

# National People of Color HIV/AIDS Working Group Talking Points

**T**hank you for allowing us to come and speak with you today on this most urgent matter – the domestic HIV/AIDS epidemic and its disproportionate impact on people of color.

We are here today to discuss how HIV/AIDS fits into the broader spectrum of public health issues facing this country, and the Federal agencies that address them. Hopefully, this will provide some guidance on prioritizing funding vis-à-vis HIV/AIDS prevention, care and treatment and the Minority HIV/AIDS Act.

## **Who is the National People of Color HIV/AIDS Working Group?**

The organizations that compose the National People of Color HIV/AIDS Working Group represent the different ethnic groups that have been most heavily impacted by HIV/AIDS since the epidemic began nearly three decades ago: People of African descent/African Americans; Latina/s; Asian and Pacific Islanders; and Native Americans, Alaska Natives and Native Hawaiians.

Together, these groups represent nearly 70% of all new HIV/AIDS cases reported to the Centers for Disease Control and Prevention (CDC) each year. Members of these communities often learn that they are HIV positive later than their white counterparts, increasing the likelihood that they may die from the disease. Indeed, well over half of the more than one million people who have died of AIDS in the United States since 1981 have been people of color. People of African descent/African Americans alone represented nearly 50% of all AIDS deaths in this country.

Moreover, in August 2008, the CDC announced that re-evaluation of its HIV incidence data revealed that over 55,500 new HIV cases occurred each year from 2003-2006, with 56,300 cases in 2006 alone. These numbers are approximately 40% higher than the CDC's previous estimate of 40,000 new HIV cases annually, an inaccurate estimate that had been used for over ten years.

The distribution of HIV in communities of color has remained relatively the same, despite the new numbers from the CDC. Nearly half – 45% – of all new HIV cases occur among People of African descent/African

Americans, followed by Latinos at 17%; Asian and Pacific Islanders at 2%, and Native Americans at 1%. African American women, gay men of color and men who have sex with men (MSM) of color also are testing positive for HIV in shockingly high numbers.

## **Impact of Socio-Economic and Health Disparities in Communities of Color**

HIV/AIDS does not exist in a vacuum. People of color living with HIV/AIDS also are disproportionately impacted by hepatitis A, B and C; tuberculosis; heart disease; breast cancer; diabetes; and STDs, most notably syphilis and gonorrhea and Chlamydia.

HIV/AIDS and these co-morbidities in communities of color are the direct result of the socio-economic disparities unfortunately often common to them. These include:

- High rates of poverty
- Lack of access to health care
- Lack of access to education
- High rates of unemployment and under-employment
- Lack of access to adequate and low-income housing
- Racism and xenophobia
- Sexism and homophobia

These socio-economic disparities often mean that people of color do not have the opportunity to take advantage of preventative health care measures. They do not learn of their illnesses until later, when they require more aggressive – and more expensive – treatment. Many do not have a primary care doctor, but are dependent upon emergency rooms, which are the most inefficient and costly routes to health care in this country.

## **Socio-Economic and Health Disparities, Young People of Color and Incarceration**

Socio-economic disparities also undermine the health of young people. Many minority students drop out of high school due to inadequate academic preparation prior to starting school. They often must enter the workforce at a younger age than their white counterparts to assist their families. Minority youth also are more likely to become parents at a younger age, which may prevent them from completing their education.

Without a high school diploma or college education, many youth of color find themselves unable to access high paying jobs and/or employment with health benefits. Too many of these youth violate the law and enter the justice system at a young age, which increases the odds for recidivism and further undermines their chances for a college education and meaningful employment.

Moreover, the relationship between incarceration and HIV/AIDS and its co-morbidities – particularly STDs and hepatitis – cannot be overstated. Incarcerated populations, in which minority groups are heavily represented – often engage in high-risk behaviors, including unprotected sex, tattooing and needle sharing. Studies have shown that inmates do enter prisons and jails HIV negative and leave HIV positive. Since many prison and jail systems do not require access to preventative health care screening for HIV and other conditions, individuals may re-enter their communities without knowing their HIV status and/or without proper linkages to HIV care and support.

### **Lack of Health Care Infrastructure in Communities of Color**

People living in minority communities often do not have the same access to health care facilities and providers found in mainstream society. In short, there are fewer hospitals and clinics in communities of color – and, by extension, fewer nurses and doctors.

This means minorities often have to go outside of their communities to seek care from health providers that may not have culturally- or linguistically-competent staff. Several studies have demonstrated that culturally- and linguistically competent health care providers play a major role in improving health outcomes in communities of color. Their patients are more likely to return for follow up appointments and comply with prescribed medications and medical regimens.

Moreover, we are worried that fewer people of color are choosing public health as a profession, which is creating a shortage of culturally competent medical practitioners in the U.S. The impact of this shortage is impacting communities of color, where qualified medical professionals already are in short supply. This will further diminish the relationship between communities of color and health care providers, escalating the already poor health outcomes common among all minority groups.

### **Stigma and Fear Fuel HIV/AIDS Rates in Communities of Color**

Stigma and fear play substantial roles in fueling HIV/AIDS and its co-morbidities in ethnic communities. In the U.S., HIV/AIDS has disproportionately impacted gay men and men who have sex with men, whose sexuality is heavily stigmatized in many communities, since the epidemic began in 1981. This stigmatization has helped fuel HIV infection rates among sexual minorities— lesbians, bi-sexuals, gays and transgenders – in communities of color. In addition, it has forced many sexual minorities – particularly gay men and men who have sex with men of color – to be secretive about their sexuality and engage in more risky sexual behavior.

The stigma associated with HIV often prevents heterosexual minorities from getting tested – or encourages them to believe they are not at risk in the first place. Again, this means that people of color may not learn their HIV status until their infection has progressed to late stage HIV disease or AIDS. It also makes their treatment plan more difficult and expensive, and increases their likelihood of dying from the disease.


In addition to the stigma associated with AIDS, some ethnic groups have cultural and historical reasons for avoiding health care of any kind. For instance, many People of African descent/African Americans mistakenly believe that they may become infected if tested for HIV due to the medial malpractice that occurred during the Tuskegee syphilis experiments, from 1932-1972. Asian and Pacific Islanders, along with Native Americans, Alaska Natives and Native Hawaiians, have experienced similar maltreatment by U.S. doctors and researchers, giving them reason to avoid Western health care.

Many people of color, particularly in Latino and Asian and Pacific Islander communities also avoid medical assistance due to their immigration status and fear of deportation. Again, they are more likely to seek health care later than others, meaning they are probably will not receive treatment for HIV/AIDS and other co-morbidities until their disease has progressed to later, less treatable, stages. They also may not be able to access care due to language barriers, or simply because they are moving around too often due to unstable housing and work schedules.

### **National People of Color HIV/AIDS Working Group Recommendations**

The National People of Color HIV/AIDS Working Group calls on the Obama administration to keep in mind the following as formulates the National AIDS Strategy:

- A National AIDS Strategy is necessary due to the socio-economic and health disparities associated with HIV/AIDS and its impact in communities of color. This does not necessitate, however, a health care system separate from that addressing other health issues. We need to integrate HIV/AIDS prevention, testing, treatment and care within the overall health systems of this nation. The social determinants associated with HIV/AIDS differentiate it from other diseases; however, health care providers should be able to address all of the possible health needs faced by people of color, whether or not they are living with HIV/AIDS, in a comprehensive, culturally- and linguistically-competent manner.
- Support a three-year extension of the Ryan White HIV/AIDS Treatment and Modernization Act of 2006 and the Minority HIV/AIDS Initiative, with a few key




fixes. These critically important discretionary funding streams offer a foundation for discussion between the Obama administration, national AIDS leaders and other stakeholders in developing a comprehensive approach to health services in the United States, establishing a National AIDS Strategy and carrying out national health care reforms. On a larger scale, these entities could work together to determine how the important medical, supportive and pharmaceutical services provided through Ryan White and other discretionary funding for HIV fits into a larger reform of health care access for all.

- Ensure that effective, culturally-competent HIV prevention and comprehensive sexual education is well disseminated and supported in communities of color. We cannot “treat” our way out of HIV/AIDS. Prevention must be seen as a priority in this strategy to reduce the number of people contracting HIV in the first place. This means providing comprehensive sex education and forums addressing the social determinants that fuel HIV infection, such as stigma, in public spaces within communities of color, including schools, churches and community centers. All of these approaches must encourage open, safe dialogue among all ages, genders and sexual orientations.

We also must keep in mind that the prevention programs rolled out must be culturally-competent and linguistically appropriate in scope and practice. What works in a Latino community may not work in an African American one. In addition, we need solid evidence-based research based on field work detailing the social networks, biomedical determinants and behaviors that drive HIV/AIDS incidence in our communities. How else will we be able to determine if these prevention programs are working in the future?

- Build the leadership of communities heavily impacted by HIV/AIDS. That means supporting community-based organizations and leadership to carry out HIV/AIDS strategies themselves.
- Encourage and support HIV vaccine research. The only path to a cure is the development of an HIV vaccine that works for everyone. Vaccines are the only way viral epidemics have been stopped in recent history.
- Address the relationship between immigration laws and health disparities in this country. This means lifting all immigration bans associated with HIV/AIDS and protecting illegal immigrants seeking health care – and those living with HIV/AIDS in particular – against deportation.
- Expand programs for low-income housing, utility bill relief and food stamp initiatives for those living with HIV/AIDS and its co-morbidities. We cannot build the health of a nation without ensuring access to the basic necessities of life and stable housing.
- Address issues around gender and HIV/AIDS. Girls and women have unique health concerns, since in many families, the primary caretakers are women, many of whom sacrifice their health for their children and are not aware of their own susceptibility to HIV and other diseases. Transgenders also have unique physical and mental health issues that play an important role in their success in accessing HIV prevention and health care, and complying with medical treatments.
- Support large scale community-based programs that counter stigma around HIV and homosexuality. These will be particularly important in empowering young sexual minorities in communities of color to learn and experience their sexuality safely, in a society that understands and accepts them.
- Lift the federal funding ban on needle exchange programs and expand harm reduction and substance use programs. Harm reduction offers many people access to drug rehabilitation and care. These programs must be holistic and treat the drug users and their families, particularly when children may be separated from their parents/guardians entering care.
- Provide incarcerated persons access to comprehensive HIV/AIDS prevention, HIV screening, care and education. Incarcerated persons living with HIV/AIDS need to be provided appropriate treatment and discharge planning before re-entering society. Prisoners who have access to condoms, voluntary testing and comprehensive



health care will be less likely to contract or transmit HIV while incarcerated and when returning to their communities.

- Fund programs that support, and increase the visibility of, HIV/AIDS prevention, treatment and care programs at the grassroots level. We need to continue to build the infrastructure of faith- and community-based organizations delivering services to those hardest hit by the AIDS epidemic.
- Support the training of a new generation of qualified clinicians, including doctors, nurses, dentists and pharmacists who can provide culturally- and linguistically-competent services in communities of color, whether they are located in rural areas, Native American reservations, or urban centers. We must ensure that historically underserved and marginalized communities have access to appropriate health care services provided by well-trained medical professionals

We also must encourage young people of color to enter public health professions by providing incentives, such as scholarships and paid internships, to those studying minority health issues. In addition, the National AIDS Strategy must call for increased support, and establishment of, national centers offering culturally- and linguistically-competent clinical training to ensure proper execution of HIV/AIDS prevention, testing, treatment and care reforms.

### **Final Thoughts on HIV/AIDS Policy**

Again, thank you for having us here today to talk to you about HIV/AIDS and other health and social disparities impacting communities of color. As you meet with leaders in the AIDS movement, please note that many of them do not look like us. So often, our numbers are used by organizations run by members of mainstream society to obtain resources. We are concerned that these resources may not be reaching those communities most in need.

We need government entities – such as the Office of Minority Health and the Office of National AIDS Policy – whose employees include members of populations that have been disproportionately impacted by HIV/AIDS since epidemic began three decades ago. This will help mitigate the stigma and fear associated with HIV/AIDS and other chronic diseases undermining the health of communities of color in this country. Ultimately, we want to people of color to have the resources they need to make informed decisions about their self-care in every facet of their lives, whether it is employment, education or health care. Improving the health outcomes of minorities improves the futures not only of people of color, but also the country as a whole.