

SUMMARY:**African-Americans, Health Disparities, and HIV/AIDS**

Damon A. Dozier

Representing the National Minority AIDS Council, Mr. Dozier presented some findings from a study conducted by that organization. The study culminated in a report entitled “African American Health Disparities HIV and AIDS”, which was led by Dr. Robert Fullilove of Columbia University. Within this report, there was data presented that provided a glimpse of the status of African Americans living with HIV and AIDS (as of 2003, there were 555,000 African Americans living with HIV and AIDS, which represents 50% of all domestic HIV and AIDS cases). In addition, the report also examined issues of homelessness and its affect on HIV and AIDS in African American communities; it examined poverty and incarceration and factors that cause health disparities in this population. A particular focus of the report was an examination of the ways in which health disparities fit into the larger rubric of the African American community and ways in which to address those same disparities that disproportionately impact those communities.

Mr. Dozier suggests that a CDC and NIH come up with a more robust research portfolio for Black men who sleep with men (MSMs), because there is so little information on behavioral interventions for this sub-group, although they are the hardest hit when it comes to the HIV epidemic.

The current state of funding for prevention, testing, and treatment is at its lowest point and there needs to be an increase in dedicated funding if there is to be efficient and effective testing, treatment, and counseling intervention for those most at risk and affected by HIV and AIDS. Mr. Dozier presented the results of a study that looked at a

sample where 46% were HIV positive. Of that sample, 67% were not aware of their status. Although there are many factors that contribute to this lack of communication or knowledge, Mr. Dozier pointed to several key factors that were important. First, HIV prevention for African Americans, particularly the black male population is not designed in such a way that their needs are met as well as the factors that contribute to the lack of awareness of their HIV status.. Secondly, African American community leaders have failed to develop, promote and sustain leadership among Black MSMs. Without that leadership and support, the issue of homophobia, or social stigma, will continue to polarize the black community around the disease. Financial and budgetary factors, in particular at the state Medicaid and Medicare level, also play a role in the effective provision of care or prevention services to minority populations.

Mr. Dozier specifically discussed other factors that contribute to the rise of HIV infection rates in the black community including the high incarceration rate of black males and intravenous drug use. He presented data from research done by two University of California, Berkeley researchers, with results revealing that the higher incarceration rates among Black males over a period of time explains the substantial share of the racial disparity in AIDS infection among black women and women of other racial and ethnic groups.

Mr. Dozier noted that one issue that harms the African American community is the lack of federal funding for programs such as needle exchange. Mr. Dozier said there are a large number of African American cases assigned to intravenous drug use and yet federal funds have not been allocated to address those needs. It is important to note that needle exchange programs have been proven to be effective in some areas of the country

(particularly Baltimore and New York), which may be a starting point to address some of these issues.

SUMMARY:

Lifting the Veil of Fear: The Impact of the Unknown

Kali Lindsey

Mr. Lindsey represented the National Association of People with AIDS, which consists of an African American and Latino network that focuses on the issue of HIV testing and ways in which people living with AIDS cannot only help to increase the number of persons voluntarily participating in testing programs, but also help in understanding how the stigma associated with HIV testing can be decreased from a personal perspective.

Once the Centers for Disease Control and Prevention released its report on HIV/AIDS, with recommendations for increased testing and counseling, the National Association of People with AIDS largely supported the recommendations but offered these reservations: First, HIV testing must remain voluntary, not only as a precursor for people to have access to care but also to address concerns people may have about the information they receive after they are tested. Secondly, there needs to be steps put in place that ensures people are fully aware of information prior to being tested, as well as assurances of confidentiality in HIV testing. Thirdly, addressing the stigma about HIV/AIDS in the African American community is the key to changing the role of the disease in this community. In particular, one stigma that many people believe is that “it is better not to know.” This is an issue that has far reaching consequences given that the person with the positive HIV diagnosis may be rejected, as well as may not have access to the necessary types of services post diagnosis. Fourth, there has to be an understanding that in the myriad of issues faced by African Americans on a day to day basis, HIV is not the worst thing that could happen to the individual.

Given that current HIV prevention messages are not addressing stigma, nor meeting the needs of the entire community, it is time to listen to and use new voices and adopt new strategies. One of the most effective strategies is the distribution of lubricants and condoms.

In addition, it is important that the effects of increased testing must be understood in the local context. This understanding needs to include an examination of how an increase in testing will impact the health care system, and ensure that the needs of those with a positive diagnosis are met.

Mr. Lindsey made several suggestions including that the government create safeguards against abuses and breaches of confidentiality in HIV testing settings; public health officials should develop and pilot new models to expedite and improve voluntary HIV counseling and testing services; and, given that increased funding will be needed with an increase in HIV/AIDS diagnosis, policy makers should create meaningful linkages from testing to available, accessible health care.

SUMMARY:

HIV/AIDS Interventions in the Black Community: Taking the Social Context Seriously

David A. Williams, Ph.D., MPH

Dr. Williams started his presentation by talking about the complex challenges faced by the African American community. He notes that there is a “complex web of causation” that drives these issues and challenges. One of the driving forces affecting these complex challenges faced by African Americans is residential segregation.

Racial residential segregation is one of the most fundamental causes of racial disparities in health in the United States. Challenges from this causation affect all aspects of African American life, from employment, education, neighborhood environments and housing, to behavior constraints. For example, David Cutler, an economist did a large study following young African Americans and whites as they entered the labor force. Results of the study showed that the impact of segregation was completely responsible for differences in income, education and employment.

Dr. Williams also noted that the issue of poverty for African Americans is different than for other groups, and provided several examples illustrating that issue. He pointed to the fact that middle class blacks live in poorer areas than whites with a similar social economic status, and that poor whites live in much better neighborhoods than poor blacks. In addition, the results of a study that used a measure they called “economic hardship” found that blacks were more likely than whites to experience the identified economic hardships, even after holding constant things like income, education, employment, and owning their own home.

Dr. Williams cited these examples of race and hardship, to demonstrate how African Americans are more likely than whites to experience impoverishment (Bauman 1998):

1. Unable to meet essential expenses
2. Unable to pay full rent or mortgage
3. Unable to pay full utility bills
4. Had utilities shut off
5. Had telephone shut off
6. Evicted from apartment

After statistically adjusting for these factors, there was evidence of racial differences on all measures. Dr. Williams further emphasized that SES is linked to exposures to health enhancing resources, exposures to health damaging factors, exposure to particular stressors, and the availability of resources to cope with stress. In fact, SES is a driving force of the distribution of variations in health.

HIV testing within such a context of poverty and so many social ills will not be effective without a greater investment of resources to improve the social economic infrastructure in disadvantaged communities. In addition, a more comprehensive and broader approach to the issue needs to be developed if the interventions are going to be effective. This is particularly pertinent when discussing access to care and interventions in the black community.

Another factor affecting HIV/AIDS prevention efforts within the African American community is the prevalence of conspiracy beliefs. Although some may be quick to dismiss the prevalence of these beliefs, it is important to note that conspiracy

beliefs are grounded in the historic experiences of the black community. In fact, there are several implications that come from these conspiracy beliefs, one of the bigger ones being that there might be those who are suspicious of both prevention messages regarding HIV and other public health problems.

A national survey of blacks during 2002 and 2003 found that 58% of blacks believe a lot of information about AIDS is being held back; 48% believe HIV is a man-made virus; 53% believe a cure for AIDS exists, but is being withheld from the poor; and that people who take the new medicines for HIV are human guinea pigs for the government (44%). However, an astounding 75% do believe that medical and public health institutions are trying to stop the spread of HIV in black communities. Effective interventions should include a frank discussion of conspiracy beliefs as well as a demonstrated commitment to end current discrimination. Taking into account the special characteristics and needs of vulnerable populations is crucial to effective delivery of health care services.

SUMMARY:
Community Perspective
Steven Wakefield

What we know about the African American community is that they do not participate in HIV/AIDS research once they receive a positive diagnosis, largely because of their mistrust of the government. Mr. Wakefield noted that in order to make a difference in black communities, we have to acknowledge people's attitudes and beliefs – and when we talk about beliefs, it is not just what people know but also what people believe. For example, we need to address the biggest urban myth today which is that Magic Johnson has somehow beat HIV/AIDS and therefore people do not have to worry. The reality of the situation that needs to be communicated is that Magic Johnson takes the same medications that everybody else does but the difference may be that he has access to good health care and was diagnosed early.

These are some other facts that are known about African Americans: they tend to go to health care providers that look like them; they go to church and the people most at risk are in the church community; the majority of people who go to church are women; the major transmitters of the disease are men; and, we know that behavioral change counseling and drug treatment and sterile equipment access works. However, we don't know enough about health care access, or nearly enough about the effects of incarceration and how to impact the criminal justice system around the issue of HIV.

There are several challenges for targeted interventions. One of the challenges is examining how to target the population in areas at greater risk. Another challenge for targeted interventions is to build partnerships in communities with community groups who have some expertise. He encouraged NIDA to do some networking and target

interventions where it is known there is an epidemic and to target intervention programming in a way that will reach the people who need to be reached. For example, he said, in 2006 the Kaiser Family Foundation found that 53 percent of Black Americans get their information about HIV/AIDS from media-related sources. In addition, Mr. Wakefield noted that there are many other issues that we need more information on including the impact of drugs on HIV pathogenesis; access to adequate health care; testing for those that are incarcerated; and, teenagers and HIV/AIDS.

SUMMARY:

HIV and the Faith Community

Reverend Makeba D'Abreu, M. Div.

Reverend D'Abreu works with church groups to improve the health status of African Americans by building the capacity of faith communities to address life-threatening diseases, particularly HIV/AIDS. The church is one of the most important institutions in the African American community. It has the potential to influence major changes, if it so desires. The challenges faced by the church, however, revolve around conflicts involving theology, morality, and even compassion. Reverend D'Abreu noted that "awareness of HIV and AIDS is both remote and imminent" in churches. There are people in churches who say that HIV and AIDS are not really a problem and then there are those that have had someone they know to die from the disease. HIV and AIDS can be an embarrassing issue for the church. Talking about sexuality and sexual orientation have traditionally been taboo subjects in the black church, and one that can carry a heavy stigma.

However, the church can do things on a large scale that affects this disease, or something as simple as information dissemination in the church bulletin. The greatest obstacle the church has to overcome is the perception of the black church as one size fits all. It is not homogenous. There are many different types of churches and many different forms of practice. While organizing black churches, Rev. D'Abreu said she found some barriers to testing such as a lack of resources, a lack of knowledge, a perceived lack of support from the leadership and/or the congregation, insufficient personnel, and inadequate facilities. She called for the black church to re-think its theological constructs

and to remember that the people who are most affected by HIV and AIDS are already in the church.

SUMMARY:**Drug-Using Populations and HIV Within Medical Settings**

Beny Primm, M.D.

Many factors influence our health, including unequal health care access and treatment; unjust economic and environmental conditions; unsafe living and work conditions; poor social and community networks, and unhealthy personal lifestyles.

Dr. Primm discussed the links between drug abuse and HIV, finding that they are interacting chronic diseases. He found that there is strong evidence that drug use interferes with optimal HIV management, which causes impaired long-term adherence to a treatment regimen, lower rates of viral suppression, and delayed access to medical care and Highly Active Anti-Retroviral Therapy (HAART).

One of the key issues presented by Dr. Primm was the concept of comprehensive care. The main goals of comprehensive care is to reduce the rate of patient relapse and overall patient morbidity. As such, comprehensive care will allow entities to provide all around services to address the myriad of problems patients may have coming into care. The type of services provided could include the provision of primary medical care, testing for STDs and other infectious diseases, provision of pharmaco-therapies, individual and group counseling for HIV and AIDS patients, liaison with criminal justice systems and legal aid, and immigration. An integrated model of care delivery that is patient focused rather than provider focused may permit a greater collaboration of sub specialties, thereby offering needed services to patients.

Dr. Primm presented some information on the incarcerated population. He noted that a significant proportion of HIV-infected former inmates engage in behaviors with a

high risk of transmitting HIV. Such behaviors play a significant role in the transmission of the virus within their communities. Indeed, he said, incarcerated individuals are a captive audience for HIV transmission risk reduction interventions, treatment, and the treatment of substance abuse disorders as we have seen in New York with Dr. Primm's Key Extended Entry Program (KEEP). In that program people in the prison system are treated in prison and then go straight into a substance abuse treatment program as soon as they are discharged from prison. There are barriers, however, to sustaining long-term treatment and interventions for the incarcerated who are also substance abusers. These barriers include poverty, unstable housing, poor social support networks, depression, and low educational status and job skills. Treatment can work and it works better if it is comprehensive. Comprehensive treatment is cost effective and by developing interventions to reduce HIV transmission we can impact communities in which HIV and incarceration are both endemic.

SUMMARY:**Tailoring HIV Prevention Services to the Needs of African-American/Older Adults**

A. Kathleen Burlew, Ph.D.

There is an increase in the proportion of HIV cases in persons over the age of 50 and African Americans are disproportionately represented in the group of women over the age of 50 who are affected by AIDS or HIV. A 2001, 2002 study by the Centers for Disease Control and Prevention found among women over age 50, African American women were 50% of AIDS cases and 65% of HIV cases.

In conducting her own research project of this population, Dr. Burlew examined gender differences and knowledge of HIV transmission among older and younger African American males and females in Cincinnati, Ohio. The sample consisted of 448 respondents ages 18 to 75+. There were age differences found. The younger age group had higher scores on the knowledge of HIV scale than the older group and males had higher scores on the knowledge scale than females. The findings suggest a need to target African American women over the age of 50 for HIV prevention messaging.

Two studies that examined risk factors of the older African American age group were conducted by Willingham, one study consisting of 200 African American women over age 50 living in rural South Carolina and another study conducted by Francis Jackson, which included both African American men and women over age 50. In both studies it was found that respondents perceived their HIV risk as very low. For those women who said they were engaging in less risky behaviors, the studies found those respondents to have more confidence, more self-efficacy for condom use and more comfort in communicating with their sexual partners about sex. An interesting finding, which proved to be counter intuitive, is that for the older African American women who

reported more discussion with their peers about their sexual behaviors they were the ones less likely to be engaging in safer sex behaviors. This, according to Dr. Burlew, is the opposite of how the younger age group responded to discussion among their peers.

Dr. Burlew suggests to NIDA that more prevention research is needed on older African Americans, especially older women. What do we still need to know about this population? Are African American women saying something to each other that discourages safer sexual behavior? How do we replace those messages with healthier messages now that we have isolated some of the risk factors for the older African American population? Those are the questions driving research relative to older African Americans and particular African American women over the age of 50.

SUMMARY:

Infectious Disease Counseling and Patients' Education Deficits for Incarcerated
Torrance T. Stephens, Ph.D.

This presentation described the health care needs of incarcerated populations, specifically as they relate to general and mental health, sexually transmitted illnesses, and other infectious diseases. As a Clinical Psychologist, Dr. Stephens said his goal is to make incarcerated clients cooperate in their own health care, health maintenance, health promotion, and health prevention. When you put the needs of this population in perspective, he said, the problems and issues seem overwhelming. Federal, state juvenile and local correctional facilities house significant numbers of individuals. In all, there are 2.5 million people incarcerated and 800,000 of them revolve annually through the parole and probation system who return to the community from which they came. Over the past five years there has been a surge in tuberculosis outbreak in prisons, and hepatitis outbreaks and increased rates of sexually transmitted infections. In fact, chronic hepatic B virus (HBV) infection and tuberculosis are substantially more common in the incarcerated population than in the general public.

Therefore, there is an urgent need to implement interventions such as patient education and counseling to reduce health risks in this population. Part of the patient education has to be on adherence to medical regimens. In addition, the education and information that is provided has to be in a language that is preferred and appropriate to the targeted group. When designing these interventions, Dr. Stephens emphasized the importance of taking patient related factors into account.

Recommendations are for more primary research; extensive program intervention and evaluation; establishing strategic partnerships; reformulating health and criminal

justice policy; developing linkages between correctional health care and academic health and medicine; and, funding to implement patient education and counseling.

SUMMARY:**Routine HIV Testing as a Way to Eliminate Health Disparities**

Emma Simmons, M.D., MPH

Dr. Simmons made the case that routine HIV testing by primary health care providers can have a dramatic impact on health disparities in the African American community. She cited these statistics: 1.2 million people in the United States have HIV; 25% of them are not aware of their serostatus. African Americans represent 43% of people living with AIDS in the United States; African Americans represent 51 percent of those diagnosed with HIV/AIDS; and, African Americans account for one of the highest percentage and rates for heterosexual transmission. (API have a higher proportion of women who are exposed through heterosexual contact, but have a much smaller number of women who are HIV infected.) Lack of knowledge of HIV infection, she feels, can have dramatic implications on continued transmission of the virus, particularly if it remains untreated. Most people don't know that HIV has a long incubation period and that if detected early can have great potential for an improved prognosis. Increased primary care input and participation in HIV testing and diagnosis can prevent the spread of the disease because primary care health professionals are the initial point of contact for people who access the medical system. Primary care physicians provide continuity of care and are accessible to people in the community in which they live.

In a study conducted by Dr. Simmons and her colleagues in disadvantaged, predominantly black and Latino communities in Mississippi and Rhode Island, it was found that there is a huge discrepancy between a patient's perceived risks of acquiring HIV and their actual stated risk factors. This was especially true among African-American women. Simmons et al also found that 86 percent of the respondents wanted

regular, routine HIV testing and counseling by their own primary care doctor and not an HIV counselor. One-time routine screening for HIV can reduce the annual transmission rate in the United States by approximately 20 percent (Sanders et al. *New England Journal of Medicine* 2005). HIV incidence has been constant at about 40,000 for the last ten years. Illicit drug users who have been HIV tested are less likely to have unprotected vaginal sex (Robles et al, *Drug Soc* 1996; 9(1-2) 173-84) Another study found that HIV testing decreases unprotected sexual intercourse, which accounts for a significant percentage of HIV transmission. (DiFrancesco W. *Acquired Immune Deficiency Syndrome* 2005; 39(5): Fox *AIDS* 1987; 1:241-6).

SUMMARY:**Participatory Research: Opportunity & Challenge**

Celia B. Fisher, Ph.D.

Dr. Fisher's presentation focused on the commonly agreed upon definitions and expectations of participatory research. She said this type of research is a collaborative process that engages community members, employs local knowledge in understanding health problems and the design of intervention, and invests community members in the processes and products of the research. One of the issues around participatory research is that there are multiple stakeholders and gatekeepers. There are gatekeepers to the type of research that will be performed, gatekeepers that can keep investigators out. These can include those funding the research to family members, communities, and the participants themselves. In spite of this, there are many advantages to participatory research. It can reduce health disparities by drawing upon community knowledge and observation; it can improve research inequities in terms of resources and power; it can avoid exploitation by having the community involved in some of the decisions; and it can help with economic growth, community infrastructure and self-sustaining intervention.

There are also challenges. For example, when should community participation enter the research endeavor? Communities are different, so how do you define a community? In reference to HIV testing and counseling programs, Dr. Fisher said people with HIV, people who are drug abusers, who are African American are a minority and a less powerful minority within the ethnic minority group itself. How do we make sure that the community is speaking in their best interests? As scientists, researchers have a first obligation to the participants and not the entire community. A big issue for ethnic minority communities is, should community members be invited to be authors on the

dissemination of results? Toward this end, Dr. Fisher said she has developed a co-learning model, which means that scientists and community members come together with two different types of expertise and learn from one another. This can ultimately lead to a product that is greater than the sum of its parts.