



INSTITUTE FOR HISPANIC HEALTH

REDEFINING HIV/AIDS FOR LATINOS

**A Promising New Paradigm for Addressing
HIV/AIDS in the Hispanic Community**

**White Paper
Executive Summary**

National Council of La Raza
Raul Yzaguirre Building
1126 16th Street, NW
Washington, DC 20036
www.nclr.org

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Background

Within the context of the changing demographics of HIV/AIDS among Latinos and an evolving national strategy to address the disease, the National Council of La Raza (NCLR) conducted an extensive qualitative needs assessment of HIV-positive and high-risk Latinos at 14 sites in the U.S., including Puerto Rico. The NCLR Latino Families HIV/AIDS Needs Assessment involved 121 in-depth interviews with HIV-positive Latino men and women and 18 focus groups involving 201 participants in an effort to better understand the context of HIV risk behavior in the lives of Latinos.

This white paper combines findings from the NCLR Latino Families HIV/AIDS Needs Assessment, academic research presented during the Latinas and HIV/AIDS Summit in 2005, findings from the working groups at the Summit, and a review of the existing literature to outline a proposed new strategy designed to reduce the incidence and improve treatment of HIV/AIDS in the Latino community.

Changing Demographics of HIV/AIDS in the Hispanic Community

While accounting for 14% of the U.S. population, Latinos currently constitute 19% of the cumulative 944,306 AIDS cases diagnosed since the beginning of the epidemic and 20% of all people in the U.S. living with AIDS. Moreover, a recent report by the Agency for Healthcare Research and Quality found that “New AIDS Cases” was ranked as one of the disparities in quality of health which was worsening only among Latinos when compared to all other racial/ethnic groups. Furthermore, Latinos were the only group to experience a doubling of heterosexual infection in new HIV cases between 2001 and 2004, from 23% to 51% among women and 5% to 11% among men. These trends indicate that many Latinos at risk for infection are ignored by HIV prevention efforts targeting only those groups historically perceived as high risk.

In spite of the consistent and disproportionate increase in HIV infection and AIDS cases among underserved Latinos, there has been little attempt to understand the context of their risk for HIV infection or the causes for new transmission patterns. Increasingly, the national focus has shifted from programmatic strategies to prevent HIV infection toward treating it as a chronic disease that can be managed.

This more passive approach to HIV/AIDS prevention and reliance on treatment, combined with other factors, severely and adversely increases the impact of the virus on the Latino community. Hispanics are the most likely to learn of their HIV status late in their disease progression, the least likely to gain access to quality HIV/AIDS-related health care, and the most likely to die within 18 months of an AIDS diagnosis. Furthermore, the current paradigm accepts, rather than challenges, shortcomings in today’s HIV testing and reporting procedures, which contribute to the incomplete picture of the epidemic’s impact on Hispanics.

Although advances in HIV/AIDS treatment have led to declines in new diagnoses and deaths among Whites and other minorities, these advances continue to be more slowly experienced among the Latino population. In fact, with an increase of eight percentage points, Latinos were the only racial or ethnic group to have experienced an increase in the rate of AIDS deaths between 1999 and 2003. Furthermore, Hispanics are more likely than African Americans or non-Latino Whites to be tested for and diagnosed with HIV/AIDS after the disease has already progressed to a more serious stage.

Why HIV/AIDS Disproportionately Affects Hispanics

Today's approach to HIV/AIDS is confounded by the Latino population's lack of access to culturally- and linguistically-competent health care and the gap in information on HIV/AIDS and its impact on the community. In particular, there is an overwhelming demand for new definitions of HIV infection risk which inform communities, health professionals, and public health providers of both the context of HIV risk as well as modes of transmission. Furthermore, adaptations of HIV/AIDS education materials originally designed to prevent HIV among English-speaking gay males and intravenous drug users (IDUs) continue to account for the vast majority of public health information and fail to reach the newest casualties of the epidemic.

The causes of the disproportionately high rate of HIV/AIDS in the U.S. Hispanic community are complex. Although the Latino population is extremely diverse, its members share common factors that may place them at increased risk of HIV/AIDS: discrimination, stigma, homophobia, socioeconomic hardship, overcrowding, poverty, rigid gender roles and expectations, high mobility, isolation from family and country of origin, and marginalized status. Some causes – such as poverty, low levels of education, and lack of access to adequate health care – reflect the experiences of other underserved populations and are beginning to be incorporated into national and community-based public health programs.

Cultural and social barriers also inhibit access of Latinos to effective prevention, testing, and treatment programs. Key barriers include:

- Hispanic sexuality and gender roles, including the effects of *machismo*
- Parental inhibitions regarding sexual education
- The impact of acculturation on risk behaviors
- High Latino concentrations among migrant workers, who experience disproportionate HIV/AIDS risks
- Immigration status, which inhibits Hispanic access to treatment
- Ineffective HIV prevention and outreach campaigns

Promising Strategies: A Family Focus

The clear consensus of the academic research and the Latinas and HIV/AIDS Summit, confirmed by NCLR Latino Families HIV/AIDS Needs Assessment participants of both genders, is that the next generation of Hispanic-focused HIV/AIDS prevention, outreach, and education programs should focus on the Latino family. Specifically, HIV prevention projects targeting Latinos should premise efforts on the following themes and messages:

- **Using culturally-based values and beliefs** to construct prevention efforts regarding the growing risk of HIV among Latino families, particularly females who may be in long-term perceived monogamous relationships
- **Targeting Hispanic families** and emphasizing the need for sexual communication with their partners and their children about HIV/AIDS risk
- **Highlighting the responsibility of Hispanic men** to protect their partners and their families by communicating about their risk behaviors and using condoms
- **Promoting awareness among Hispanic youth** of both their growing risk for contracting the virus and the gender and privilege issues related to the factors motivating sexual behavior as it relates to a sense of personal power among young women (the ability of a young woman to attract a male)

Recommendations

A major, multisite demonstration project emphasizing this family-focused paradigm should be designed and implemented, incorporating the following attributes:

- **Creating culturally- and linguistically-relevant HIV prevention and testing media campaigns targeting the Latino family, with a particular focus on heterosexual women and youth.** Knowing that in the eyes of many Latinos at risk for HIV infection the virus affects only those who fall into the traditional HIV risk categories of IDU, males having sex with males (MSM), and sex workers, greater emphasis needs to be placed on designing media campaigns that target the entire Latino family.
- **Reducing the stigma through the participation of HIV-positive Latinos willing to be part of the media campaign.** Recommendations from participants in the NCLR Latino Families HIV/AIDS Needs Assessment found that messages that raised awareness, rather than incited fear, were desired.
- **Using a pan-Latino Spanish-language approach with materials that are sensitive to lower educational levels.** Materials should be in basic Spanish, at a literacy level that is accessible to the majority. An exception to this recommendation might be when developing materials targeting youth, who often identify with specific word uses.
- **Linking outreach and prevention activities with CBOs, educational and religious institutions, and AIDS Service Organizations (ASOs) in the development of HIV outreach and education programs.** Mentoring relationships among organizations allows for creative endeavors that can in turn provide services to other institutions such as those of an educational and/or religious nature.
- **Creating, supporting, and evaluating *promotores*-based HIV/AIDS programs.** *Promotores* programs have been widely used throughout developing countries and provide underserved and often linguistically-isolated communities with needed health-related information. These programs are just beginning to take hold in the U.S. and are quite successful in both educating and providing participants with culturally- and linguistically-relevant information combined with the social support needed for behavior change.
- **Working with CBOs in the development, testing/evaluation, and placement of outreach educational activities.** CBOs and Latinos frequenting these organizations for services are the experts and should be included in all aspects of program development. These organizations must be assisted in the measurement of the effectiveness of their programs so that they are better able to document and promote wider-scale replication of best practices.

If this family-focused, culturally-competent approach demonstrates positive results in community settings, it can and should be used to inform a nationwide redefinition of HIV/AIDS prevention, outreach, and education strategies targeting the Latino community.

Our nation's future economic prosperity depends on a healthy and thriving Latino population, the largest and youngest minority group in the U.S. It is projected that by 2050, 24% of the U.S. population will be Hispanic, and dramatically reducing the growing incidence of HIV infection among Latinos should be a national priority. The development of new, creative, and effective HIV prevention, outreach, and AIDS management strategies that meet Latino-specific needs are crucial to curbing the spread of HIV. Eradicating the stigma associated with infection through targeted intervention, early access to testing and treatment, and improving knowledge and methods of preventing the spread of this virus through outreach and education are essential steps in our society's shared battle against HIV/AIDS among Latinos.