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CONSULTATION ON MITIGATING HIV-RELATED HEALTH DISPARITIES

RECOMMENDATIONS FOR THE NATIONAL HIV/AIDS STRATEGY

APRIL 2010

A diverse group of experts convened to discuss the President's articulated goal of "reducing HIV-related health disparities" within the context of a National HIV/AIDS Strategy (NHAS) in January 2010. The development and implementation of a NHAS offers a unique opportunity to change the course of the HIV/AIDS epidemic in the United States. The Strategy must represent real change and must call on all agencies of the federal government, the business sector, medical providers, community service organizations and those affected, infected and at risk of HIV to work together toward clearly articulated and measureable goals supported by effective and innovative strategies. All of this work must be done within the framework of addressing the significant health disparities that exist within the HIV/AIDS epidemic. To that end, consultation participants and other stakeholders offer the following recommendations and framework to address HIV-related health disparities in the U.S.

Human Rights Framework:
Every person has a basic human right to health.

Every person has a basic human right to health yet the HIV epidemic in the U.S. is characterized by structural barriers that systemically violate this axiom. Those with fewer resources, and those who are socially stigmatized or marginalized, are more likely to acquire HIV and less likely to get tested and have access to an acceptable standard of care, which includes access to appropriate drug therapies, and consequently tend to have poorer health outcomes. This result is due to complex factors, including bias and discrimination based on race/ethnicity, sexual orientation, gender, socio-economic status, age, developmental status, and geography. We submit the following recommendations to strengthen a human rights-based approach to addressing the domestic HIV/AIDS epidemic.

Mine Existing Resources to Inform the Analysis and Response to HIV-Related Health Disparities: The World Health Organization (WHO) report on social determinants of health, and other primary scholarship, should inform the NHAS's recommendations on HIV-related health disparities. The WHO report says:

> *The social determinants of health are the conditions in which people are born, grow, live, work and age, including the health system. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels, which are themselves influenced by policy choices. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries.*
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> *Responding to increasing concern about these persisting and widening inequities, WHO established the Commission on Social Determinants of Health (CSDH) in 2005 to provide advice on how to reduce them. The Commission's final report was launched in August 2008, and contained three overarching recommendations:*

1. Improve daily living conditions;
2. Tackle the inequitable distribution of power, money, and resources; and
3. Measure and understand the problem and assess the impact of action.

Determine How HIV-Related Health Disparities are Similar and Different from Other Forms of Health Inequity: The National HIV/AIDS Strategy (NHAS) must recognize that the severity of HIV-related health disparities is likely a product, to some degree, of prejudice towards factors associated with HIV: racism, homophobia, xenophobia, the stigmatization of drug use, and associated bias and discrimination unique to HIV. The fact that HIV is primarily sexually transmitted, currently incurable, and disproportionately apparent in gay and people of color communities contributes stigmatization and structural neglect that fuels disparities.

- At the same time, the NHAS must recognize and address the reality that the racial and gender disparities in diagnosis and treatment access that are reflected in available data on HIV/AIDS in the United States are mirrored in a host of other diseases, and a likely product of bias on the part of health care providers and other elements institutionalized within the health care system.

- Political will and leadership are essential to addressing the social drivers of HIV (racism, sexism, homophobia, classism, geography, poverty, addiction, and violence) and their long-term effects, and to identifying and prioritizing concrete measure to address these factors.

- Therefore, achieving the President's goal of reducing HIV-related health disparities will require ONAP, in collaboration with the NHAS Intergovernmental Task Force and PACHA, to work ***both within the context of the NHAS and to actively seek other vehicles for eliminating structural oppressions and their impacts as articulated above***. These measures would include, in part:

    - An Executive Order declaring all unwarranted disparate treatment of people with HIV in federal employment, services and programs to be in violation of the Rehabilitation Act of 1973 and at odds with Administration policy.
    - A mandate from the Administration to all federal agencies to develop written policies that affirm the intent of the Executive Order and that explicitly prohibit discrimination on the basis of HIV status.
    - Increase resources for and enforcement of Title VI, including incentives for improved collection and use of aggregate data tracking diagnosis, treatment and health outcomes; and mandates to federal enforcement agencies, including the Department of Justice and HHS/Office of Civil Rights, to investigate and address uneven allocation or administration of resources that have a disparate impact on people of color and minority communities.
    - Through policy and law, the federal government must respond to the health disparities of immigrants, particularly the undocumented.

Strategic Impact: Systemic change at the national, state, and local level

To be effective, in addressing HIV-related health disparities, the NHAS approach must be simultaneously national and local:

- Understand that the concept of wellness is community-defined and must be pursued with community input.
- Prioritize a response that goes beyond the medical community to a culturally relevant and holistic approach to wellness.
- Utilize a framework that recognizes social determinants of health, including individual, community and environmental levels of impact and intervention.
- Recognize and address geographic disparities in resource allocation.
- Develop and utilize leadership focused on peer, indigenous, and community-based networks.

To be effective, in addressing HIV-related health disparities, the NHAS approach must leverage other major Administration priorities and initiatives including but not limited to:

Health care reform implementation
Economic revitalization
Education reform
Jobs creation

In addition, the NHAS approach should identify opportunities for systemic change in criminal justice and housing.

Tactics must be measureable and identify those responsible.

We offer some examples as a starting point. Those writing the plan will need to further develop these concepts and identify measureable outcomes:

a. **Improved Data Collection and Reporting:** There must be a mandate to make data robust and usable; standardized with regard to collection, analysis, and use across federal agencies and the private sector; and actionable (connected to markers and goals). In addition, surveillance data must be improved to ensure an accurate picture of the epidemic. This is particularly critical for heterogeneous populations that are currently homogenized by broad racial and ethnic categories.

b. **Reverse Funding Inequities:** Gross underfunding is driving disparities, as seen in current ADAP crisis and in specific regional and population differences.

   i. Funding structures can be disincentives to create critical programs in underserved communities and populations, e.g., excessively low overhead rates are impossible for community-based organizations,—particularly in communities of color,—to absorb.
   ii. Funding allocations should be driven by timely epidemiologic and other relevant data and by the stated goals and outcomes of NHAS.

iii. Explore tying funding levels with demonstrated compliance to anti-discrimination laws and strategies to boost the number of people who accept testing and access and stay in care.
iv. Reforms in funding distribution must not result in destabilizing divestments from any currently funded jurisdiction; at the same time these reforms must gradually move toward parity in funding based on disease burden for all geographic areas, including rural and southern jurisdictions.

c. **Strengthen the Safety Net, Including a Renewed Commitment to Ryan White and Housing Opportunities for People with AIDS (HOPWA):** The continuation of Ryan White and HOPWA funding and services are essential, even when health reform and the NHAS are fully implemented.

d. **Increase Widely Available, HIV Education Campaigns as a Means to Mitigate HIV-Related Stigma**: Utilize a combination of sustained social-marketing campaigns and high-visibility leadership – at the national, community, and population levels. It is time for another Surgeon General's letter to every household in the U.S. on the nature of HIV, its diagnosis and treatment, including specific information on how HIV is, and is not, transmitted.

e. **Explore Concentrated Localized Responses:** Embrace models such as Health Renewal Zones and centers of excellence to address multiple disparities occurring in a community at the same time.

f. **Develop Client-Centered and Integrated Models of Prevention and Care:**

i. Screening and testing services, which must be available in all healthcare settings.
ii. Community-based testing programs, which are essential to getting people into care.
iii. Testing, linkage, provision of care, and retention in care efforts which must prioritize client/patient needs over provider preferences.
iv. Incorporate high-quality prevention services into the ongoing medical care of persons living with HIV.

g. **Invest in Workforce Development**: The NHAS must focus on developing and incentivizing a diverse healthcare workforce. In addition, the NHAS should include an explicit commitment to address provider bias through cultivating culturally relevant providers, provider trainings, and leadership development of peers as part of a prevention and care infrastructure. Developing a "healthcare corps" will assist with addressing disparities by facilitating access to and retention of the hardest-to-reach populations, and in targeted geographic areas.

h. **Name, and Address, the Stigmatizing Impact of Government-Endorsed HIV-Related Discrimination:** The continued tolerance of state and federal laws and policies that reinforce perceptions of people with HIV as toxic, irresponsible and dangerous to be around is at odds with a national agenda to increase diagnosis and treatment of HIV, and undermines the related goal of reducing HIV stigma. Actions to address this significant problem must include clear

statements against such policies and incentives to eliminate them, such as promoting the use of Ryan White funding incentives to repeal HIV-specific criminal laws.

i. **Invest in Legal Services:** Provision of **legal services** is critical to addressing discrimination and the failures of institutions and systems, including benefits and the provision of services. Legal services are effective at ensuring equity and helping identify systematic failures that drive health disparities. In addition, provision of legal services is highly cost-effective.

j. **Protect and support community-based organizations** to ensure continuation of high-quality, anti-discriminatory services by community gatekeepers.

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