



LATINO/HISPANIC HIV/AIDS FEDERAL POLICY RECOMMENDATIONS ADDRESSING THE LATINO AIDS CRISIS

I. INTRODUCTION

A. THE LATINO/HISPANIC HIV/AIDS CRISIS

HIV/AIDS continues to threaten the health and well-being of many communities in the United States, including diverse Latino/Hispanic [hereinafter referred to as Latinos] communities. Latinos overwhelmingly believe, when surveyed, that HIV/AIDS is one of the most urgent health problems facing the nation today.¹ Federal resources for HIV care have not kept pace with the epidemic and funding to prevent the disease among Latinos has remained largely flat. This reality has impacted the ability to maintain prevention and care as the most important tools to reduce the spread of HIV/AIDS. When surveyed, Latinos respond that AIDS is the second most urgent health problem facing the nation today after cancer.² Almost one-half of Latinos report that HIV/AIDS is even more of an urgent problem in their communities today than a few years ago compared to 15% of Whites.³

Among the many health disparities experienced by racial/ethnic groups in the U.S. and its territories, the severity of the HIV/AIDS epidemic in minority communities relative to non-Hispanic Whites is particularly acute. The Latino HIV/AIDS epidemic is still ignored or set aside for inaction by most policy makers and elected leaders. This neglect occurs despite the fact that Latinos comprise about 15.3% of the population in the U.S. and Puerto Rico, but account for 19% of people reported living with AIDS and 24.8% of HIV diagnoses since the beginning of the epidemic.⁴ Furthermore, due to HIV-specific name based reporting restrictions and a failure to include Puerto Ricans in the counting of U.S.

Latinos, almost 40% of the Latino population remains uncounted in national HIV reporting or even AIDS reporting.⁵ The following chart details the HIV/AIDS incidence and prevalence among Latinos and non-Hispanic Whites⁶:

	Latinos	Non-Hispanic White
Reports HIV/AIDS 2006	25.5	8.2
Reports AIDS in 2006	15.4	5.4
Reports AIDS diagnosis within 12 months of HIV+ test	14.0	5.1
Reports deaths due to HIV 2006	5.5	1.9
Prevalence living with HIV/AIDS	191.5	68.1
Prevalence AIDS cases since 1981	418.8	194.3
Prevalence HIV diagnosis since 1981	103.6	49.2
Prevalence AIDS deaths since 1981	182.2	120.3

Given these realities, HIV/AIDS remains a threat to the well being of Latino communities in the U.S., District of Columbia, Puerto Rico and the Virgin Islands. According to Centers for Disease Control and Prevention (CDC) data, more than 42% of Latinos were diagnosed with full-blown AIDS within a year of testing positive – meaning they didn’t become aware of or connected to care for their infection until extremely late in the course of their illness. Latinos have higher rates of testing “late” (developing AIDS within one year of a positive HIV test) as opposed to “early” (do not develop AIDS within one year of test).⁷

One implication of late testing is that the person with HIV/AIDS begins care and treatment with a more damaged immune system (lower CD4+ T Cell and higher viral load) than people who tested early. They are less likely to benefit fully from the newer treatments. Late testers can be expected to decrease their life span by several years. Another issue is that the HIV positive Latino may un-



LATINO/HISPANIC HIV/AIDS FEDERAL POLICY RECOMMENDATIONS

ADDRESSING THE LATINO AIDS CRISIS

knowingly place others at risk for infection. One study shows that among a sample of Latinos and Blacks that tested late, 66% were aware of their HIV risk. However, they believed that “self-care” avoids illness (“I can handle it myself”).⁸ Overall, the number of Latinos who died of AIDS remained constant from 2000-2006 compared to a 19% decline in AIDS deaths among Non-Hispanic Whites.⁹ The trajectory of the HIV/AIDS crisis among Latinos is even more alarming if we appropriately adjust estimates upwards due to routine *undercounting* of Latino HIV/AIDS cases. This acute health disparity reflects an HIV/AIDS crisis among Latinos that demands immediate attention, understanding and action at the national level through committed leadership, enlightened policies, and targeted resources.

B. NATIONAL LATINO/HISPANIC AIDS ACTION NETWORK (NLAAN)

The National Latino/Hispanic AIDS Action Network (NLAAN) is dedicated to: (1) educating the Latino public, media, elected officials and health policy decision-makers and disseminating broadly the National Latino/Hispanic AIDS Agenda (the central Federal policy recommendations of the Agenda are summarized in this document); and (2) encouraging Latino communities across the country to form their own agendas for action. NLAAN had its roots in a series of meetings that started in August 2006. A network of concerned Latinos, including community leaders, health and service providers, and representatives of state and local health departments, began meeting to develop a national response to the Latino HIV/AIDS crisis outlined above. NLAAN developed the Latino AIDS Action Agenda and network goals in January 2008, when 330 participants from across the U.S. and its territories convened for a National Summit in Washington, D.C. Support for the Summit was provided by Abbott Laboratories, Gill Foundation, OraSure Technologies Henry van Ameringen Foundation, Office of AIDS Research, and National Minority AIDS Council.

The next Summit is being planned for January 2010 in Washington DC and the website (www.latinoaidsagenda.org) was developed for NLAAN information, materials and supporting documents.

II. KEY RECOMMENDATIONS FROM THE 2008 NATIONAL LATINO /HISPANIC HIV/AIDS ACTION POLICY AGENDA

A. THE NATIONAL LATINO/HISPANIC AIDS ACTION NETWORK (NLAAN) SUPPORTS THE DEVELOPMENT OF A COMPREHENSIVE NATIONAL AIDS STRATEGY REFLECTING THE NEEDS OF ALL AFFECTED COMMUNITIES.

Latinos must work in partnership with all groups, legislators and government agencies to achieve a comprehensive national AIDS strategy in the U.S. The public health crisis produced by HIV/AIDS demands leadership and a commitment of resources for the development of a comprehensive national HIV/AIDS plan. The need is great and the time is now.

B. THE FEDERAL GOVERNMENT MUST ACKNOWLEDGE THE HIV/AIDS CRISIS IN LATINO COMMUNITIES AND DIRECT AGENCIES WITHIN FEDERAL JURISDICTION TO DEVELOP CONCRETE STRATEGIES TO INCREASE ACCESS TO HIV TESTING, PREVENTION AND TREATMENT.

❶ **Declare a *heightened national response* to address the epidemic among Latinos.** The Department of Health and Human Services (HHS) must adopt a *heightened national response* to HIV/AIDS in the Latino communities of the U.S. and its territories. HHS should direct all of its agencies to specifically address the Latino HIV/AIDS epidemic, and report annually on steps taken and the impact of those steps. HHS should gather these reports annually and submit them to the relevant Congressional oversight committees and



LATINO/HISPANIC HIV/AIDS FEDERAL POLICY RECOMMENDATIONS

ADDRESSING THE LATINO AIDS CRISIS

the Congressional Hispanic Caucus and be made available to the public. NLAAN offers its services to Federal agencies in developing concrete steps of implementing a heightened national response to the current crisis in the Latino community.

2 Assure access to culturally and linguistically competent quality care and prevention.

Core elements of the coordinated heightened national response should include effectively promoting HIV testing with informed consent in all Federally funded health care systems, and ensuring that all HIV-positive Latinos have access to culturally and linguistically competent HIV/AIDS prevention, treatment and social services as measured by compliance with the Office of Minority Health's *National Standards on Culturally and Linguistically Appropriate Services in Health Care and Prevention Services*.¹⁰

3 Assist Latino prevention providers in the development and implementation of local solutions.

The CDC must extend its capacity building support of state and local health departments and community based organizations to strengthen the function of Latino community-based organizations. In addition, CDC and the National Institute of Health (NIH) must support community-based participatory research in behavioral HIV prevention interventions and the effectiveness of these interventions with distinct Latino subpopulations.

4 Pass the Early Treatment for HIV/AIDS Act (ETHA).

Congress must pass bipartisan bill HR-3326, ETHA would give states the option of providing Medicaid coverage to people living with HIV and would mark a shift in current Medicaid policy, creating significant health, economic and public health benefits. Currently, Medicaid eligibility requires that people with HIV must demonstrate they have an AIDS defining condition in order to qualify for services that would actually help prevent disability and delay the onset of an AIDS diagnoses.

C. EXPAND THE FOCUS OF HIV PREVENTION BEHAVIORAL INTERVENTIONS FROM MODELS OF INDIVIDUAL RISK TO INCLUDE STRUCTURAL MODELS OF COMMUNITY VULNERABILITY AND RESILIENCY, AND DEVELOP STRATEGIES RESPONSIVE TO THE STRUCTURAL-ENVIRONMENTAL REALITIES THAT DRIVE HIV TRANSMISSION FOR LATINOS.

1 Improve the understanding of factors that contribute to HIV risk among Latinos.

CDC and NIH must join with community-based organizations, national Latino and HIV/AIDS organizations and coalitions, researchers, Latinos living with HIV/AIDS, local health resources, health departments and other stakeholders to improve the understanding of the social, cultural, and environmental factors that contribute to HIV risk among Latinos. A disproportionate level of attention goes to behavioral models of risk that are solely focused on the individual while a scarcity of attention is given to the community interventions or interventions that address the contexts of risk. There are structural-environmental variables that increase behavioral risk for Latinos by interacting with individual and situational variables to enhance the likelihood of HIV infection. If we incorporate contextual variables that increase or decrease the likelihood of infection among Latinos (e.g.: acculturation, substance use, gender roles, poverty, discrimination, isolation, mental health, and immigration status) we can improve opportunities to prevent HIV infections and facilitate early access to medical care for Latinos living with HIV/AIDS.

2 Develop strategies for combating stigma.

CDC, NIH and Health Resources and Services Administration (HRSA) must commit to developing concrete strategies for combating social stigmas that lead to increased risk taking behaviors, delayed HIV diagnosis and discontinuance of care. This requires investment in, and partnerships with organizations (corporate, media, faith-based,



LATINO/HISPANIC HIV/AIDS FEDERAL POLICY RECOMMENDATIONS

ADDRESSING THE LATINO AIDS CRISIS

etc.) beyond HIV/AIDS providers and health departments. HIV/AIDS stigma must be tackled through the development and launch of social marketing campaigns targeting Latinos and Latino specific-risk factors, and complemented by anti-stigma community based interventions.

D. PROVIDE EPIDEMIOLOGICAL DATA THAT ACCURATELY REPRESENT HIV/AIDS AMONG LATINOS.

❶ **Provide complete HIV/AIDS data.** CDC must provide more complete and accurate state- and territory-level race/ethnicity, country of origin, risk behavior, and HIV incidence and prevalence data on an annual basis.

❷ **Count Puerto Rican Hispanics/Latinos HIV/AIDS Cases.** CDC must end its practice of failing to integrate Puerto Rico-specific data into estimates of Latino HIV/AIDS cases presented in the annual CDC National HIV/AIDS Surveillance Report and other reports. Accurate data are essential to decision-making in directing prevention and care funding.

E. INCREASE THE AMOUNT AND FLEXIBILITY OF FEDERAL FUNDING FOR HIV PREVENTION AND CARE FOR LATINO COMMUNITIES.

❶ **Increase CDC funding for Latino HIV prevention.** Congress must increase CDC funding for HIV prevention by \$600 million more or a total of \$1.3 billion in core HIV prevention with specific carve-outs to address the epidemic among Latinos. Preventing HIV is cheaper than treating HIV/AIDS. If state and local health departments are given sufficient resources to scale up HIV prevention programs, it will have a substantial impact on the epidemic.¹¹ This must be accomplished by increasing the total allocation rather than by cutting other priorities.

❷ **Increase Ryan White funding by 10% (\$1,971,161,353¹²):** Congress must also increase

funding for the Ryan White HIV/AIDS Treatment Modernization Act by 10% with a similar carve-out to address people of color. Ryan White Part A must be increased and amended to meet the needs unique to each locality, and restrictions on jurisdictions' ability to use the funds for nutrition, housing, transportation, traditional case management and other essential services. Funding for Ryan White Part B must be augmented due to the increased lifespan and growing HIV resistance among those with HIV/AIDS, and must include new drugs and more specialized care needed to maintain health.

❸ **Congress must pass HR 2736, the HIV Emergency Local Partnership Act (HELP).** HELP 2007 amends the Public Health Service Act to require the Secretary of Health and Human Services to award grants to eligible entities located in communities wherein racial or ethnic minorities comprise a majority of the population and can provide comprehensive HIV/AIDS service to racial and ethnic minorities in those communities. Fifty million should be allocated for a pilot grant program within the Minority AIDS Initiative to encourage qualified community health entities to cooperate with each other to provide comprehensive HIV/AIDS services for racial and ethnic minorities in their localities.

F. DEVELOP IMMIGRATION POLICIES THAT RESPECT THE HUMAN RIGHTS AND PROTECT THE HEALTH OF PEOPLE LIVING WITH HIV/AIDS.

❶ **End the HIV Ban.** Congress has passed HR-5501, repealing the ban on HIV positive immigrants entering or residing in the United States. The decision to strike the HIV ban from the Immigration and Nationality Act is a historic measure that advances the human rights of all persons living with HIV/AIDS. NLAAN calls on HHS and the Office of Homeland Security to update its regulations following the President's signing of



LATINO/HISPANIC HIV/AIDS FEDERAL POLICY RECOMMENDATIONS

ADDRESSING THE LATINO AIDS CRISIS

legislation to reauthorize PEPFAR, (President's Emergency Plan for AIDS Relief - HR 5501).

The HIV travel and immigration ban performs no public health service, is unnecessary and ineffective and helps to advance the stigma that has long been associated with the disease in the Latino community. While thankful to our allies on the Hill who fought to end this injustice, NLAAN calls on HHS to remove the remaining regulatory barriers to HIV-positive visitors and immigrants.

② Mandate humane health care in detention facilities for people living with HIV/AIDS.

Congress must pass HR-5950 (Detainee Basic Medical Care Act of 2008). Department of Homeland Security (DHS) and HRSA must establish policies requiring that all immigrants with HIV/AIDS be treated with respect for the health and humanity of these individuals, as well as that of our nation. HHS and Congress must jointly ensure that all public health guidelines which govern the Federal Prison system that normally apply to U.S. prisoners with chronic diseases are made mandatory for persons in DHS detention for alleged immigration violations. There have been too many unnecessary HIV/AIDS and other deaths occurring while in DHS detention.¹³

G. CONGRESS MUST ACT IMMEDIATELY TO RESOLVE THE HIV/AIDS CRISIS IN PUERTO RICO.

① Congress must permit HHS to transfer Ryan White funding from political entities in Puerto Rico to an independent third party administrator. Congress must stop the deterioration of health care for people living with HIV/AIDS in Puerto Rico. In relation to its population of 3.9 million, Puerto Rico has the fifth-highest concentration of AIDS cases in the United States and its territories with a rate of 21.8.¹⁴ As of 2005, Puerto Rico had the second highest rate of HIV related deaths, over three times the national death rate.¹⁵ Health care for

people with HIV/AIDS in some parts of the Island borders on non-existent. Federal officials have stated that the main culprit is the island's historically poor management of countless of millions of the available dollars allocated for AIDS care under the Ryan White Act: 2007 Federal allocation was \$53 million. Both grantees of these Federal funds have been non-compliant in their grants management and as a result, have been placed under prolonged restrictive status. Many clinics have not received drugs on time, and the health of community-based organizations that assist people living with AIDS are being threatened due to delays or non-payment for reimbursable services by government entities.

Giving HRSA the authority to transfer funds for care to a third party goes to the heart of each state and city's limited discretion in administering HIV care funds. This must be done in a manner which does not invite Federal intervention in numerous other jurisdictions. But concerns over outside interference aside, "contracting out" would be a far more preferable option to the current situation which harms people living with HIV/AIDS and the programs that serve them. We must improve accountability and create an oversight mechanism to ensure that those living with HIV get the care they need. Local programs must be paid for services rendered in a timely manner.

② Congress must eliminate "cap" on Medicaid funding for Puerto Rico for people living with HIV/AIDS in the Island. Where States receive Medicaid reimbursements of 50% - 80%, Puerto Rico receive 20% due to a fixed dollar limit on Federal participation, known as the Medicaid cap. This limit leaves Puerto Rico striving to breach a 30% gap in services funding; the difference between the cap at 20% and the statutory minimum of 50% available to the States. Congress must resolve these limitations to facilitate care similar to that of the States.

③ There must be a significant expansion of prevention programs for male and female



LATINO/HISPANIC HIV/AIDS FEDERAL POLICY RECOMMENDATIONS

ADDRESSING THE LATINO AIDS CRISIS

intravenous drug users. Improved access to clean syringes in the Commonwealth through local funding is vital to the health and well being of Puerto Rico where the use of contaminated syringes is the primary cause of HIV infections and intravenous drug users account for a majority of new infections.

H. CONGRESS MUST DIRECT THE FEDERAL GOVERNMENT TO FUND SOUND PUBLIC HEALTH PRACTICES THAT HAVE BEEN PROVEN TO REDUCE HIV INFECTION, INCLUDING ACCESS TO STERILE SYRINGES.

Despite these state and local efforts, the CDC reports that a significant percentage of new Latino infections in 2006 resulted from sharing syringes (13% of men and 15% of women).¹⁶ Countless studies have documented that syringe exchange does not lead to increased drug use and that the exchanges themselves are valuable points of engagement with health care systems for an otherwise hard to reach population.¹⁷ Given the success of needle exchange programs in lowering infections and serving Latinos who inject drugs, we call on Congress to take action now.

I. THE FEDERAL GOVERNMENT MUST RECOGNIZE AND INVEST IN DEVELOPING LATINO COMMUNITY LEADERSHIP TO BROADEN SUPPORT FOR ADDRESSING THE HIV/AIDS EPIDEMIC.

If Latino communities throughout the U.S. are to reduce the stigma associated with HIV/AIDS and accept and adopt routine HIV testing, the Federal government must develop leadership from within the Latino community. One successful model for enhancing such leadership is the poorly funded Leadership Campaign on AIDS in the Office of the Health and Human Services Secretary. Some local health departments including the Florida

Department of Health, the Los Angeles County Department of Public Health, and the New York State Department of Health have begun to reach out to Latino communities in their respective localities to ensure that the HIV/AIDS prevention message is transmitted in partnership with local media and Latino celebrities both frequently and consistently. More programmatic and financial assistance is needed to reach every sector of the Latino community, particularly within emerging Spanish-monolingual Latino communities where Spanish language media and educational sources are not yet available.

This document is a summary of the recommendations for federal policy changes for the LATINO/HISPANIC AIDS ACTION AGENDA. For more detailed information, visit www.latinoaidsagenda.org

- ¹ Kaiser Family Foundation *Survey of Americans on HIV/AIDS* (conducted March 24–April 18, 2006) Chart 2 HIV/AIDS in Your Community.
- ² Kaiser Family Foundation *Survey of Americans on HIV/AIDS* (conducted March 24–April 18, 2006) Chart 32 HIV/AIDS in Your Community.
- ³ Kaiser Family Foundation *Survey* Chart 39.
- ⁴ Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report, 2006. Vol 18). Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention; 2008. (Hereinafter referred to CDC Report 2006). Page 41 and 45, Tables 20 and 22 <http://www.cdc.gov/hiv/topics/surveillance/resources/reports/2006report/pdf/2006SurveillanceReport.pdf> and U.S. Census Bureau Press Release on May 17 2007 Release on Minority Population Tops 100 Million, Table 1 (hereinafter referred to as 2007 Census Report.)
- ⁵ When reporting HIV data the CDC excludes California, Connecticut, Delaware, District of Columbia, Georgia, Hawaii, Illinois, Kentucky, Maine, Maryland, Massachusetts, Montana, New Hampshire, Oregon, Pennsylvania, Rhode Island, Vermont and Washington states. See Table 12 CDC Report 2006 p. 24 Table 12. The CDC is unable to report the number of Latinos living with HIV or AIDS because census information about age and race categories was lacking
- ⁶ CDC Report 2006 for incidence see Tables 5A, 5B, 2, 7. For Prevalence see Tables 8, 19/21, 20/22 and 7. For population estimates that were used in these calculations see U.S. Census Report 2007. For detailed citations please look at the main body of the Latino AIDS Action Agenda available at www.latinoaidsagenda.org.
- ⁷ Schwarz S, et al. Late diagnosis of HIV infection: Trends, prevalence and characteristics of persons whose HIV diagnosis occurred within 12 months of developing AIDS. 2006 J. Acquire Immune Deficient Syndrome 43:4 pp 491- 494
- ⁸ Hu DJ et al. Characteristics of persons with late AIDS diagnosis in the United States, American Journal of Prevention Medicine 1995 Mar-Apr(2):114-9
- ⁹ CDC Report 2006 p. 12 Table 2
- ¹⁰ <http://www.omhrc.gov/assets/pdf/checked/finalreport.pdf>.
- ¹¹ NASTAD, The Policy Agenda, An Action Plan to Support the HIV Prevention Blueprint
- ¹² Calculated from Kaiser State Health Facts (www.statehealthfacts.org) reporting of 2007 Ryan White budget for all subdivisions.
- ¹³ Nina Bernstein, "New Scrutiny as Immigrants Die In Custody," The New York Times, June 26, 2007;
- ¹⁴ CDC HIV/AIDS Surveillance Report, 2006. Vol 18.
- ¹⁵ <http://www.statehealthfacts.org/comparemaptable.jsp?ind=527&cat=11>
- ¹⁶ CDC Report 2006: Pages 41-46, Tables 20 and 22.
- ¹⁷ HHS Press Office (April 20, 1998). "Research shows needle exchange programs reduce HIV infections without increasing drug use." Accessed July 7, 2007. Available at <http://www.hhs.gov/news/press/1998pres/980420a.html>