A Partnership for Change

Florida Black Leaders' Advisory Group

Response to the

Acknowledgements

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Declaration of Commitment

This document seeks to secure a five year commitment from the Florida Department of Health and the Florida Black Leaders Advisory Group towards scaling up HIV/AIDS prevention and care efforts in order to accelerate reductions in HIV/AIDS disparities among blacks in the State of Florida.

As lay persons, advocates, healthcare providers, and government officials, we have joined together - in an unprecedented effort - to offer concrete solutions that will help to reduce new infections among blacks in Florida by 25 percent by 2015; increase those who are aware of their HIV status by 25 percent in the next 5 years; increase access to care and improve health outcomes for people with HIV; and reduce HIV-related health disparities.

By signing this declaration of commitment, the Florida Department of Health, Bureau of HIV/AIDS is agreeing to commit to doing our part to make the National HIV/AIDS Strategy a reality for blacks in the State of Florida. We stand ready to work with the Florida Black Leaders Advisory Group to accomplish this goal through the year 2015.

This document should remain on file in the Bureau of HIV/AIDS and reviewed at a minimum of once a year to ensure that these recommendations are being incorporated in all the Bureau of HIV/AIDS plans to address HIV/AIDS in Florida.

Executive Summary

On July 13th, 2010, the White House released its National HIV/AIDS Strategy (NHAS). President Obama committed to developing a National HIV/AIDS Strategy with three primary goals: reducing the number of people who become infected with HIV; increasing access to care and optimizing health outcomes for people living with HIV; and reducing HIV-related health disparities. The President stated that the National HIV/AIDS Strategy "will require the commitment of all parts of society." As members of the Florida Black Leaders Advisory Group (FBLAG), we deem the NHAS paramount to address HIV/AIDS among blacks in Florida.

In Florida, through 2009, 1 in 42 non-Hispanic black males and 1 in 63 non-Hispanic black females were living with HIV/AIDS. This compares with 1 in 205 non-Hispanic white males, 1 in 1,139 non-Hispanic white females, 1 in 113 Hispanic males, and 1 in 438 Hispanic females. There are HIV/AIDS disparities between blacks and whites, and disparities between Hispanics and whites, but the black-white gap is the widest by far. Although blacks represent 11 percent of Florida's adult population, they account for 49 percent of the newly reported AIDS cases and 51% of the newly reported HIV cases in 2009. In 2009, the HIV rate per 100,000 population was 114, over 7 times higher than that for whites (17). Of the 2,639 HIV cases reported among blacks in 2009, 64% were males and 36% were females. Of the 1,451 females reported with HIV in 2009, 66% were black, 19% were white and 14% were Hispanic. Blacks accounted for 60% of the total of 1,412 resident HIV deaths in Florida in 2008 (the most recent year for which data are available). HIV remains the leading cause of death among black females, ages 25-44 in Florida. However, for black males, HIV dropped to the second cause of death for the first time. In Florida, at least 1 in 12 black men who have sex with men (MSM), compared to 1 in 29 white MSM, and 1 in 18 Hispanic MSM is living with HIV/AIDS.

Despite the numerous challenges facing Florida's black communities - the spread of HIV seems to be relentless worldwide - and the virus that causes AIDS now affects men (gay and straight), women, and children of every age and ethnic group. The FBLAG is aggressively pursuing interventions and programs to impede its spread. This is why we support the National HIV/AIDS Strategy. We believe this historical document provides the framework for the Florida Department of Health, Bureau of HIV/AIDS and our community partners to make significant progress in reducing the spread of HIV within the next five years.

The NHAS discusses "focusing on high-risk communities, directing money to states with the highest need based on reported cases of HIV/AIDS, and recognizing the unique needs of affected populations." Although, as members of the Florida Black Leaders Advisory Group, we agree with directing money to states with the highest need and recognizing the unique needs of affected population, we disagree with the use of the term "high-risk communities." As a body, we are all in agreement that the term "high-risk" provides a false since of security to individuals in our communities. History has proven that when public health programs take the focus off of a particular sexually transmitted disease or an entire population, rates of infections increases and the disease becomes more prevalent.

For example, the NHAS has the black community and gay/bisexual men as two separate high risk communities to reach. Under the umbrella of gay and bisexual men, there is a myriad of cultural and ethnic backgrounds present: some that will respond to general marketing for gay and bisexual men and some that will not. The social marketing tools that are effective at reaching gay and bisexual men of the black community may be totally different. Therefore, addressing the entire black community instead of just risk groups may be more effective considering the stigma and heterosexism in most black communities. Although we recognize the importance of addressing particular sub-populations who are more disproportionately impacted by HIV/AIDS, we are all at risk! We cannot repeat the mistakes of the past by placing blacks in risk groups. The FBLAG recommends that the State of Florida address the entire black population.

In light of the economic downturn, we are disappointed that the NHAS did not go far enough to address funding to eliminate the AIDS Drug Assistance Program (ADAP) waiting list in Florida and in other states across the country. Considering the issues and problems our state is facing statewide with ADAP, we would like assurance that money which is targeted to racial/ethnic minority communities for prevention is not touched. Prevention is always touted as a crucial piece of the puzzle when we address ways to combat HIV/AIDS, but it is always given the short end of the stick. Those who are positive need their medications, but we cannot be myopic in this struggle and cut programs that are working in communities which are hit the hardest. For example, if “Closing the Gap” money was diverted to ADAP’s coffers, it would be a travesty to black communities which are receiving much needed programs from this source of funding. We would be trading those whose futures are in peril against those who are already infected. We understand that there is no easy solution here, but moving money out of prevention is not the right answer.

We are acutely aware that the majority of individuals on Florida’s ADAP waiting list are black. With increase emphasis on routine HIV testing and individuals knowing their HIV status, the State of Florida must make life saving medications available to individuals who cannot afford them. The ADAP waiting list creates a barrier to care - when it is extremely important that our clients have continuity of care. Without access to ADAP, our black clients will perceive there is no incentive to stay in care. The pharmaceutical companies’ patient assistance programs are an enormous benefit to our clients who are unable to access the ADAP program. The patient assistance programs have created huge workload issues for staff and a financial strain on small minority organizations. Lead agencies throughout the state are concerned they will not have enough funds to sustain their programs to the end of the contract period. The bureau has provided funding to hire patient navigators in Broward, Duval, Hillsborough, Miami-Dade, Orange, Palm Beach, Pinellas, and Volusia. Staff in these counties devote their time to assisting those clients on the ADAP waiting list to apply for the appropriate patient assistance program.

The Florida Black Leaders Advisory Group is also saddened the White House did not provide new HIV/AIDS prevention and care dollars to carry out the recommendations in the NHAS. It is of

tremendous importance that the Florida Department of Health, Bureau of HIV/AIDS re-align HIV prevention and care funding to address the needs of black men who have sex with men and black women in our state. These two populations have been the most disproportionately impacted by HIV/AIDS in the black community. Without new money, it will take a multi-faceted approach to address the HIV/AIDS needs of blacks in our state.

Together we must strive to be innovative in addressing social determinants of health, cultural, environmental, and behavioral factors, in order to carry out the recommendations in the NHAS. We insist the bureau uses the public health ethics approach to eliminate HIV/AIDS disparities among blacks in Florida. We also recommend the Florida Department of Health, Bureau of HIV/AIDS makes a five year commitment to reduce HIV/AIDS in Florida's black communities.

We implore the Florida Department of Health, as well as other individuals, community-based organizations, AIDS service organizations, county health departments, businesses, and groups to use this document and other existing resources to help individuals in Florida's black communities. We hope this document will empower and encourage the Florida Department of Health in its efforts to address HIV/AIDS in our great state. The FBLAG is committed to continuing our efforts to address this critical health issue among blacks in Florida.

Reduce New Infections Among Blacks In Florida By 25 Percent By 2015

Recently, there has been a great deal of discussion regarding the test-and-treat strategy to stop HIV/AIDS. Research has proven that a decreased viral load lowers the risk of HIV transmission and effective treatment lowers viral load to undetectable levels. However, there is no evidence that test-and-treat actually works. The FBLAG recommends that the Bureau of HIV/AIDS requests funding from its national partners to explore this promising strategy in a high incidence community, such as Liberty City, Miami-Dade County, or Ft. Pierce, St. Lucie County.

We are extremely encouraged with the recent clinical trial research regarding pre-exposure prophylaxis and a vaginal microbicide. We recommend that you assign someone on your staff to follow the research concerning the clinical trials and provide periodic reports to our communities.

The NHAS calls for increase testing; it sets a goal of increasing those who are aware of their status by 25% in the next 5 years. This is an achievable and realistic goal. This is in line with Test, Link to Care, Plus Treat - as well as the increase testing the CDC is pursuing. Florida can do this by increasing test sites in the communities which are most impacted; however, we are cognizant of the fact that the Bureau of HIV/AIDS has made many efforts on behalf of this goal.

We appreciate the fact that Florida has one of the largest HIV testing programs in the United States

with nearly 400,000 tests performed last year. We understand HIV testing is only part of the department's comprehensive prevention efforts to reduce HIV/AIDS among blacks. We recommend the Bureau of HIV/AIDS enhances the following initiatives to reduce HIV/AIDS among blacks:

- Continue to establish HIV testing as a routine part of medical care;
- Expand the state's voluntary rapid testing program to include black community-based organizations;
- Improve the "We Make the Change HIV/AIDS" media campaign aimed at increasing awareness in minority populations;
- Increase contracts with organizations serving blacks - including community and faith-based groups - that provide education, counseling, support and other preventive services;
- Establish and support programs, such as Sistas Organizing to Survive (SOS), Silence is Death, Finding Our Voices, Man Up, Targeted Outreach for Pregnant Women Act, and Black Leadership and Multicultural Conferences on HIV/AIDS;
- Concentrate HIV testing in black communities;
- Hire more indigenous workers in the state health office and in county health departments to provide services to black communities;
- Include rural/smaller communities when allocating prevention and care funding. It has been documented recently that one of the most significant factors to HIV infection is poverty, which is more common in rural communities, particularly in the south;
- Examine epidemiologic data to determine whether the level of effort and commitment of resources to black MSM and black women are proportionate to the needs of black MSM and black women in the state;
- Ensure that funded CBOs have the knowledge base and capacity to implement evidence-based behavioral interventions for black MSM and black women. To ensure accountability, develop performance indicators for CBOs and AIDS service organizations (ASOs) that serve black MSM and black women in partnership with community partners;
- Fund CBOs to implement new and innovative approaches that target emerging issues in HIV prevention, including use of the internet to promote CTR and PCRS; interventions to curb use of illegal substances such as crack, cocaine, and crystal methamphetamine; and community mobilization and empowerment strategies;
- Consider partnering with community stakeholders to design programs that address stigma and homophobia as these may prevent black MSM from seeking HIV testing and entering care. If possible, funds should be made available to create demonstration projects that focus on sub-populations of black MSM, such as young black MSM in high incidence areas;
- Develop strategies to educate the community about the impact of HIV/AIDS on black MSM and how stigma and homophobia fuel the epidemic. Keep HIV/AIDS in the minds of the general public to create a climate of acceptability and to normalize HIV prevention, testing, and care;

- Work with the Florida Legislature, CDC, and other partners to develop structural level interventions such as HIV criminalization, incarceration and mass imprisonment, and anti-bullying legislation. This is key to addressing the epidemic and reducing the alarming rates in black communities;
- Work with the Department of Education and other community partners to encourage comprehensive sex education in schools. Children under the age of 18 are having sex too; we need to ensure young black men and women are being educated about safe ways to engage in sexual activity. This is particularly important given the hyper-sexualized images painted and displayed in hip hop music and media.

Increase Access To Care And Improve Health Outcomes For People With HIV

HIV/AIDS disparities are not evenly distributed throughout the state and are more extreme in some counties than in others. It is documented that compared to whites, many blacks delay seeking care after their initial diagnosis. Additionally, persons who do seek care often drop out and are inconsistent in their medical appointments and medication adherence. There are compelling personal and public health benefits to getting a recently diagnosed HIV-infected person into care before he or she gets sick. The personal benefits include delayed disease progression, early initiation of antiretrovirals, and regular monitoring of immunologic status (CD4+ cell count) and virologic status (HIV-1 RNA copies in plasma). The public health benefits include reducing HIV transmission, due to earlier reduction in infectious HIV-1 RNA copies in the blood, and earlier entry into prevention for positives programs in clinical settings.

It goes without saying that cuts to Florida's ADAP program significantly jeopardize our ability to increase access to care and improve health outcomes for people living with HIV/AIDS. Persons living with HIV/AIDS who adhere to their drug regimens are less likely to infect others because of a reduced viral load. If we do not appropriately fund ADAP, we are minimizing any attempt of achieving this goal. We are faced with not only having to overcome problems related to resistance, but also additional problems related to availability of the drugs. Florida has spent a considerable amount of time convincing people to go onto highly active antiretroviral therapy (HAART) and assuring them that if they made the decision to start, they would need to continue. By instituting an ADAP waiting list, clients who were disenrolled may present with more resistant strains of the virus in the future.

In addition to this, we must have linkage to care. Care does not need to - nor should it - overshadow prevention as it often does. Care is prevention! These two components must be allies or we suffer as a community. We must not only offer care, but we must ensure that people and their issues are being addressed. The providers of care should be reflective of the recipients of care in the black community. Agencies which are not sensitive to the culture, who are not endemic to the community are not as effective and the community is disenfranchised.

Recommendations

- Request funding from the federal and state governments to adequately fund the ADAP program;
- We understand the State of Florida received approximately 9 million dollars to help eliminate/reduce the number of individuals on the waiting list. After receiving the funds, we were told the money did very little to reduce the number of individuals on the waiting list (it only helped to sustain the individuals currently enrolled in the program). We recommend the State of Florida, Bureau of HIV/AIDS consult with financial advisors or an economist to assist the bureau with making financial decisions and developing long-term solutions on sustaining the ADAP program and eliminating the waiting list. In addition, include members from this group in deliberations regarding the ADAP program in the future;
- The Florida Department of Health, Bureau of HIV/AIDS should make public its methodology of funding and critical questions must be asked to ensure resources are following the epidemic. The NHAS urges states to examine its current funding streams to ensure the funding is matching the epidemiological profile of the state (i.e., are resources - financial and human - going to disproportionately impacted communities?). The only way to achieve this critical NHAS goal is to implement it on a state level first.
- There is only one ADAP pharmacy in Miami-Dade County. The bureau should establish more ADAP pharmacies in communities to increase adherence and reduce barriers to care;
- Change the ADAP policy to allow case managers to pick up pharmaceuticals for clients who have difficulties getting their medications. If a client is sick, has an emergency, or has transportation issues and fails to make the ADAP appointment to pick up medications, the client is disenrolled.
- Hire at least one patient navigator in every area in the state to assist clients on the ADAP waiting list to apply for Patient Assistance Programs;
- Simplify the ADAP paperwork and enrollment process. Some of the paper work is too complicated for clients.

Take deliberate steps to increase the number and diversity of available providers of clinical care and related services for people with HIV

- Work with the United States Department of Health and Human Services and Florida's Agency for Health Care Administration to address reimbursement issues for care providers. Many providers are unwilling to accept Medicaid and Ryan White due to the insufficient dollar amounts they are reimbursed.
- Task HIV/AIDS Program Coordinators (HAPC) with the primary responsibility of identifying black medical providers (i.e. Infectious Disease Doctors, primary care physicians) to treat HIV patients.
- Identify and recruit minority providers (e.g. black, Hispanic and women physicians/

ARNPs). Create a campaign program for providers to make them aware of their community needs, as well as the impact of the epidemic in their respective communities and across the state.

- Use Ryan White Part B funds to contract with black physicians to provide care for blacks living with HIV/AIDS.
- Bureau of HIV/AIDS and Part A providers should contract with black community-based organizations for case management services.

Reduce HIV-Related Health Disparities

It will involve greater engagement and commitment from the black community and many groups - federal, state, and local governments, black leaders, churches, civic organizations, businesses, schools, parents, policy makers, and those living with HIV/AIDS - to mobilize a comprehensive response to the HIV/AIDS crisis among blacks. We realize that reducing HIV/AIDS is not solely the responsibility of the Florida Department of Health. We must engage all segments of the community.

The NHAS also calls for neighborhood outreach. It discusses effective, inventive, and endemic programs. It is important that they can be evaluated and substantiated as working to curtail the virus. But it is also important for the state to encourage and invest in new programs and new ideas. It is time to put outreach workers back into the bars and on the streets to do the work we once did. Allow communities the chance to come up with new and novel ways of reaching the people in the black community.

Adopt community-level Approaches to Reduce HIV Infection in High-Risk Black Communities

Approximately five years ago, the Bureau of HIV/AIDS invested in community mobilization to reach different segments of Florida's population. The Florida Black Leaders Advisory Group is extremely impressed with the community mobilization efforts of the Bureau of HIV/AIDS. The two initiatives that have demonstrated tremendous success are the "Silence is Death and Sistas Organizing to Survive (S.O.S.) initiatives." We recommend the bureau continue to enhance and improve their community mobilization efforts. During an era of declining resources, community mobilization initiatives are very cost effective when the community takes ownership of the problem. It is very important that the Bureau of HIV/AIDS begins to target non-traditional parts of our community to assist with reducing stigma and discrimination that cause individuals to avoid learning their HIV status, disclosing their status, or accessing medical care.

Recommendations

- The Bureau of HIV/AIDS must insist that county health departments sustain effective community mobilization initiatives targeting black communities;

- Continue to fund success strategies such as Sistas Organizing to Survive, Silence is Death, and Finding Our Voices;
- Develop community-level interventions that target all segments of the black community, not just those perceived to be at "High-Risk."

Reduce Stigma and Discrimination Against People Living With HIV

In order to reduce stigma, we have to attack stigma directly in the black community. Some will say that this has been done with little success, but we think it has not been done effectively. For this to work, we must not worry so much about being a little controversial. We feel equating AIDS with other ills in the black community can help to start bringing down some of the walls.

Dr. Kevin Fenton of the CDC stated that we must start looking at HIV in the context of sexual health as well. This is to lessen the stigma of those who are newly diagnosed and to get others to feel that there is no shame in testing for this virus. We feel this goes along with the idea of creating a campaign against stigma. We must get past puritan ideas of HIV, those who are tested, and those who are infected. This is one of the biggest hurdles to overcome in our community. Our people are dying of AIDS and there are those who are more afraid of what people will think rather than facing the reality of this virus.

Recommendations

- Empower persons living with HIV/AIDS to disclose and speak authentically about their needs to their family members, friends, and the community as a whole.
- Create a social marketing campaign to help reduce stigma and discrimination.
- Engage and empower smaller grass root and storefront churches to do prevention and outreach.
- Reach out to the congregation of churches whose family members are living with HIV/AIDS. Encourage them to speak out against stigma and discrimination.
- Appoint Faith AIDS Coordinators in each area of the state to focus on getting people of faith more involved in HIV/AIDS.
- Partner with businesses, corporations, and organizations to promote HIV prevention and care in black communities.
- Try to normalize HIV/AIDS by educating the community that it is a chronic illness.
- Moving forward, it's imperative that Florida Department of Health, Bureau of HIV/AIDS ensures that the right combination of interventions and programs is being implemented. Programs that reach all sections of the black community from heterosexual black men and women to injection drug users.

Notes

A Partnership for Change

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