than [whether] we get a few more dollars from the government to fund a program, which is also important. But it is, at some level, a Band-Aid—although a needed Band-Aid. We are never going to transform behaviors or understandings without that kind of secondary discussion of sex and sexuality.

HJAAP

I'm wondering if you've woven HIV/AIDS into your new work.

COHEN

The new project is focused on African American youth and their politics, their political understanding of themselves, and their understanding of the state. It's a pretty incredible moment because you have a generation that has grown up in a supposedly post-segregated society — at least *du jour* segregation. But as we've done focus groups, the data suggests that these young people don't feel empowered. They don't feel like they are full citizens in the U.S. They often feel like they're under surveillance. They're demonized. They're harassed by different agents of the state, and one of the most interesting and troubling things that we found initially in terms of our focus group data is that young people talk about strategies of invisibility. I've called it a kind of politics of invisibility. If the police don't see me, they can't harass me. If my parole officer doesn't see me, he can't have me sent back. If my teacher doesn't see me, they can't fail me or put me in special learning or kick me out. If my caseworker doesn't see me, she can't hassle me or take my kids away. There is underlying strategy of invisibility — which might be a strategy of survival at some level — but it contradicts everything that we know about democratic society, where the expectation is visibility and voice. I am very interested in how young people, particularly African American young people, think politically about themselves, the world, and, in particular, this country and their placement in it.

I'm making an argument that how young people understand themselves politically has an impact on what they do in terms of individual sexual, social, and intimate relationships, which goes back to HIV and AIDS. If I feel like I have no power in the world, the only place I may be able to exude some power is in intimate relationships, in decisions over sex, or to be more sexual. I don't want to disconnect the discussion of power and politics from the discussion of seemingly individual level behaviors and decision making. I have a team of graduate and undergraduate students working on this project with me, and we are mounting a new national survey of young people ages fifteen to twenty-five that's been funded by the Ford Foundation. The idea here is that to really understand their decision-making processes and how they think about the world, we have to move away from merely counting behaviors. If you look at a lot of the literature studying African American youth, it's

focused on outcomes. Did they get pregnant? Did they have sex? Do they carry a weapon? Have they been involved in violence? Those are important things to know, but it's also important to know how these young people came to make decisions about those behaviors, and that's really more of the focus of this new project.

HJAAP

You laid many foundations with *The Boundaries of Blackness* and *Say It Loud* for future research, and I'm sure you'll do the same with this project.

COHEN

It's a very exciting moment. It's an incredible population to be engaged with, and it doesn't take me that far away from HIV and AIDS because the numbers among young African Americans are pretty astounding in terms of HIV and AIDS. For example, one of the things we want to know is, if you ask them what are the three most important issues that they face, does HIV and AIDS even show up on the map for them or is that just something that's in the background. They grew up with this epidemic, so trying to get a sense of how they understand the epidemic will be very interesting.

ENDNOTES

1 *The Boundaries of Blackness* analyzes the political response, or lack thereof, to HIV/AIDS in the African American community.

2 *Say It Loud: I'm Black and I'm Proud* was the first nationwide survey of gay, lesbian, bisexual, transgender, and queer Black Americans.

Restoring Our Faith: HIV/AIDS and Black Faith Communities

An Interview with Pernessa Seele

Interview conducted by Erica L. McKnight

Pernessa Seele is founder and CEO of The Balm In Gilead. Ms. Seele is recognized around the world for her work as a pioneer in mobilizing and educating Black churches to become engaged in the fight against AIDS. She also serves as an advisor to the Health Brain Trust of the U.S. Congressional Black Caucus and as a consultant to the Mailman School of Public Health at Columbia University. Ms. Seele earned a master of science degree in immunology from Clark Atlanta University.

Erica L. McKnight of the Harvard Journal of African American Public Policy interviewed Pernessa Seele on 19 March 2005.

HJAAP

What is the mission of The Balm In Gilead?

SEELE

At The Balm In Gilead, our mission is to build the capacity of faith communities throughout the African Diaspora to address HIV and AIDS.

HJAAP

What was the motivation for establishing your organization?

SEELE

Before there was The Balm In Gilead, I was one of the first AIDS educators in New York City. The AIDS epidemic was young — it was new. I found myself at Harlem Hospital. And it was [during] the first three days of work at Harlem Hospital that there were all these people living with HIV and dying all around us. There was nobody from the church. And that was not my experience of the Black church.

Historically, Black folks have been there when you're sick and definitely there when you're dying. And I just got an idea to have a Harlem week of prayer for the

Erica L. McKnight is a second-year master in public policy student at the John F. Kennedy of Government with a concentration in education policy. A Washington, D.C. native, Erica is a 2002 graduate of Spelman College.

healing of AIDS. The purpose of that Harlem week of prayer was to bring the faith community of Harlem together. The churches, the mosques, Ethiopian Hebrews — everybody. It was the first time that everybody had come together for a week of prayer, and it happened to have been for HIV and AIDS.

I asked folks to come together for prayer, but I was also asking them to participate in some kind of educational forum during the week. The catalyst was to bring the faith community together. It was modeled after a revival. And it worked.

In 1989, the church was being devastated by HIV. The mosque was being devastated by HIV. People were saying that the church didn't want to deal with it. But it wasn't that the church didn't want to deal with it — the church didn't know how to deal with it. Putting AIDS education into a context of prayer, into a context of something that was culturally and spiritually appropriate, opened the door for the faith community to start addressing HIV and AIDS.

The Harlem Week of Prayer took off. After the first year I swore I would never do it again. I didn't have any money, and nobody knew what I was doing. When it was over, I was like, "I'm never going to do this [again]." The next year, I was doing it again. The Harlem Week of Prayer became the Black Church Week of Prayer, and we just finished the Sixteenth Annual [Black Church Week of Prayer].

The Week of Prayer received so much energy around it that people started calling me about the Week of Prayer, as if it were an organization. So I had to create an organization to put the Week of Prayer into. And that's how The Balm In Gilead was born. Pastors, church leaders, and [congregations] needed and wanted to be trained around HIV. They wanted to develop AIDS ministries. We had to create an institution that would allow us to provide services and build the capacity of churches to do that work. But to this day, the catalyst continues to be a day of prayer.

HJAAP

Could you talk more about The Balm In Gilead's role in combating HIV/AIDS in the African American community?

SEELE

The role of the faith community is at the core of addressing HIV/AIDS in the African American community. The major problem of AIDS is stigma. And the birth of the AIDS stigma came from the universal church — the universal faith community. At the core is this myth, this idea, this belief that AIDS is a sin. That is the message that the faith community has taken around the world. That did not come out of the African American church. It came out of the universal church.

The African American church is no more homophobic than any [other faith community]. The fundamental role of the church is to dismantle that which [the universal church] so successfully created, which is the stigma of AIDS. It is the stigma of AIDS that stops people from getting information, getting treatment, and giving or getting care. We have got to start to dismantle the AIDS stigma, and that's the fundamental purpose of getting faith communities involved.

The second purpose is education. There is no institution in the African American community that can educate the masses like the church. The church also has the structure. We have a women's ministry, men's ministry, youth ministry, and prison ministry. We have all of the auxiliary ministries that are being affected by HIV. We must build the capacity of the faith communities in Mobile, Alabama and in Omaha, Nebraska. We must build the capacity of the churches that are in the community to address HIV/AIDS holistically.

HJAAP

How does The Balm In Gilead work to build the capacity that you just spoke about?

SEELE

In addition to our week of prayer, we also provide training to pastors in terms of leadership development, sermon development, and how to think through what might be done in communities. We provide technical assistance on how to begin to develop an AIDS "ministry," which is the language of the church. In the secular world, it's called an AIDS program.

We also provide dialogue on how to do a needs assessment for what might be needed in the congregation of a community and what the community is comfortable with. That's very, very important to the church because some churches are not where other churches are. Some churches may say, "We are in a community that's being devastated, and we want to start an HIV testing clinic. We want to give out condoms." Another church may say, "We believe in abstinence only and want abstinence programs." The Balm In Gilead meets the churches where they are. We provide technical assistance and support for churches to do that which they say they want to do in a very effective way.

Oftentimes, most churches get involved with The Balm In Gilead through the Week of Prayer. They never talk about HIV, but they begin with prayer. We now have data to show that, after sixteen years, a church that started with prayer now has a major outreach, direct-service component. They have grown in their awareness of HIV and what the needs of the community are. A church that started five years ago may have a striving AIDS program. That AIDS program may mean that they are giving out brochures on Sunday or that they have a youth forum once or twice a year. That is how we build the capacity of the faith community to address HIV/AIDS in these communities — where they are.

HJAAP

How have Black congregations responded to The Balm In Gilead's work?

SEELE

The overall response has been very good. We need more response. My goal is to have every Black person in America talking about HIV and talking about it effectively. Certainly, we are not where we want to be. But we can look at where we were

sixteen years ago, when churches were not saying anything, to now where we have model churches around the country that we can point to and say, "Look at Metropolitan Denominational Church in Nashville, [Tennessee] and the work they're doing. Look at Bethel AME Church in Bloomington, Delaware, where they are testing two hundred people and have a holistic, direct-service management program right there in their church." We can go on and on listing model programs that are in the African American community. But certainly we have to continue to work hard to get those churches that are so wrapped up in the stigma of AIDS that they have not been able to break through to address the problem of AIDS.

HJAAP

Could you talk more about the challenges you faced in terms of church leaders expressing resistance to candid dialogue about HIV/AIDS prevention?

SEELE

When we began addressing HIV/AIDS in the early 1980s, misinformation came out of the public health community. We can see the lasting impact of that. It was GRID [gay-related immunodeficiency disease], it was a gay man's disease, and it was never going to affect the heterosexual community. All of that initial information that was put into the community still has an impact on the African American community. The African American community is still stuck on HIV as a homosexual disease [or the idea that] homosexuality causes AIDS.

I call that kind of erroneous thinking — which has its root in misinformation—the new mis-education of the Negro. We have recycled the mis-education of the Negro when it comes to HIV and AIDS. That [thinking] still has a strong hold on our community, and the major struggle and hardship that we face at The Balm In Gilead in terms of addressing resistant church leaders is to somehow get them to understand that addressing HIV does not have anything to do with their theological position on homosexuality.

Everybody in the Black community is affected by HIV. We need pastors to understand that. We're not asking them to give up their theological position; we're asking them to effectively do HIV education. Let's do prevention services to provide support for people living with HIV. There's so much to do. Let's do something. You don't want to deal with the gay community, deal with the youth community. You don't want to deal with the youth community, deal with the elderly community. Everybody is affected in our community. Do something.

HJAAP

In general, do you believe that faith-based initiatives have helped or hurt in addressing HIV/AIDS in the Black community?

SEELE

In general, the faith-based community has helped [to address] HIV in the Black community. As we continue to see more and more African Americans and Africans addressing HIV/AIDS in a holistic, positive, and spiritual way, it chips at the dismantling of "AIDS is a sin." But we have to have more churches to speak boldly and loudly that everybody is a child of God, whether you're living with HIV/AIDS or not. Everybody has a right to AIDS education and to life itself. Those messages coming from the church have great impact on the positive movement of addressing HIV/AIDS in our communities.

HJAAP

Should Black churches play a more prominent role in shaping public policies affecting the management and prevention of HIV/AIDS in the African American community?

SEELE

Yes. At The Balm In Gilead, we are working now to begin an African American Faith Policy Institute to do just that. The need is so great. As we have been struggling for sixteen years and working to build the capacity of faith communities to address HIV, we also have to build the leadership capacity to get pastors on the front line of policy and advocacy in shaping policy that is affecting our community. Every HIV/AIDS policy affects Black people. So it's very critical. And historically, policy development out of the African American community has come out of our churches. The leadership of the church becomes very, very much involved in policy development.

HJAAP

You mentioned that you are working to create a new policy institute. Does The Balm In Gilead do any other advocacy or lobbying work?

SEELE

I work very closely with the Congressional Black Caucus in their Office of Health Disparities with the Honorable Donna Christian-Christensen (D-Virgin Islands, At-Large). In addition to working and speaking with our historical institutions, I'm on the board of AIDS Action in Washington, D.C., which is the nation's HIV/AIDS advocacy group. It's a holistic approach in terms of bringing a voice of policy — grassroots policy development as well as regional, state, and national policy development.

What's unique about the Black experience is that no matter what group you're talking to, they all are rooted in the church. We are unique people when it comes to our faith. It is our faith that shapes how we move the direction of the institutions that we are running. Again, that's why the faith community is so critical.

HJAAP

Does The Balm In Gilead support any current legislation on HIV/AIDS issues?

SEELE

We definitely support the full reauthorization of the Ryan White Care Act. And I just learned that one in every four Black men living in Harlem has HIV. One in four in Harlem. When you've got those kinds of numbers, we don't have the choice of deciding whether we're going to do condom [education] or not. Or whether we're going to do abstinence-only programs or not. Or whether we're not going to do needle exchange programs. When our numbers are off the chart like that, we have to do everything. We have to support every kind of intervention. We need to support it. Those of us who believe this get in trouble because the conservative members of the community say, "Oh well, you can't support everything." Well, when your house is on fire, you've got to use all kinds of water to put it out. The liberal community and the conservative community must come to the table and understand that we must join forces here. Black liberals and Black conservatives must join forces to fight HIV in our community. Because the liberal view is not going to save all the people, and the conservative view is not going to save all the people. We need both liberal and conservative views fighting for one common good—fighting HIV and AIDS.

HJAAP

What can African Americans learn from other countries' approaches to combating the HIV/AIDS pandemic in our communities?

SEELE

There are two things that come to mind that we can learn. One is that the epidemic does not go away because you don't do anything. At The Balm In Gilead, we work with five African countries: Cote d'Ivoire, Nigeria, Kenya, Tanzania, and Zimbabwe. We can look at the devastation of AIDS in Africa and see the same statistics in some parts of our community — like Harlem, where one in every four Black men [is infected with HIV]. One in every four people living in South Africa has HIV. To do nothing means that the epidemic is going to overtake your community.

The second thing we have to learn is that, as the Black community in America, no one is coming to save us from this epidemic. We are not getting an increase in funding from the U.S. government. Most of the foundations do not specifically address HIV/AIDS in our communities. If we do not begin to seriously address HIV/AIDS ourselves — in our homes, in our communities, in our churches, on our jobs, in our streets — we, as a race of people, are going to be wiped out.

We hear a lot about Uganda and AIDS today. But I remember when I went to Uganda in the 1980s. Nobody was talking about Uganda and AIDS. Uganda was one of the first countries devastated by HIV/AIDS in the world. Nobody went to Uganda to save Uganda in the 1980s. Now, it's a model country. But look at the loss

and devastation that had to happen before the light was shined on Uganda. What did Uganda have to do to get to this point? Well, one thing Ugandans did was talk about HIV. HIV had to become the topic of the community because people were dying everywhere. We have got to make HIV the topic of the African American community. We have got to take money out of our own pockets to begin to address HIV. We are waiting for someone else to come and put prevention messages in our community. And it's not happening. If we learn anything from other countries, we're going to have to learn that to not address it, to not talk about it, means that the epidemic is going to overcome us.

We have got to begin to take hold of what we can do for ourselves. Uganda is living and breathing today because Uganda had to save itself. No one cared to save Uganda. But Uganda had a holistic approach to addressing HIV, and the African American community must do the same thing. In the African American community, we are at the brink of a situation in which we have to understand that we have to save ourselves. Because we've got communities in Harlem, communities in the South, that have one in four people living with HIV. And twenty years from now, we're going to be wiped out if we don't begin to understand that we've got to save ourselves.

HJAAP

How does that transformation happen?

SEELE

By doing what you're doing. By all of us doing what we can. If there's an opportunity for a Harvard journal to talk about HIV in the African American community, take it. If there's an opportunity for me to speak at a church, take it. Talk about HIV to the guy next to you. Or at the breakfast table with your children. Educate our children so that they're educating their friends. Everybody has got to do what they can. It doesn't matter how big. It doesn't matter how small. But we have got to do something.

HJAAP

What are some of the biggest challenges that The Balm In Gilead faces in working to achieve its mission?

SEELE

Getting African Americans to understand that we have got to take hold of this epidemic. That's our biggest challenge. And that relates to funding. We are constantly looking outside of the community to fund the work for the African American community. We need African Americans to fund the work. Our biggest challenge is getting the Black community to understand that we have got to save ourselves. The Balm In Gilead's approach is to work through churches and through the faith community.

Saving Ourselves: African American Women and the HIV/AIDS Crisis

Avis A. Jones-DeWeever

ABSTRACT

The HIV/AIDS epidemic may be the most formidable threat the African American community has ever faced. AIDS has become the leading cause of death among African Americans aged 25 to 44 — the prime child-bearing and wage-earning years (KFF 2003). And while both African American men and women are disproportionately victimized by this disease, Black women are increasingly becoming the faction most affected by AIDS. This piece identifies the various factors that have led to the increasing prevalence of HIV/AIDS among African American women and delineates promising strategies for successfully facing this crisis.

THE FEMINIZATION OF AN EPIDEMIC

The AIDS epidemic of the 21st century presents a much different challenge than the one faced at its initial emergence roughly 20 years ago. After years of aggressive safe-sex campaigns aimed initially at the gay community and significant advancements in drug therapy, AIDS has become much less White, gay, and male. In the 1990s, women became the fastest-growing demographic group afflicted with AIDS. Between 1993 and 2001, the proportion of African American women diagnosed with the disease grew at an astonishing rate, increasing by 40 percent in less than a decade (McNair and Prather 2004). Today, African American women are 23 times more likely to be diagnosed with AIDS than White women and account for 64 percent of new HIV infections (KFF 2003; KFF 2004). Similarly, among teenagers aged 13 to 19, African American girls account for 61 percent of new AIDS cases (KFF 2003).

As compared to White women, African American women are significantly more likely to acquire HIV/AIDS through heterosexual sex than through intravenous drug use (KFF 2003). What is so different about Black women as to cause such a concentration of HIV/AIDS within this population? While not all-encompassing, certainly one major factor can be found in Black women's love of and loyalty to Black men. Since African American women represent the faction least likely to form

Avis A. Jones-DeWeever, Ph.D., is the study director for poverty and income security at the Institute for Women's Policy Research. Her work examines the causes and consequences of poverty on the well-being of low-income women and families while identifying effective programmatic strategies that result in poverty reduction. Dr. Jones-DeWeever would like to thank the Institute for Women's Policy Research for its support and particularly acknowledge the assistance of Elizabeth Circo in the development of this work.

romantic relationships outside of their race, the fate of Black women is particularly vulnerable to the well-being — or lack thereof — of Black men (Staples 1981).

LINKED-FATE: BLACK WOMEN AND THE PLIGHT OF BLACK MEN

Black men and women share a linked-fate, and any lasting solution to the HIV/AIDS crisis among African American women necessarily dictates aggressive efforts to also reduce infection rates among African American men. With respect to the AIDS epidemic, HIV infection among African American women has become a by-product of America's war on drugs and its resulting mass incarceration of Black men. The resultant effect of mounting Black male incarceration has significantly increased Black women's exposure to the virus that causes AIDS by both increasing the likelihood that a pairing will occur with a sexual partner who has spent time in prison and significantly widening the existing Black sex-ratio imbalance due to the large numbers of Black men extracted from the community (Braithwaite et al. 1996; Lane et al. 2004).¹ With respect to the problem of AIDS in prisons, much more can be done to reduce the transmission of HIV behind bars and, in so doing, ultimately decrease the vulnerability of Black women.

Currently, less than 1 percent of the nation's jails and prisons allow inmates access to condoms, despite estimates that 7 to 12 percent of all inmates report being raped an average of 9 times while imprisoned (Lane et al. 2004). Add to this the risk of transmission through consensual sexual activity, intravenous drug use, and crude tattooing methods, and the high-risk nature of the prison environment becomes evident (Lane et al. 2004). Certainly, the ostrich-method of fighting AIDS in prison by sticking one's head in the sand is not working. While this approach may provide the convenient excuse of ignorance, it does not abdicate responsibility for the lives of those touched by this disease, both within prison cells and beyond.

While safer prison environments may address part of the problem, a broader goal might involve working towards the reduction of mandatory minimum sentences to which Black men are subject that ultimately destabilize Black communities by exacerbating the sex-ratio imbalance.

In addition, although the popular notion of the "down-low" brother — a man who considers himself heterosexual but has sex with women and men — may be overstated, the very real dangers associated with homophobia within the Black community is not emphasized enough. Significant anti-gay sentiment in both the Black church and the larger community drives such behavior underground. As a result, African American men who have sex with men are less likely than men of other racial or ethnic backgrounds to admit to being attracted to the same sex (CDC 2003). According to one study by the Centers for Disease Control, more than 1 in 3 of these "nondisclosures" admitted to having a recent sexual relationship with a woman. And specifically among Black nondisclosures, 1 in 7 was found to be HIV positive (CDC 2003). Thus, relegating homosexual activity to the closet in the name of morality unnecessarily endangers the lives of women who ultimately find themselves ill-equipped to protect against a threat they never saw coming.

THE POVERTY PROBLEM

On a broader scale, the prevalence of poverty within the African American community creates an environment fertile for increased levels of vulnerability among Black women. The social and geographic isolation of impoverished neighborhoods significantly minimizes partnering options and ultimately heightens the negative implications of the Black sex-ratio imbalance. In addition, the lack of jobs and inadequate educational opportunities make illegal, income-generating activities viable options for those struggling to survive. Such conditions increase one's likelihood of becoming entangled in the criminal justice system — an environment that is 4 times more prone to AIDS prevalence than the general population (Maruschak 2002). And once a criminal record is established, becoming integrated into the formal economy becomes all the more challenging, making it exceedingly difficult to break the cycle. These and other stressors associated with poverty, such as limited access to health care, the likelihood of substance abuse, and increased levels of psychological and physical stress, ultimately lead to increased incidences of AIDS within impoverished neighborhoods (Gilbert 2003).

Heightened risks for acquiring AIDS in poor communities explain only half the problem as it relates to poverty. Less frequent health screenings among the poor increase the possibility of people unwittingly carrying and spreading the virus. And for those who have already tested positive, poverty serves as a significant barrier to much-needed treatment. As a result, African Americans are much more likely than Whites to postpone seeking appropriate health care due to the lack of transportation or the fulfillment of other needs believed to be more immediately pressing, such as paying for food or housing (KFF 2003). Given the above-mentioned implications, it becomes clear that any comprehensive strategy for countering the AIDS crisis in the African American community must have at its core a complete assault on poverty. Concurrent to this struggle, African American women must actively seek to save themselves by valuing their bodies and their lives through self-empowerment and aggressive self-protection.

SELF-EMPOWERING SOLUTIONS FOR THE AFRICAN AMERICAN WOMAN

Research suggests that effective HIV intervention strategies targeted at African American women take into account cultural and societal factors while also emphasizing the importance of individual actions. This mix of information and empowerment helps participants gain an increased sense of self-assuredness while also acquiring the necessary tools for better communicating demands to sexual partners. Evaluations of this approach have shown that experimental group participants were more likely than those in the control group to report both consistent condom usage and a greater likelihood of choosing to not have sex when a condom was not available (DiClemente and Wingood 1995). Unfortunately, such interventions are often the exception rather than the rule. Most AIDS prevention programs targeting African American women place a much greater emphasis on individual behavior than the social and cultural contexts within which these women find themselves

immersed (McNair and Prather 2004). As a result, such programs run the risk of being deemed irrelevant to the target audience's life experience, in much the same way that AIDS prevention strategies targeted towards gay men fail to connect with African American men who both self-identify as heterosexual and have sex with men. Although well-intentioned, such culturally irrelevant strategies ultimately miss the mark in terms of connecting with the intended audience.

While increasing the number of culturally relevant HIV prevention programs targeted to Black women would be ideal, true self-empowerment would allow women the ability to protect themselves without having to rely on male capitulation. Microbicides offer this option. Although not yet available to the public, microbicides could come in a variety of user-friendly forms such as gels, creams, and suppositories and could ultimately save countless lives by providing a layer of protection against HIV as well as a wide variety of other sexually transmitted diseases. Both contraceptive and non-contraceptive versions of microbicides could be developed to preserve women's contraceptive choices while also protecting against possible AIDS transmission. Unfortunately, the lack of adequate funding for research and development has delayed the introduction of microbicides to the public. Major pharmaceutical companies have failed to significantly invest in research in this area because of doubt about the profitability of this method of protection. The failure of the private sector to respond to this need makes it increasingly important to mobilize public-sector investment in order to make microbicides broadly available as perhaps the most significant advancement in women's reproductive health options since the introduction of the pill (Global Campaign for Microbicides n.d.).

CONCLUSION

Significantly reducing the prevalence of HIV/AIDS among African American women will take both broad-scale social activism as well as much more intimately targeted approaches that focus on the real lives and circumstances of Black women. Larger goals worth pursuing include fighting against the mass incarceration of Black men while also working towards the creation of more "safe" prison environs, working towards the amelioration of poverty, attacking homophobia within the Black church and among the broader African American community, and fighting for greater public investment in the research and development of microbicides. Concurrently, grassroots efforts should include a strong emphasis on the creation and implementation of culturally relevant anti-AIDS programs by and for African American women and girls.

The AIDS epidemic must be met with a level of fervor perhaps unseen since the civil rights movement. And much like that historic movement, to meet this challenge, we must draw on the varied strengths of the community including broad-based grassroots activism along with political, intellectual, and religious leadership. While ambitious, the sheer gravity of this threat requires a multi-pronged solution that seeks to reach women where they are in a way that is both socially and culturally relevant to their life experience. This challenge must be met, and this fight must be fought with the same passion and intensity that is necessary to wage the fight of our lives.

REFERENCES

- Braithwaite, Ronald L., Theodore M. Hammett, and Robert M. Mayberry. 1996. *Prisons and AIDS: A Public Health Challenge*. San Francisco: Jossey-Bass.
- Centers for Disease Control and Prevention (CDC). 2003. HIV/STD Risks in Young Men Who Have Sex with Men Who Do Not Disclose Their Sexual Orientation—Six U.S. Cities, 1994-2000. *MMWR* 52(5): 81-85. <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5205a2.htm>.
- DiClemente, Ralph J., and Gina M. Wingood. 1995. A Randomized Controlled Trial of an HIV Sexual Risk Reduction Intervention for Young African American Women. *Journal of the American Medical Association* 274:1271-1276.
- Gilbert, Dorie J. 2003. The Sociocultural Construction of AIDS Among African American Women. In *African American Women and HIV/AIDS: Critical Responses*. Edited by Dorie J. Gilbert and Ednita M. Wright. New York: Praeger.
- Global Campaign for Microbicides. n.d. About Microbicides. Washington, DC: Global Campaign for Microbicides. http://www.global-campaign.org/about_microbicides.htm.
- Henry J. Kaiser Family Foundation (KFF). 2003. *Key Facts: African Americans and HIV/AIDS*. Washington, DC: Kaiser Family Foundation. <http://www.kff.org/hivaids/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=19520>.
- . 2004. *HIV/AIDS Policy Fact Sheet: The HIV/AIDS Epidemic in the United States*. Washington, DC: Kaiser Family Foundation. <http://www.kff.org/hivaids/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=32947>.
- Lane, Sandra D., Robert A. Rubinstein, Robert H. Keefe, Noah Webster, Donald A. Cibula, Alan Rosenthal, and Jesse Dowdell. 2004. Structural Violence and Racial Disparity in HIV Transmission. *Journal of Health Care for the Poor and Underserved* 15(3): 319-335.
- Maruschak, Laura M. 2002. HIV in Prisons, 2000. *Bureau of Justice Statistics Bulletin*, October.
- McNair, Lily D., and Cynthia M. Prather. 2004. African American Women and AIDS: Factors Influencing Risk and Reaction to HIV Disease. *Journal of Black Psychology* 30(1): 106-123.
- Staples, Robert. 1981. *The World of Black Singles: Changing Patterns of Male-Female Relations*. Westport, CT: Greenwood Press.

ENDNOTES

- 1 Pairing with a sexual partner who has spent time in prison is a factor that, in and of itself, increases one's chance of exposure to the AIDS virus.

The Lost Generation: A Documentary Film

Review of *A Closer Walk* (2004)

Directed by Robert Bilheimer

Reviewed by Eleni Andreadis

The haunting beauty of *A Closer Walk*, Robert Bilheimer's stunning documentary film about AIDS, creeps under the audience's skin from the first frame. As Cole Porter's "Every Time We Say Goodbye" begins, the camera follows a Ugandan doctor who is about to examine a fragile, dying child ironically named Lucky, who barely fills the hand that examines her. "There are thousands and thousands like her," the doctor adds. It soon becomes clear that *A Closer Walk* is not the average documentary that comfortably lets its viewers sit back, detached. From the first moments, it arrests the audience's attention with the impact of a train racing towards them at full speed.

As viewers come to realize, that is the sort of immediate threat that AIDS poses to humanity. Those expecting the usual treatment of the topic, with a barrage of accusations aimed at pharmaceutical companies and political leaders—justified as those accusations may be—will be surprised. Academy Award nominated director, writer, and producer Bilheimer has crafted this film in a way that requires the audience to leave busy thoughts behind and surrender to an emotional and sometimes painful experience.

Actors Glenn Close and Will Smith narrate the film, posing the question repeated by UN Secretary General Kofi Annan: "What kind of people are we?" The narrators question how humanity could have allowed "a preventable and treatable disease to thrive in the human family for over twenty years, killing more than sixty million of its members." The simplicity of the question is both startling and affecting.

Life is immensely colorful through Bilheimer's lens, in sharp contrast to the bleak story unfolding before the camera. The most poor, marginalized, and dispossessed in countries around the world, from Uganda to Ukraine and India, appear across our screen to dispel the myth that AIDS is only prevalent in Africa. In between the portraits of the people we meet and the voices of activists and scientists we hear, the screen blacks out to present alarming facts about the most tragic epidemic in human history. One such fact brings the reality of this epidemic to the American consciousness by revealing AIDS as the leading killer of African Americans between ages twenty-five and forty-nine.

Eleni Andreadis is a master in public policy candidate at the John F. Kennedy School of Government at Harvard University. After two years of consulting for the British Home Office in London, she worked for Coral Cay Conservation in Honduras and Friends of the Earth in Britain. In addition to earning a bachelor degree in business at Britain's University of Bath, Eleni trained at the London Centre for Theatre Studies.

The film takes its audience to Africa, where "AIDS . . . is a nightmare" and entire generations have been lost. As one South African activist points out, victims have come to believe that their lives are not valued as much as privileged Westerners living on "islands of wealth." A Ugandan doctor recounts the "awesome task" of sending patient after patient back home to die when he knows that there are drugs that can manage the disease. We also meet Olivia, a gifted young girl with dreams. Unfortunately, her dreams, as we soon discover, will remain just that. A sexually abused child that left school to take care of her infected mother, she too will die of AIDS soon after giving us her last words on screen.

Bilheimer then moves his focus beyond Africa, to other corners of the world where the impact of the disease is lesser known. Infection is mounting in countries of the former U.S.S.R., where needle-sharing among those addicted to drugs is prevalent. And the stories of women in developing countries, for whom sexual intercourse with a landlord or a violent husband "is not a choice but a means of survival," punctuate how women are especially hard-hit by the disease. In India, while the government remains in denial about the magnitude of the epidemic, the film shows female AIDS patients who are forced to share makeshift beds with two or three other women. And when one may have thought it could not get much worse, Glenn Close reminds us, "Where women are affected, so too are children." The geographic separation that is initially clear starts to blur as the film progresses and viewers realize the common themes extending across geographic boundaries.

The film does not ask for charity. It is much more ambitious than that. His Holiness the Dalai Lama asks for "more compassion." Reverend Cleaver in Missouri challenges the "Church of Jesus Christ to actually act like the Church of Jesus Christ," while renowned economist Jeffrey Sachs questions how the epidemic has been allowed to freely reign on the watch of a generation brought up to believe the Holocaust would never be repeated. Nongovernmental organizations argue for an international effort to defend a child's undeniable right *not* to become infected. AIDS is not about feeling sorry for some faraway misfortune, they argue, but about restoring basic compassion throughout humanity to establish basic rights for all across the world.

As expert after expert assures us, the solution is simple. We meet Paul Farmer, a Partners In Health doctor that has set up a successful clinic in Haiti treating AIDS patients.¹ He was told it could not work. However, he defies economists and policy makers, delivering the most hopeful message of the film: "It *is* cost-effective *and* sustainable . . . if economists aren't interested, then they need to get out of my way."

Geoffrey Oryema's magical "Nomad" draws the film to a close as viewers find out where the people they met are today. Bilheimer leads his audience to realize the unavoidable fate of the people the camera lens did not focus on, who will quietly join the lost generations without a more concerted global effort to fight the disease. The film ends with a clear message: "Now you know, and you can help."

Produced in association with the Global Health Council and dedicated to Jonathan Mann, a former Harvard faculty member who was an inspirational force in the battle against AIDS, this delicate protest leaves one disheartened but hopeful that humankind has a solution to this devastating pandemic.² The film's major aim is to motivate viewers to change the status quo without waiting for political leaders

to step up to the challenge. This ambitious aim is summarized in the opening line of a letter Bilheimer has posted to the film's Web site: "Welcome to the revolution that will help bring an end to AIDS."³

ENDNOTES

1 Partners in Health is a global nonprofit organization that aims to bring modern medical science to those in need, with health policy initiatives spanning from programs combating AIDS and women's health issues in Haiti and Massachusetts to tuberculosis in Siberia.

2 Jonathan Mann dedicated his life to the fight against AIDS before his tragic death in a plane crash in 1998. In addition to establishing Project SIDA, a collaborative AIDS research project, Mann also directed the WHO's Global Program on AIDS and served as a professor at the Harvard School of Public Health, where he founded the Francois-Xavier Bagnoud Center for Health and Human Rights. Robert Bilheimer developed the idea for this film project in collaboration with Jonathan Mann.

3 www.acloserwalk.org

palgrave
macmillan

JOURNALS

Journal of Public Health Policy

Editors:

Anthony Robbins,
Tufts University School of Medicine, Boston, USA
Phyllis Freeman, *Professor Emerita,*
University of Massachusetts, Boston, USA

The *Journal of Public Health Policy* continues its 25 year tradition: an accessible source of scholarly articles on the epidemiologic and social foundations of public health policy, rigorously edited, and progressive.

It provides an exciting platform for airing controversy and framing policy debates - honing policies to solve new problems and unresolved old ones.

New to Palgrave Macmillan in 2005

For further information and to request a **FREE** sample copy, please contact:

Palgrave Macmillan Journals
Houndmills, Basingstoke, Hants RG21 6XS, United Kingdom
Telephone: +44 (0)1256 357893
Email: subscriptions@palgrave.com

In North America
Roxanne Hunt, Palgrave Macmillan Journals Subscriptions
175 Fifth Avenue, New York, NY 10010, USA
Telephone: 1-800-747-3187

Visit www.palgrave-journals.com/jphp

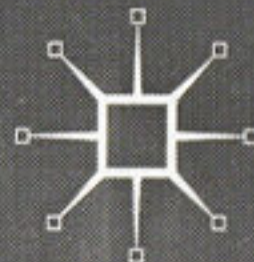
JOURNAL OF
Public Health Policy



Publication Details

ISSN: 0197-5897
Volume 26 (2005)
4 issues per year

In 2005 all
institutional and
personal print
subscriptions include
full online access.





Harvard Journal of African American Public Policy

RESERVE YOUR COPY OF VOLUME XI TODAY

The 2005 issue of the *Harvard Journal of African American Public Policy*, "**Invisible: HIV/AIDS in the African American Community**," is currently available. The journal is a must-read for scholars, students, social scientists, and practitioners with an interest in understanding the social and political complexities of HIV/AIDS within various policy arenas. "**Invisible**" aims to reframe this issue beyond the field of healthcare to reveal the far-reaching implications of this growing epidemic within the African American community. Contributors to Volume XI include:

- ◆ **Cathy J. Cohen**
Director of the Center for the Study of Race, Politics, and Culture
University of Chicago
- ◆ **Robin G. Steinberg**
Executive Director of The Bronx Defenders
- ◆ **Pernessa Seele**
Founder & CEO of The Balm In Gilead, Inc.

COMPLETE THIS FORM TO ORDER YOUR COPY TODAY!

YES, please sign me up as an annual subscriber to the **Harvard Journal of African American Public Policy.**

\$10 students	Payment enclosed
\$20 individuals	Bill my VISA MC
\$40 libraries & institutions	

Name (print) _____

Address _____

City _____ State _____ Zip _____

Card # _____ Exp date: _____ / _____

Signature _____

Mail this form to:

Harvard Journal of African American Public Policy
 John F. Kennedy School of Government ◆ Harvard University
 79 John F. Kennedy Street ◆ Cambridge, MA 02138
www.ksg.harvard.edu/HJAAP ◆ Email: hjaap@ksg.harvard.edu
 Phone: (617) 496-0517 ◆ Fax: (617) 384-9555

house05

Harvard Journal of African American Public Policy

AVAILABLE BACK ISSUES: 1992–2004

VOLUME X – SUMMER 2004

Politics and Progress: A Presidential Platform for 2004

The New Southern Political Landscape, the Black Vote and Election Reform—*Melanie Campbell*

Remembering Roosevelt: Reflections on Race and the Republican Party—*DeWayne Wickham*

Redefining Devolution—*Marc H. Morial*

VOLUME IX – SUMMER 2003

Black Middle Class Poverty Consciousness—*Christopher Tyson*

Economic Salvation: Homeownership and the Black Church—*Wayne Thornhill*

The Ouémé Child Survival Program—*Kendra Blackett and Carmen Coles*

VOLUME VIII – SUMMER 2002

Fighting Corruption in Africa: Lessons from Malawi—*Bruce Bolnick*

Reparation to Black America: A Legal Analysis—*Tiffany McKinney*

Black Men Fenced in and a Plausible Black Masculinity—*Gregory Hampton*

VOLUME VII – SUMMER 2001

Race as a Plus Factor in Undergraduate Admissions—*Carol M. Swain*

The Prison Moratorium Project—*Kate Rhee and Rashid Shabazz*

Color-Blindness Is Not the Same Thing as Racial Justice—*Glenn C. Loury*

VOLUME VI – SUMMER 2000

A Tribute to the Honorable A. Leon Higginbotham, Jr.

The Bridge over the Racial Divide—*William Julius Wilson*

VOLUME V – 1999

Health and the Black Community

AIDS and the Black Community—*Nora I. Osemene and James Essien*

Violence and the African American Community—*Lisa D. Benton*

Black Women and Depression—*Hazel Trice Edney*

VOLUME IV – 1998

Welfare Reform and the Black Community

Strategies for Addressing Welfare Reform—*Shelia Coates and Dale Alston*

Adapting to Segregation—*Percy C. Hintzen*

Commentary—*Lewis Diuguid*

VOLUME I – 1992

Measuring Job Discrimination—*Franklin J. James and Steven W. DelCastillo*

Disparate Bank Lending Patterns—*Sadie R. Gregory*

Blacks and Coalition Politics in the 1990s—*William Julius Wilson*

Harvard Journal of African American Public Policy
John F. Kennedy School of Government
Harvard University
79 John F. Kennedy Street
Cambridge, MA 02138