



**INSTITUTE FOR HISPANIC HEALTH**

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# **REDEFINING HIV/AIDS FOR LATINOS**

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

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## Acknowledgments

The National Council of La Raza's (NCLR) health programs are housed in the Institute for Hispanic Health (IHH), which maintains the vision "to improve the health and well-being of Hispanics." IHH works to reduce the incidence, burden, and impact of health problems in the Hispanic community by working in close partnership with NCLR Affiliates, government agencies, private donors, and other Hispanic-serving organizations to design and deliver quality science-based health interventions using approaches that are culturally competent and linguistically appropriate. IHH's approach emphasizes an integrated and holistic view of health care issues and needs facing Latinos.

In 2005, NCLR and California State University, Long Beach (CSULB) established the NCLR-CSULB Center for Latino Community Health, Evaluation, and Leadership Training (NCLR-CSULB Center), which works to support and evaluate health promotion and disease prevention programs in underserved Latino communities nationwide with an emphasis in southern California.

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.

Quotations in this document were selected based on their ability to represent the general HIV risk experiences of Latinos as revealed through the literature, the Summit proceedings, and the NCLR Latino Families HIV/AIDS Needs Assessment. Pseudonyms were selected by all participants to protect their identities. Quotations from the NCLR Latino Families HIV/AIDS Needs Assessment participants are italicized.

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## Executive Summary

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.

# I. BACKGROUND

Despite a 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 these 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 change is a result of the advent of Highly Active Antiretroviral Therapy (HAART) and the use of protease inhibitors initiated in 1997 (Miller, 2005).

This more passive approach to HIV/AIDS prevention and reliance on treatment, combined with other factors, severely and adversely increases the impact of the disease 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.

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.

Within the context of the changing demographics of HIV/AIDS among Latinos and an evolving national strategy to address the disease, from 2000 through 2003 the National Council of La Raza (NCLR) conducted a large qualitative analysis 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.

One of the major focal points of the Needs Assessment was to inquire about Latinos' exposure to HIV/AIDS information and prevention messages and to consider the cultural and linguistic relevance of the messages for which they reported recall. Sites involved in the assessment included: Los Angeles, California; San Ysidro, California; Hartford, Connecticut; Miami, Florida; Silver Spring, Maryland; Jamaica Plains, Massachusetts; Hattiesburg, Mississippi; Paterson, New Jersey; Manhattan, New York; Durham, North Carolina; San Juan, Puerto Rico; El Paso, Texas; Harlingen, Texas; and San Antonio, Texas.

The Needs Assessment unveiled major themes surrounding increased risk for HIV/AIDS in the Hispanic community, including access to health care and health education, cultural definitions of family and gender roles, religion, socioeconomic status, discrimination, levels of acculturation, and media message exposure among a population of Latinos utilizing the services of community-based organizations (CBOs). Although many of the individuals who participated in the Needs

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\* The terms "Hispanic" and "Latino" are used interchangeably by the U. S. Census Bureau and throughout this document to identify persons of Mexican, Puerto Rican, Cuban, Central and South American, Dominican, and Spanish descent; they may be of any race.

Assessment could be defined as “high-risk” under current criteria (e.g., homosexual, injection drug user), many more did not, addressing the need to focus on a broader group and various subsets of Latinos to effectively target HIV/AIDS at the community level.

In an effort to further explore the specific factors that increase Latinos’ risk for HIV infection and the issues related to HIV/AIDS management, NCLR, California State University, Long Beach (CSULB), and the Los Angeles-based Latino Coalition Against AIDS held the Latinas and HIV/AIDS Summit in December 2005. Sponsored by the Congressional Hispanic Caucus Health Task Force, the Office of Minority Health (OMH), and the Latino Coalition Against AIDS, the Summit provided a unique opportunity for academic researchers, CBOs, policy-makers, and peer health educators to review the most up-to-date HIV/AIDS research on the U.S. Hispanic community and to share experiences and best practices from the field. Although the focus was on Hispanic women in particular, the overall emphasis was on families and the daily contexts of HIV risk. Participants convened for academic presentations followed by working groups that focused on key topics, including examining culture and family; economics and HIV risk; increasing access to HIV testing; reproductive health and HIV risk; creating effective HIV prevention and media messages; and *promotores de salud* (lay health educators) and health education models for HIV prevention.

## II. CHANGING DEMOGRAPHICS OF HIV/AIDS IN THE HISPANIC COMMUNITY

### A. Overview

While there are major gaps in data documenting the incidence of HIV/AIDS within the Hispanic community, the available research shows that it affects Latinos in all regions of the country, that its disproportionate effects have historically impacted Hispanic subgroups differently by both ethnic origin and birthplace, and that it is increasingly transmitted through heterosexual contact, placing an augmented burden upon Latino women and youth.

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 (Kaiser Family Foundation, 2006). The growing incidence of HIV and AIDS within the Hispanic community diverges from the disease’s historical patterns of transmission with HIV affecting heterosexuals, Hispanic women, and adolescents more than in all other racial/ethnic groups except for African Americans. Moreover, a recent report by the Agency for Healthcare Research and Quality (2005) 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.

With the exception of Latinos and African Americans, rates of new HIV infections and AIDS cases have decreased among all risk groups and racial and ethnic minorities. In 1993, when Hispanics accounted for 11.5% of the U.S. population, it is estimated that they represented 17.6% of all new HIV (not AIDS) cases in the U.S. In 2004, when Hispanics represented 14% of the population, the proportion of Hispanic HIV cases grew to 21%. Over the same period, new cases of HIV among Whites fell from more than 45% to 30.5%, a drop that far exceeds the relative decrease in Whites as a percentage of the U.S. population (Centers for Disease Control and Prevention [CDC], 1993, 2005). Moreover, despite the advances in treatments that are prolonging the progression to full-blown AIDS, diagnoses among Latinos increased by 8% between 1999 and 2003 alone, an increase greater than for any other racial/ethnic group.

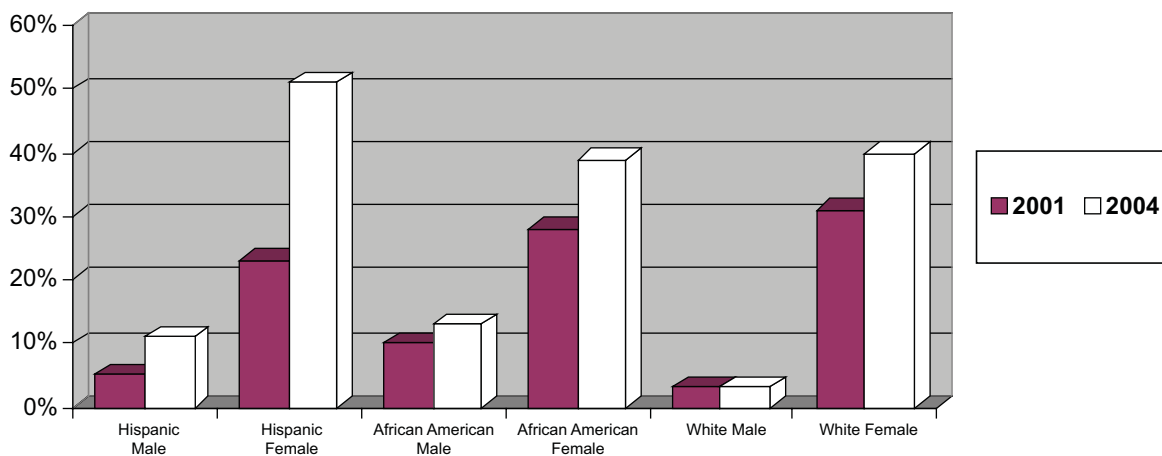


## B. Heterosexual Transmission

The disproportionately rapid increase of the disease among Hispanics can be attributed to its increasing spread through heterosexual contact. Within the past three years Latinos represent the only racial/ethnic category wherein heterosexual infection has more than doubled among both males (5% to 11%) and females (23% to 51%), indicating a transition in transmission that mirrors data from Africa and some Latin American countries, where the male-to-female AIDS case ratio continues to rapidly decrease (Frasca, 2005).

**FIGURE 1**

### Heterosexual Transmission Among Latino, African American, and White Males and Females in 2001 and 2004



Source: Centers for Disease Control and Prevention. (2004). *HIV/AIDS Surveillance Report, 16*. Atlanta: U.S. Department of Health and Human Services.

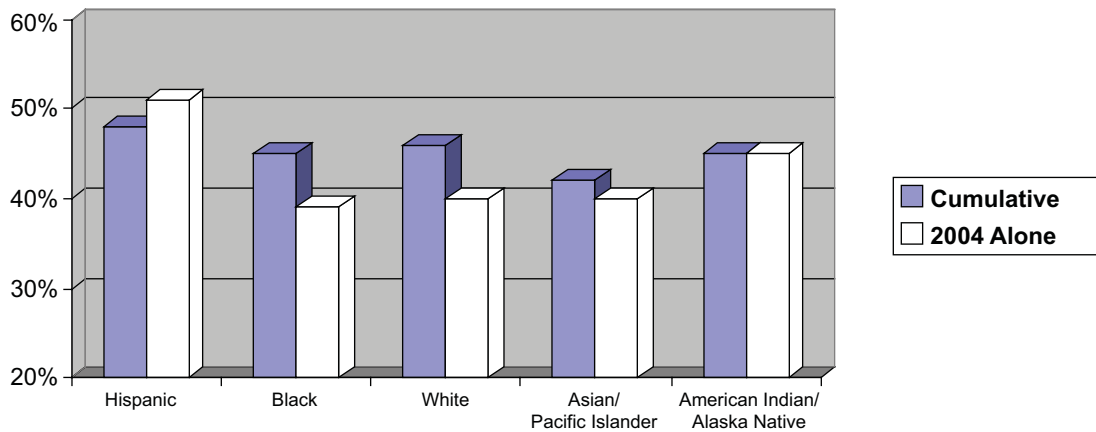
Not surprisingly, the resulting increase in heterosexual transmission among Hispanic women far exceeds increases in other racial and ethnic categories. In 2004, among the new HIV cases for Latinas, 51% were caused by heterosexual contact, 19% by intravenous drug use (IDU), 1% by receipt of blood or blood components or tissue, and 29% through other/risk not reported or identified.

From 2004 to 2005, Latinas' heterosexual infection rates increased from 48% to 51% (CDC, 2004, 2005), whereas heterosexual transmission for all other racial/ethnic groups has either remained the same or decreased. By 2004, Latinas were more likely than all other racial and ethnic groups to be infected through heterosexual transmission, and this alarming trend continues. Given their lack of understanding of their risk for contracting this deadly disease, the overall percentage of Latinas with HIV/AIDS continues to grow.

As confirmed by the NCLR Latino Families HIV/AIDS Needs Assessment, an overwhelming proportion of the 29% of those who cite "other/risk not reported or identified" contracted the disease through heterosexual activity, suggesting that official data understate the actual incidence of transmission of the disease through heterosexual contact.

**FIGURE 2**

**Female Heterosexual Transmission Rates by Racial/Ethnic Group Comparing 2004 and Cumulative Data through 2004 in 42 Confidential Name-Based Reporting Areas, Including Puerto Rico**

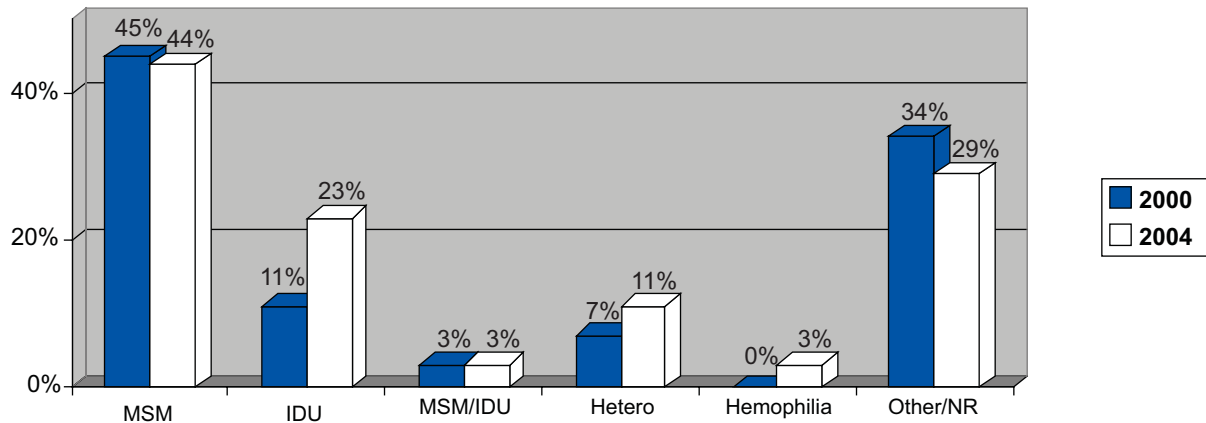


Source: Centers for Disease Control and Prevention. (2004). *HIV/AIDS Surveillance Report, 16*. Atlanta: U.S. Department of Health and Human Services.

The incidence of the disease as a result of heterosexual contact has also significantly impacted Hispanic males who are the second most likely racial/ethnic group to be infected via this mode of transmission and the second least likely to be infected through homosexual contact. In 2004, 44% of Hispanic male HIV cases were caused by males having sex with males (MSM), followed by injection drug use (IDU) at 23%, heterosexual contact (11%), and an equal share caused by a combination of MSM/IDU and hemophilia/coagulation disorder-related blood or blood product transfusion (3%) (CDC, 2005). In comparing these data with those from 2000, the only two transmission modes demonstrating an increase were IDU and heterosexual. The rise in IDU is most likely the result of the inclusion of Puerto Rico in national data profiles due to the commencement of name-based reporting of HIV.

**FIGURE 3**

**2000 (34 areas) and 2004 (42 areas including Puerto Rico) New HIV Infections among Latino Males in Areas with Confidential Name-Based Infection Reporting**



Source: Centers for Disease Control and Prevention. (2004). *HIV/AIDS Surveillance Report*, 16. Atlanta: U.S. Department of Health and Human Services.

### C. Geographic Dispersion

As the Latino population continues to spread throughout the United States, Latinos with AIDS are now found throughout the country, with rapid increases taking place in the southern United States (CDC, 2005). Although in 2004 the ten regions with the highest rates of Hispanic AIDS cases – California, Connecticut, Florida, Illinois, Massachusetts, New Jersey, New York, Pennsylvania, Puerto Rico, and Texas – accounted for 89% of all Latinos estimated to be living with AIDS (CDC, 2005), the highest increases in overall AIDS rates are occurring in the southern corridor.

While these AIDS case rates should be interpreted with caution due to the South’s relatively small Latino population, considerable strategic changes are necessary for effective health services and prevention efforts given the definitive growth of the Latino population in the southeastern U.S. and other emerging areas that have experienced rapid growth of their respective Latino populations within the past ten years (National Council of La Raza, 2004a). These areas often have health program and social service infrastructures that are unable to provide culturally- and linguistically-appropriate services and appropriate care.

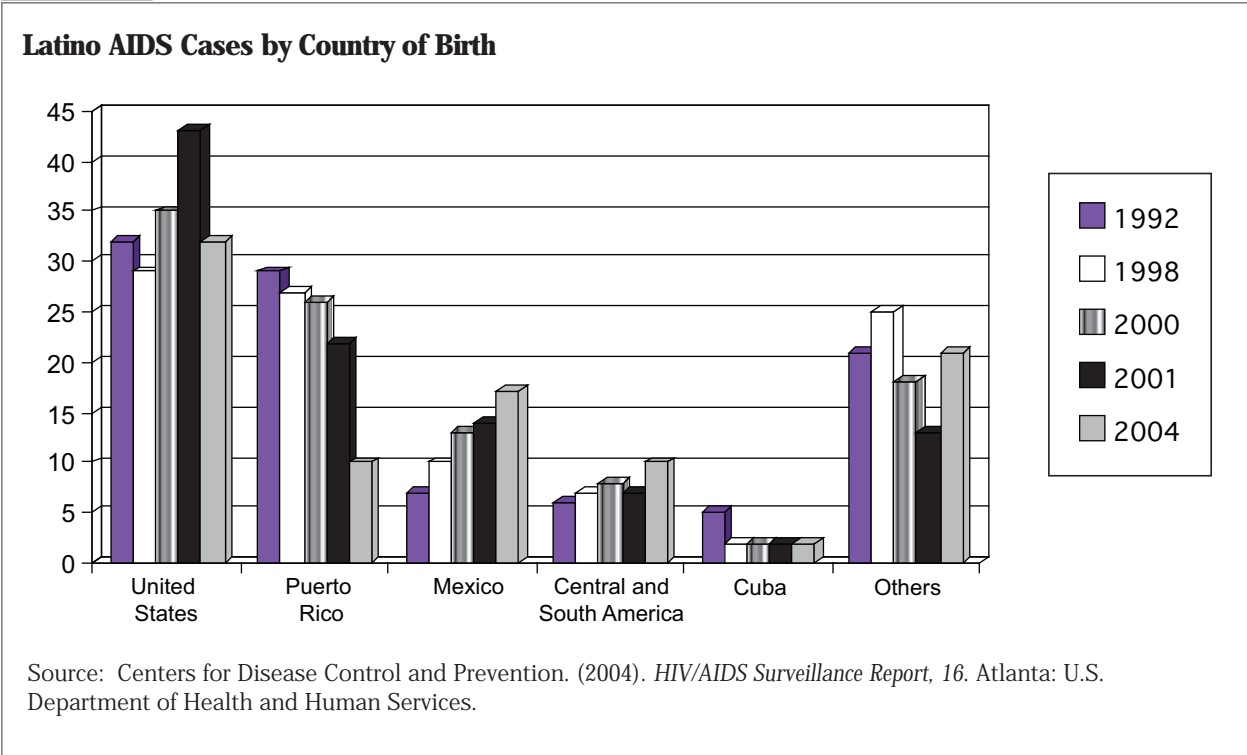
### D. Country of Origin

While there are still significant gaps in information on the impact of AIDS on Latinos of different countries of origin, examination of the incidence of AIDS cases among Latinos of varying birthplaces demonstrates recent increases in AIDS cases among those born in Mexico and Central and South America.

In 1992, the majority of Latinos with AIDS were born either on the U.S. mainland (32%) or in Puerto Rico (28%). However, by 2004, the percentage of AIDS cases among Puerto Rican-born dropped to 10%, a trend that continues. The most recent increases in AIDS cases are, however,

among Mexican-born Latinos – a trend that calls for more study, especially among Mexican migrants who may live in higher-risk environments and, as a result, be exposed to and consequently participate in high-risk behavior. From 1992 to 2004, AIDS cases increased from 7% to 16% for Latinos born in Mexico (CDC, 2005). The rapid rates of increase among Mexican-born and to a lesser extent Central American and South American-born suggests that there is a need to target potentially linguistically isolated communities with less access to health care and health-related information.

**FIGURE 4**



### III. IMPACT OF HIV/AIDS ON LATINOS

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 (Ayala & Nuño, 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. Although the incubation period of untreated HIV to AIDS is generally agreed to be ten to 12 years, 65% of HIV-infected Latinos are diagnosed with AIDS within one year of learning of their HIV seropositivity. In addition, Hispanics have been found to present for initial HIV testing at later stages of infection, with low CD4\* cells and high viral loads (Neal & Fleming, 2002). According to the CDC, 39% of Latinos with HIV were diagnosed with AIDS within one year of testing positive, compared to 38% of Whites and 39% of African Americans. However, these data should be interpreted with caution as only 40% of the Latino population is represented in the CDC's *Annual Surveillance Report* due to the use of code-based reporting in densely Latino-populated states, such as California and Illinois (CDC, 2005).

From 1993 to 2002, estimated AIDS prevalence among Latinos rose by 130%, compared to a 68% increase among non-Hispanic Whites (Ayala & Nuño, 2003; CDC, 1993). Although the introduction of HAART in 1997 curbed AIDS cases among all populations, Latinos continue to experience a decline in AIDS cases which is significantly less than that of non-Hispanic Whites (56% vs. 73%, respectively), indicating less access to HIV-related care and treatment. According to Ayala & Nuño (2003), resource allocation for HIV/AIDS has been markedly less in states with the largest growth in Latinos, receiving less funding per AIDS case for both prevention and care than the national average.

### IV. WHY HIV/AIDS DISPROPORTIONATELY AFFECTS HISPANICS

#### A. Overview

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.

Other issues are more specific to the Hispanic culture and social structure within the U.S. and require more study. The NCLR Latino Families HIV/AIDS Needs Assessment, for example, specifically examined the cultural definitions of family and gender roles, sexual practices, and levels of acculturation in order to identify common behaviors of U.S. Hispanics which lead to increased risk for HIV and AIDS. Other research has examined the lack of access to culturally- and linguistically-appropriate prevention information, immigration policy, inadequate understanding

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\* A measure of the number of helper T cells per cubic millimeter of blood used to analyze the prognosis of patients infected with HIV. A normal count is 1,000; when the count is low – about 200-400 – the body is more susceptible to infections.

among health care professionals of Latino-specific needs, substance abuse prevention and treatment services, as well as the role that male migrant workers may play in spreading HIV/AIDS (Ayala & Nuño, 2003; Castañeda, 2000; Diaz & Ayala, 2001; Pleck, Sonenstein, & Ku, 1993; Vargas Carmona, Romero, & Burns Loeb, 1999).

All available research and case studies show that there are multiple causes that impact men, women, youth, and diverse Hispanic subgroups differently. How these risk factors place Latinos at risk for HIV infection is largely unrecognized by medical and public health experts and unknown by the very Hispanic subgroups most vulnerable to contracting the disease. The following analysis should guide educational and prevention message campaigns for Latino groups not traditionally categorized as at high risk for HIV infection.

## **B. Poverty: The Unspoken Risk Factor**

Although a great deal of HIV prevention information has emphasized individual behavior change, the fact remains that among African Americans and Latinos in particular, poverty and its consequences, or the “built environment” as termed by public health professionals, has also been proven to impact HIV risk. Deprived socioeconomic circumstances confer diminished control over daily lives, which may contribute to a sense of resignation and powerlessness toward issues such as health and well-being. A focus on immediate survival needs often inhibits access to information and resources, as well as the ability to administer preventive self-care.

Access to health care and information for those living in poverty is further complicated by the cost of transportation and child care, inflexibility of hourly-wage jobs, and low education levels, which frequently accompany poverty. The choices forced by economic considerations can also negatively impact the family structure and parent-child relationships, and can contribute to mental health issues and increased substance abuse problems. For many reasons, the individual residing in low-income communities is subjected to a lifestyle that increases his/her risk for contracting HIV/AIDS.

Latinos continue to be concentrated in the lowest-paying jobs, have the second-highest rate of unemployment, and have the lowest rate of homeownership and asset accumulation. It is estimated that at least 23% of Latinos live in poverty. The rate is even higher among Latino children who represent nearly 31% of children living in poverty (Ramirez & De la Cruz, 2003). Several studies have demonstrated the link between HIV risk and aspects of poverty (Sikkema et al., 1996; Zierler et al., 2000). A recent study of Massachusetts communities found that higher population density and poverty were significantly correlated with an increase in AIDS case rates; among groups wherein 40% or greater of the population was below the poverty line, the AIDS incidence was almost seven times higher. Furthermore, these increases were likely to be found in poorer neighborhoods with higher numbers of African Americans and Latinos and tended to affect HIV risk among the residents of these communities to a much greater extent when compared to Whites (Zierler et al., 2000). Moreover, availability of culturally- and linguistically-competent health information, screening, and care is particularly lacking among communities with emerging Latino populations which have little expertise in working with Latinos (National Council of La Raza, 2004a).

### C. Feminization of Poverty and HIV/AIDS

Poverty plays a particularly negative role in the lives of Hispanic women, and given their traditional responsibility as head of household, the consequent increase for HIV/AIDS risk is also felt by the entire family. Research shows that the annual median wage for Latinos is almost half that of their non-Hispanic White counterparts (Aguayo, Brown, Rodriguez, & Margolis, 2003). Close to 25% of Latino households are headed by single Latinas who are the lowest paid wage earners of any group (U.S. Department of Labor, 2004). Women from economically disadvantaged backgrounds have to deal with many social and psychological adversities that make it difficult for them to practice healthy behaviors, including their ability to access available services (Castañeda, 2000). In addition, economic dependence on a partner limits a woman's ability to leave an abusive partner or her ability to negotiate risk reduction behavior such as requiring her partner to use a condom. The daily struggles of life far outweigh the attention needed to negotiate safer sex with their partners (Romero, Wyatt, Chin, & Rodriguez, 1998). Further evidence suggests that housing issues and residential instability can also have a negative effect on preventive behaviors, such as condom use, and can lead to an increased rate of substance abuse (Kline, Kline, & Oken, 1992). Finally, the effects of Latinas living in poverty are clearly linked to increased vulnerability among children, since time constraints and other stressors impact the quality of the parent-child relationship and a mother's ability to impart critical prevention information.

While studies have shown that Latinas are less likely to be sexual risk-takers when compared to their African American and White counterparts, research also shows that poverty has the tendency to transform non-risk-takers into individuals who regularly engage in risky activity. One study of HIV risk behaviors among women in low-income, inner-city housing developments demonstrated that one-third were at risk for HIV due to their partners' behaviors. Women who were in fact at highest risk were those who accurately perceived themselves to be at high risk for HIV infection. These women were more likely to be younger and have little intention to use condoms. Despite their accurate perception of real HIV risk, these women felt relatively helpless in altering their high-risk behaviors; this fact is of grave concern and points to the few chances women actually have or perceive themselves as having when living in impoverished situations (Sikkema et al., 1996).

Likewise, while Latinas have lower rates of substance abuse than other racial and ethnic groups, a study of low-income women in Miami demonstrated that those who used substances were more likely to engage in high-risk behavior and were the least likely to use condoms (Sly, Quadagno, Harrison, Eberstein, & Riehm, 1997). Furthermore, lack of educational opportunities, which may be poverty's greatest burden, also disproportionately impacts Latinos. Latinas with low levels of education, especially those who speak Spanish as their predominant language, frequently have to negotiate an economic and social system that is particularly intimidating given their lack of knowledge and recent adaptation to the U.S. (Zambrana & Dorrington, 1998). According to the U.S. Census Bureau (2002), 67% of Latinas are high school graduates and less than 22% have earned a bachelor's degree or higher. Latinas with a college degree, however, still earn less than White women with a high school diploma (Hernandez-Truyol, 1998). Low educational attainment, monolingual Spanish, and low literacy levels further prevent some Hispanics from accessing accurate HIV/AIDS information. Since Spanish-language television and/or Spanish-language newspapers may be the only information source for monolingual Hispanics, the current placement of HIV/AIDS educational materials must ensure that the most susceptible members of the Hispanic community gain access to the critical HIV/AIDS knowledge needed to facilitate self-protection.

Women who participated in the NCLR Latino Families HIV/AIDS Needs Assessment suggested that outreach workers should provide more information on economic resources such as housing and child care to help women reduce their economic dependence on men and subsequent risks for HIV infection. One woman explained her recommendation for child care by observing:

*That way they can go out and look for a job; give them motivation to come out [of their homes] on their own.*

#### **D. Risk Among Hispanic Youth**

According to data from the Youth Risk Behavior Surveillance System, Latino high school youth are more likely to have engaged in sexual intercourse when compared to all U.S. high school students (48% vs. 46%, respectively) and are the least likely to have used a condom at most recent intercourse when compared to their White and African American counterparts (54% vs. 57% and 67%, respectively) (CDC, 2002). Although abstinence is definitively the only way to completely eliminate sexually-transmitted HIV infection, long-term studies of discordant couples, wherein one person is HIV-positive, have demonstrated successful HIV prevention with consistent condom use. Hispanic youth are the second-most-likely racial/ethnic group to contract HIV/AIDS, and their vulnerability to contracting the disease is increasing. In addition, the low socioeconomic status of many Hispanic youth, coupled with cultural stigma around sex and gender roles, likely contribute to behaviors that increase risk for contracting HIV. The increasing representation of Latino youth (aged 13-19) among new AIDS cases in 2003 (21%) also accentuates the need for increasing prevention efforts targeting this population (CDC, 2006).

Adolescent pregnancy often serves as a proxy variable for HIV/STI (sexually-transmitted infection) risk through unprotected sex. The adolescent pregnancy rates among Latinas aged 15 to 19 are more than twice that of non-Latino Whites (137.9 vs. 55 per 1,000, respectively), rendering their birthrate the highest of any ethnic group since 1995 (Martin, Hamilton, et al., 2006). As Latinos are one of the youngest racial/ethnic groups, the Hispanic adolescent population is expected to rise dramatically throughout the next 20 years; thus, increased attention to the unique issues related to their sexual and reproductive health is vital (Vexler & Suellentrop, 2006).

In direct correlation to their high pregnancy rate is the fact that Latina teens are the least likely to use contraception at first intercourse when compared to non-Hispanic White and non-Hispanic Black teens (34% vs. 22% and 29%, respectively) (Vexler & Suellentrop, 2006). Furthermore, a study of condom use failure among Latinas demonstrated a failure rate that was 86% higher than that of women in all other racial/ethnic groups (Piccinino & Mosher, 1998). Additional research suggests that Latino teens using hormonal contraceptives, such as Depo Provera, are less likely to use condoms when compared to their non-using sexually-active adolescent counterparts (Roye, 1998). These statistics may reflect Latinos' poor access to health care or – when access is gained – little education regarding sexual/reproductive health beyond pregnancy prevention. Access to contraception among Hispanic adolescents could be even more diminished by a culture that does not encourage parents to acknowledge their children's sexual activity or to talk to their children about sex.

The effects of low socioeconomic status on HIV risk could also be exaggerated among Latino adolescents for many reasons, including poor access to quality health care, less opportunity for quality time with parents due to their long work hours, or by contributing to disempowerment, which has been demonstrated to increase at-risk activity. Low-income Hispanic adolescents report higher intentions to have sex, earlier sexual initiation, more sexual partners, and lower use of contraception, including condoms (East, 1998; Norris & Ford, 1999).



Latino adolescents may face unique challenges posed by the traditional values of the culture in which they were raised conflicting with the more liberal values of U.S. culture. Traditional gender roles and *machismo*,\* still highly valued by their parents, take on new meaning for Hispanic American adolescents, and the resulting conflicts, if left unresolved, may contribute to HIV risk. One qualitative study reported that younger Mexican women may be at increased risk for HIV because they do not want to disrupt the heightened sexual intimacy they experience with their main partners by suggesting the use of condoms, believing that such requests indicate they are questioning a partner's fidelity, or that they might give their partners reason to question their own faithfulness. Negotiating condom use may mean acknowledging and even "giving permission" for a partner's infidelity (Hirsch, Higgins, Bentley, & Nathanson, 2002). The degree of acculturation may affect teens' confidence levels as well. One study found that more acculturated teens report a greater sense of control over their sexual health and disease protection compared to less acculturated teens, suggesting a higher motivation to use contraception and thus avoid pregnancy, STIs, and HIV (Villarruel, Jemmott, Jemmott, & Ronis, 2004).

Latino participants in the NCLR Latino Families HIV/AIDS Needs Assessment demonstrated a great deal of concern for youth, and were fearful that teenagers consider themselves to be invulnerable to HIV. Although few youth participated in the Needs Assessment, those who did reported party situations that often led to HIV risk behavior. "Raves" in particular were cited as high-risk situations wherein Latino youth might abuse drugs such as Ecstasy and engage in high-risk sexual activities. Among HIV-positive participants, a great deal of discussion centered on reflection of their attitudes during their youth and how the sense of invulnerability placed them at high risk:

*Teenagers, they don't understand, they don't think. [Hispanic teenagers believe], "It won't happen to me," because that's how I used to be.*

## V. STRUCTURAL FACTORS INHIBITING ACCESS TO HIV/AIDS SERVICES

### A. Lack of Access to Health Care

While access to quality health care is clearly one of the many negative products of a life lived in poverty in the U.S., the specific linguistic, cultural, and other socioeconomic realities of U.S. Hispanics further complicate their access to appropriate health care and education. Latinos are less likely than all other racial/ethnic groups to have access to the health care system.

According to the U.S. Census Bureau's (2003) *Report on Income, Poverty, and Health Insurance Coverage*, the number of uninsured Hispanics rose from 12.8 million to 13.2 million between 2002 and 2003, equaling approximately 32.7% of the U.S. Hispanic population. The Commonwealth Fund's *2001 Health Care Quality Survey* found that 46% of Latinos under the age of 65 reported having gone without health insurance some period of time in the year previous to the survey (Doty & Ives, 2002). According to a recent analysis of the *Survey of Income and Program Participation* (SIPP), Latinos were far more likely to report not having seen a physician within the previous 12 months

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\* A strong or exaggerated sense of masculinity stressing attributes such as physical courage, virility, domination of women, and aggressiveness.

when compared to African Americans, Whites, and Asian/Pacific Islanders (43% vs. 33%, 22.5%, and 33.5%, respectively). Finch and Vega (2003) found that acculturation was associated with negative health, and social support was associated with positive health. Latinos were more likely to report their health as poor or fair and less likely to report their health as excellent when compared to all other groups with the exception of African Americans, indicating a grave lack of access to care. Furthermore, while definite strides have been made in health care access and status afforded to Whites and African Americans, a recent report by the Agency for Healthcare Research and Quality (2005) found that health issues for Latinos are actually worsening when compared to all other racial/ethnic groups.

In addition to lack of health insurance, the structure of the U.S. health care system and its lack of cultural competency disproportionately affect Latinos. Language and literacy barriers and prevailing treatment modalities that run counter to Latinos' culture, beliefs, and practices all play an insidious role in increasing HIV/AIDS risk among Hispanics (Maldonado, 1999). Furthermore, Latinos are also less likely to use preventive health services than other population groups partially due to different cultures of health care practices and expectations as well as the lack of culturally- and linguistically-relevant care for Latinos in the U.S. (Zambrana & Carter-Pokras, 2001). For example, a study of Latinos in southwestern Pennsylvania (Documet & Sharma, 2004) found that for many Hispanics realized access – or actual services used – was affected more by cultural considerations than by actual availability of health insurance. For Latinos in the study, health services in the U.S. were regarded as “cool and disinterested” due to the fact that the biomedical system promotes impersonal relationships and imposes time restrictions that clients perceive as signifying lower quality of care (Documet & Sharma, 2004). It is critical that caregivers identify and treat components of a patient's whole being (Scott, Gilliam, & Braxton, 2005). This is particularly relevant for Hispanic women, who often bear the primary responsibility for meeting the health needs of their families and themselves. A Latina must learn how the health care system is organized, where to seek appropriate care, how to linguistically and culturally translate her concerns into information that will be meaningful to health professionals, and evaluate the prescribed treatment in terms of medical risk and parity with her culture and lifestyle (Amaro & Raj, 2000; Zambrana, 1988).

Since in the U.S. health-related information is usually provided only in the medical setting, Latinos' poor access to health coverage and subsequent services contributes to a large gap in their public health knowledge. Language and education level also serve as barriers to public health education through the media, health care professionals, and peers. Hispanics are less exposed to public health issues regularly reported in the English-language press, such as whether to get a flu shot, how to identify symptoms of depression, and recent research findings on diet and nutrition, which help cultivate health care “consumers.” Language and educational barriers also prevent Latinos from learning what products or environmental conditions may be hazardous to their health and limit access to books about health and health care, including HIV/AIDS (Haynes & Klinger, 2001; Zambrana, 1988). This is particularly relevant when one considers that HIV/AIDS-related information is often extremely sophisticated and designed for the well-educated White gay male (Abrams, 1990). Few materials are designed specifically for the low-income Latino immigrant population in Spanish, and with the care and attention needed to address the context of HIV risk and HIV/AIDS management issues faced by the Latino community (Rios-Ellis, 2005). Furthermore, training of medical interpreters is essential. The use of family members for translation, which often occurs in the medical setting, should be avoided (Haynes & Klinger, 2001). As discussed in greater detail under the “Recommendations” section, these efforts to transcreate (create, translate, and culturally adapt) prevention and treatment materials into Spanish and other indigenous written languages is imperative for controlling the rise in infection among Latinos.

## B. Lack of Access to HIV Testing and Treatment

Access to HIV-related information and testing often provides the impetus for increasing awareness and potential behavior change. Many of the free to low-cost clinics nationwide are not found in areas with a high Latino population, thus limiting the community's access to both testing and HIV prevention education (Ayala & Nuño, 2003). Studies also suggest that Hispanics are unaware that HIV/AIDS testing is not a uniform part of routine medical exams, and since most health providers do not view some of the most susceptible members of the community as "high-risk," the testing is under-administered (Kaiser Family Foundation, 2004a). As mentioned previously, after learning of their HIV-positive status, Hispanics are the least likely of all racial and ethnic groups to receive appropriate treatment. The overall lack of HIV-related information in Spanish which clearly illustrates the risk of acquiring the virus also contributes to the isolation of the Hispanic community from current HIV testing and care. Latinos are also often unaware of their rights regarding access to medical care and information in their language of origin as provided by Title VI of the Civil Liberties Act.

The only group of Hispanics routinely offered HIV testing are pregnant women. Due to the fact that many Latinos perceive HIV testing to be part of routine medical examinations, it is essential to gain a better understanding of the impact of perinatal HIV testing and perceptions of pregnant Latinas regarding HIV examinations. For example, a survey of Americans on HIV testing found that 22% of Latinos believed HIV testing to be a part of routine medical examinations (Kaiser Family Foundation, 2004a). By not publicly stressing the need for HIV screening among Hispanics, many will face an increased risk of infection due to a general lack of awareness. The risk increases since physicians typically remain unaware of the true burden of HIV on Hispanics and may be less likely to recommend HIV testing for this population. To illustrate the point, a national survey of sexually-active Latina teens found that 51% did not receive HIV counseling at the time of their gynecological screening (Kaiser Family Foundation, 2001).

In addition, linguistic and education-level barriers may inhibit Latinos from understanding the health-related information being provided during their health care visits. According to a recent analysis of the Behavioral Risk Factor Surveillance System (BRFSS), even when Latinos report having been tested for HIV, they are the least likely of all groups to have knowledge about the available treatment for those who test positive (Ebrahim, Anderson, Weidle, & Purcell, 2004). According to the authors:

The results of this study underscore the need to ensure that the contact of people with the health care system during a testing encounter be used to educate them about fundamental aspects of HIV/AIDS prevention and care.

This is of particular importance when working with limited-English-speaking Latinos who may have no access to Spanish-speaking providers. Interestingly, a comparison of state data from the aforementioned study regarding knowledge of available HIV treatment found that only 34.45% of the nation's Latinos live in states wherein less than 80% of the Latino population was aware of available treatment for HIV (Ebrahim et al., 2004).

Given that Hispanics tend to learn of their HIV/AIDS status late in its course, treatment should be viewed differently than for other racial and ethnic groups. Lack of insurance, underinsurance, and poor access to quality health care – as delineated above – place Latinos at greater risk of HIV-related morbidity and mortality. According to NASTAD's analysis of foreign-born immigrants in Los Angeles County, Latinos were the least likely to have known about their HIV status early in the course of their infection (Ayala & Nuño, 2003). Of all foreign-born Latinos interviewed, 47%

learned of the HIV status six or fewer months prior to their AIDS diagnosis, compared to 38% for U.S.-born Latinos, 25% for African Americans, and 23% for Whites (Campo, Alvarez, Santos, & LaTorre, 2005).

Even when Hispanics are aware of their HIV-positive status, they may be less likely to seek immediate care. For example, HIV-positive mothers who are heads of households may avoid or delay seeking care for themselves due to the responsibility they have for taking care of the family (Galanti, 2003). And even when access to health care is somewhat equalized, such as with patients in the U.S. military, baseline CD4 counts have still been found to be lower among Latinos, indicating more advanced progression of the disease (Paris, Brown, & Milazzo, 2002). Furthermore, higher viral loads and presentation with increased rates of major opportunistic infections were found among Latinos when compared to Whites (Swindells, Cobos, & Lee, 2002), contributing to advanced disease progression at the time of HIV/AIDS diagnosis as well as untimely death due to AIDS-related illnesses.

According to Ebrahim et al. (2004), populations with lower HIV prevalence may not seek testing due to the perception that they are not at risk. An analysis of the *National Health Interview Survey, 2000* concerning the barriers to HIV testing among U.S. Hispanics underscores this point. The authors found that two-thirds of Hispanics had not been tested for HIV and 88% did not intend to be tested in the future. In addition, large differences existed among Latino subgroups, with Puerto Ricans being the most likely to have been tested for HIV and Mexicans the least likely when compared to the subpopulations of Mexican Americans, Puerto Ricans, Cubans, Central and South Americans, and other Hispanics (Lopez-Quintero, Shtarkshall, & Neumark, 2005). The CDC recently published a report documenting the distribution and use of rapid HIV tests throughout the U.S. (CDC, 2005). Although it is promising to note that the 30-minute average time to get results may decrease the barriers experienced by those seeking testing, it would be interesting to determine the extent to which Latinos are currently receiving these tests.

## VI. CULTURAL AND SOCIAL BARRIERS INHIBITING ACCESS

### A. Overview

The literature identifies additional barriers to testing among Latinos which include stigma, aversion to testing, lack of knowledge, and fear of potential results. According to a report by the Hispanic Federation (Rios, 2005), specific barriers to HIV testing for Latino males include perceptions of not being at-risk and not having thought about being tested. Barriers for Latina females include lack of cultural support, knowledge, or skills needed to effectively communicate with their partners about sexual topics and vulnerability to HIV due to their male partners' high-risk behaviors (Gomez & Marin, 1996). Furthermore, findings from a national study of Latino youth showed that 39% would be concerned about other people's perceptions of them if they were to find out that they had been HIV tested. The same survey also found that Latinos did not get tested because they did not perceive themselves to be at risk (54%), don't like needles or giving blood (24%), don't know where to go for testing (20%), and were fearful of testing positive (11%) (Kaiser Family Foundation, 2004a). The causes for this lack of awareness of HIV/AIDS risk and related issues of stigma are further examined by the issues raised during the NCLR Latino Families HIV/AIDS Needs Assessment.

The changing transmission patterns of HIV/AIDS among Hispanics can be understood by examining specific cultural and social beliefs and practices shared by many Hispanic subgroups. The Needs Assessment identified common themes around sexuality, gender roles, and family structure, which help explain increased risk for HIV/AIDS among many Latinos, especially for

those living in poverty. In addition, the Needs Assessment, and subsequent studies that were presented during the Latinas and HIV/AIDS Summit, examined the role that various levels of acculturation and immigration status can play on increasing risk for the disease. Given the diversity of the Hispanic community in the U.S., great care must be taken in understanding the way that cultural and social dynamics relate to different Latino subgroups. For example, as the analysis on HIV/AIDS incidence and risk among Mexican migrant workers shows, specific situations, practices, and beliefs common to some Hispanic populations are not universal, and subsequently call for more nuance in assessing the virus's varying impact and transmission patterns among the diverse U.S. Hispanic population.

## B. Sexuality and Gender Roles

Traditional Latino culture and social practices tend to discourage open communication regarding issues of sexuality and the related themes of gender, sexually-transmitted diseases, and homosexuality. While the avoidance of these topics is common among many other racial and ethnic groups, there is a heightened sense among Latinos that such issues are taboo, and the stigma associated with STIs and homosexuality is exacerbated by rigid definitions of the role of the Latina wife and the Latino husband. Since sex is generally not discussed between married couples, particularly among those with more traditional values, conversations of condom use and/or other safe-sex discussions are even rarer and affect the critical communication and education of children on issues of sexual health. Evidence suggests that, in some cases, sexual stigma contributes to the incidence of Latinas being unaware of a husband's extramarital activities, or knowing but feeling unprepared to do anything about it. In the words of one participant in the NCLR Latino Families HIV/AIDS Needs Assessment:

*Many women are infected by their husbands. It is incredible how many housewives are infected and don't even know it.*

Finally, the stigma of homosexuality among many Hispanic subgroups may increase the secrecy – or denial – of HIV/AIDS among Hispanic men who participate in male-to-male sexual activity.

The clearest and most dangerous result of the stigma around discussing sexuality is visible through examination of contraception use. U.S. Latinos are shown to be the least likely of all other racial and ethnic groups to utilize condoms and other safe-sex practices that prevent AIDS and other STIs. Participants in the Needs Assessment stated that they were fearful of their partners' reaction to requests for condom use. Female participants reported that their male partners may become angry and even violent. In the words of one woman:

*I'm too scared to ask him to use condoms. He might think I'm unfaithful...and I'm scared of what he might do to me.*

The women in the Needs Assessment stated that they did not expect condom use among their male counterparts because rarely did a woman encounter a man who was willing to use them. One woman expressed a belief typical of participants that condoms, or STI protection and contraception in general, are not discussed in the relationship; she stated:

*I don't know how to ask him to use condoms. We never talk about those things.*

Even if condom use were to increase among Hispanics, the research suggests that additional steps would be required to reduce the rate of HIV infection. Although the rates of condom use in the U.S. have improved among all populations, Latinas are most likely to experience failure rates

when compared to all other racial/ethnic groups, pointing to a lack of education and communication on their proper usage (Jones, Darroch, & Henshaw, 2002; Piccinino & Mosher, 1998:). A high percentage of Latinas who use a contraceptive method use female sterilization (34%) followed by the pill (22%), which both offer no protection against HIV and other sexually-transmitted infections (Frost & Driscoll, 2006). Furthermore, research in Africa indicates that hormonal contraception may increase the likelihood of HIV-1 acquisition during unprotected intercourse (Lavreys et al., 2004).

Although comprehensive research is gravely lacking, certain Latino populations appear to be at higher risk of HIV infection due to lack of knowledge regarding safe-sex practices as well as exposure experienced within the context of their specific environments in the U.S. A study of migrant women by Organista, Organista, & Soloff (1998) indicated considerable lack of knowledge of condom use. While these participants did report positive attitudes toward condom use, only 23% of the sexually-active women had used them with their partners during the past year. Social norms did not permit women to carry condoms because such women would be considered promiscuous. Not surprisingly, 75% of participants reported never carrying condoms.

These barriers to communication and safer sex have devastating results for Hispanic women and their families. Many Latinas are unaware of their risk for HIV until their partners become ill, or they opt to be screened during pregnancy (Rios-Ellis, 2003). The majority of Latina HIV-positive women interviewed during the NCLR Latino Families HIV/AIDS Needs Assessment, for example, were unaware of their partners' extramarital sexual behaviors with men and/or women as well as previous or current drug use. As a result, these women did not learn of their exposure until late in the process of the disease. This is particularly true among Latinas who, for reasons ranging from cultural mores and economic dependence to domestic violence, may not question a partner's sexual behaviors, assume fidelity, or perceive themselves as unable to inquire as to their partner's HIV risk behaviors.

In fact, to admit the infidelity of one's male partner is often perceived as having personally failed in providing him satisfaction within the relationship, and condom use acknowledges a lack of *confianza* (trust) which can lead to perceptions of infidelity by both males and females. Given the many barriers Latinas experience in acknowledging and confronting the potential infidelity of their male counterparts, the popularity of the common saying, "*Ojos que no ven, corazón que no siente*" (Eyes that don't see, heart that doesn't feel), should not be surprising. This finding did not hold true for the majority of Latino male participants who were aware of their risk behaviors and whose reactions to the knowledge of HIV seropositive status would best be described as disappointment as opposed to shock. The results of this shrouded secrecy between husband and wife around sexuality, however, significantly raises these individuals' risk for contracting HIV/AIDS and other STIs.

Heterosexual HIV infection, just as it first appeared in Mexico and many other Latin American countries, is becoming very prominent among Hispanic married women and those with long-term male sexual partners. Although heterosexual contact with a primary partner is not recognized as a high-risk behavior by the CDC or within most public health circles, this type of transmission to unassuming Latina wives and long-term partners presents real challenges to overcoming the spread of the virus among certain Hispanic subgroups. Many Latinas with HIV/AIDS have had sex with only their husbands or long-term sexual partners. Changes in individual behavior, with the exception of leaving their families and remaining abstinent for life, would therefore not be applicable or appropriate or even possible given many Latinas' economic dependence on their partners. The situation is exacerbated among Latinas who are linguistically isolated, of low socioeconomic status, and dependent on their male partners for economic survival and social

access into society. In addition, women's traditional gender roles which place high value on family, procreation, and fidelity often provide a strong message to Latinas that women should "find a good man and stick with him" (Rios-Ellis, 2004).

A landmark study of Mexican migrants, for example, found that women are committed to believing in their partner's fidelity, even when there are signs to the contrary (Hirsch et al., 2002). This study also revealed the variance of expectations within younger and older married couples, with the older couples reporting that they place greater value on *respeto* (respect) and the younger couples on *confianza* (trust). This study underscored the historical error of relying on an expectation of monogamy as an HIV prevention strategy, particularly among women whose partners spend extensive time away from home, as it provides a false sense of security that is often shattered when men return from the U.S. HIV positive. The fact that safe sex has become analogous to sex with one's primary partner leads women in "stable" relationships to believe that they are protected.

Women discussed the barriers they experience to condom use, and many were found to believe that condoms were ineffective and interfered with natural and/or intimate sex (Hirsch et al., 2002). Furthermore, while women over the age of 35 were found to tolerate infidelity provided it did not lead to embarrassment, younger women were found to prefer not to know and to interpret condom use and negotiation within their relationships as an acknowledgment of a lack of trust and intimacy as well as license for infidelity. Although prevention strategies must encourage more open dialogue on sexuality, and further empower Latinas to speak more openly about extramarital activity, negotiate the use of condoms, and encourage STI testing with their partners, these responsibilities should not be expected only of women and should be done within a culturally-relevant manner. Knowing that *respeto*, *familismo*, *confianza*, and *personalismo* are all qualities that are valued within the culture, utilization of these concepts in prevention messages and outreach programs would do a great deal to create strategies that resonate with the communities being served (Hirsch et al., 2002; Karliner, Edmonds Crewe, Pacheco, & Cruz-Gonzalez, 1998; Rios-Ellis, 2003).

Latina participants in the NCLR Latino Families HIV/AIDS Needs Assessment largely confirmed these findings from the literature, pointing out both the cultural convention of their submissiveness and the *macho*, dominant status of their male partners. The women implied that they expected to be taken care of and expressed their disillusionment upon the failure of the male partners in the relationships. For example, one woman said:

*No matter how much they say they love you, and you're the woman of their life, and you are the mother of their children...they will not really take care of you.*

Another Needs Assessment participant, typical of many, stated:

*We're at risk because they're 'machos.' They like to control us. They make the decisions and it's all about them...we're just there for them. We clean, we cook, we take care of the children, we stay at home, and we give them what they want.*

Women participants in the Needs Assessment expressed their role in relationships as being culturally bound, and that the expectations of marriage and motherhood had been somewhat disappointing. Many of the women are married to men who are repeatedly unfaithful, and many others had been left by their husbands to survive economically with few or no job skills. As one Latina stated:

*I was always taught to find a man and stick with him...no matter what.*

The connection between cultural expectations of women and self-esteem and how the combined force translates into HIV risk behavior was found throughout the interview and focus group transcripts. In the words of one female Needs Assessment participant:

*Most Latinas need to learn how to love themselves. They don't think they are anything until they are married.*

Male participants in the Needs Assessment confirmed the importance of respect in the relationship, even to the extent of confusing the concept of "respect" to justify infidelity. In the words of one male participant:

*I like to have a certain kind of sex, but to even talk about this with my wife would show a lack of respect (una falta de respeto).*

While evaluation of the sexual and reproductive health issues of Hispanic women is essential to controlling the spread of HIV/AIDS, the role that men play in the spread of AIDS cannot be ignored. Traditional gender roles such as *machismo* and *marianismo*\* have been shown to increase Latinos' risk for HIV infection. *Machismo* is generally referred to as the negative patriarchal characteristics of Hispanic men which can include violence, overbearing control, and sexual aggression. One of the earliest descriptions of *machismo* sexuality by Stevens (1973) still holds true for many women today, "*Machismo* requires sexual aggressiveness proven in numerous ways, including through amorous conquests." He goes on to describe "*the casa chica*" wherein a second partner and their children would reside. What this illustrates is the quiet expectation of male infidelity, and the "good" woman's role of maintaining the household while remaining dutiful and spiritually superior to her husband's antics in the "*casa principal*" (Wood & Price, 1997). One Needs Assessment participant shared this perception:

*Latino culture teaches women to stay with their husbands, even when they find out that they are cheating. Latinas are taught that if the husband provides you with a house and food, you must stay with him and put up with whatever he does.*

The idea that the "*casa principal*" is in some way supposed to provide security is often shattered when HIV infection enters the home. In the words of an HIV-positive woman in the NCLR Latino Families HIV/AIDS Needs Assessment:

*I can't believe that this happened to me. I never left our home. He brought this (HIV) into our home and now I am infected. What will happen to our children now?"*

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\* The stereotyped gender role of females in Mexican society.



Another woman related infidelity to condom use and gendered expectations:

*I think our culture puts women at risk because the men don't want to wear condoms. If they were going to be monogamous and you could be sure there wouldn't be a need for that, but these men...I have no respect for...for a man who cheats. I don't think these men use condoms, and a lot of the times the women don't know and they think that their men are faithful because they come home from work every night.*

The reinforcement of the most negative elements of *machismo* is often increased when immigrant males come to the U.S. and are confronted with new challenges and stressors which may leave them feeling emasculated. As a result, in certain Hispanic communities, there can be an increase in domestic abuse, infidelity, and male dominance within the family. Likewise, these behaviors can lead to more secrecy around sexual behavior and increase the stigmatization and denial of MSM practices, which can increase HIV/AIDS risk. Just as multiple female conquests can be viewed as status among heterosexual males, research has shown that Latino men who have sex with men also gain status in proportion to the number of male sexual partners they have (Casas & Casas, 1994).

Studies of Latino MSMs have demonstrated that Latino males, particularly Mexicans, who have sex with men do not often classify themselves as homosexual if they are the active or inserting partner (Carrier, 1995; Carrier & Magaña, 1991). Although the receptive partner may classify himself as homosexual, he may not since rigid definitions of sexual orientation may not prove to be viable categories among Hispanics of different cultures. Furthermore, separation from family and isolation from known social support mechanisms may lead to other forms of sexual expression, and these may be exacerbated due to substance use (Chesney, Chavira, Hall, & Gary, 1982). Consequently, homosexual Hispanic males or those with a preference for sex with other males attempt to live a heterosexual lifestyle for as long as they can to avoid the social stigma of being gay in a homophobic environment and culture. In a study of gay, bisexual, and heterosexual self-identified men, the array of sexual behaviors across the categories was great with more than 70% of the sample engaging in both insertive and receptive anal sex (Doll et al., 1991).

The broader context of marginalization and its links to alcohol and drug use, other high-risk activities, and Latino male sexual behaviors also warrants further understanding. This is particularly relevant among immigrant workers who have left their families in their respective countries of origin to work in the U.S. Alcohol and drug use can lead not only to high-risk behaviors but also to poor adherence to HIV treatment (Petry, 1999). The stigma potential does not prevent males from having sex with other males, including those infected with HIV, particularly when away from their primary family. However, the combination of stigma and *machismo*, coupled with the CDC's categorization methods, undermines traditional HIV education and awareness efforts targeted to Latino males. The false security of *machismo* in a difficult environment does not result in the vulnerability needed to admit risk for HIV for most Latinos. In the words of one MSM from Mexico:

We don't put words on everything like you all do. We don't have all the labels that they have in America to describe ourselves....Everyone knows me [in Mexico]. Some people have diseases and some people don't (Smith, 2005).

Finally, for both Latino men and women, sexual stigma and taboo can negatively affect HIV/AIDS treatment as well as its aforementioned impact upon prevention. A qualitative study of African American, Puerto Rican, and White HIV-positive women who had delayed HIV care for three months or longer following initial diagnosis found that participants delayed their care due to three psychological responses to knowledge of their HIV status: denial of their status, fear and anxiety related to their illness, and chemical use and dependency to diminish the emotional strain of having HIV (Raveis & Siegel, 1998). Stigma has been found to be a principal barrier to Latinas seeking HIV care immediately following diagnosis (Campo et al., 2005). One case of a young single mother infected by her husband, recently deceased, reflects the potential gravity of the stigma. Due to the fact that she was accompanied by family members to the hospital emergency room as a result of illness, she did not disclose her HIV status to the attending medical personnel. When she returned home after being prescribed an analgesic, she died, leaving a two-year-old HIV-positive orphan (E. Gomez, personal communication, 2005).

According to Campo et al. (2005), cultural factors that may result in delay of HIV diagnosis and care include maternal role as a caregiver rather than a care-seeker, acceptance of infidelity, stigma associated with HIV infection, *machismo*, *fatalismo*, substance abuse, limited education, and mistrust of the medical community. In addition, stigma has been associated with reluctance to disclose HIV seropositive status among Latino gay males to family, friends, and partners (Mason, Marks, Simoni, Ruiz, & Richardson, 1995).

Several studies have looked at HIV/AIDS program completion and shown that Latinos, especially young Latinos, are the most likely of all racial and ethnic groups to drop out of programs. The National Institute of Mental Health Multisite HIV Prevention Trial found that the most significant factors predicting attrition were ethnicity, employment, unstable housing, and being 25-35 years of age. Latino subjects were found to be significantly more likely to drop out of the program. A University of Maryland study of a community-based, culturally-specific HIV risk reduction intervention in Chicago found that significant predictors of program participation included being older, unemployed, having higher risk reduction behavior intentions score, and lower level of depressive symptoms. Mexican women were more likely to participate than Puerto Rican women (Kim, Peragallo, & DeForge, 2005). Due to the high rates of depressive symptomology among Latinos, particularly if they are HIV-infected, mental health screening is now becoming a recommended practice among AIDS Service Organizations serving Latino-dominant populations (Rios-Ellis, 2005). This is of particular relevance given that those with dual diagnoses are more likely to have lower CD4 counts, higher viral loads, difficulty adhering to medical regimens, and more frequent engagement in risk behaviors (Salas, Jones, Garcia, & Ellis, 2005). The following quote describes the contrast between the gender expectations of an HIV-positive Latina participant in the NCLR Latino Families HIV/AIDS Needs Assessment and her life now with HIV:

*A Latina usually gets married in white, and has never been with another man except her husband. When she gets infected, that woman cannot comprehend what went wrong and she goes through unimaginable pain and anguish. The only thing that woman can say is how she loved and adored her husband.... This is the life of HIV-positive Latinas: depression, disdain. The life of an HIV-positive Latina is a scorned life.*

## C. Family Involvement

Largely as a result of sexual stigma and lack of exposure to sex education and teaching skills, Latino parents are consistently found to experience difficulty discussing sexuality and contraception with their children (Sangi-Haghpeykar, Horth, & Poindexter, 2001). One Needs Assessment participant described the difficulty experienced by Latinas regarding the sexual/reproductive education of their children:

*Many times it's very difficult when parents try to educate their children about things because the kids learn things on their own by being in the streets. It gets to the point that the kids tell us they don't want to hear anything from us because they think they know it all. Talking to your kids about sex is extremely difficult because it's still considered a taboo. Kids are curious; they want to know about sex. It's difficult when the woman is a stay home mom. That woman never leaves the home so how can she educate herself? How can she find out that she is at risk for infection?*

Perceived parental inhibition regarding sexual education as reported by adolescent Latinos has been found to contribute to low rates of condom use (Whitaker, Miller, May, & Levin, 1999). Upon examination of family functioning, Velez-Pastrana, Gonzalez-Rodriguez, & Borges-Hernandez (2005) found that sexually-active Latinos aged 12 to 16 were more likely to report low levels of parental involvement. Villarruel (1998) found that Latina girls were told to protect themselves but were not informed how to do so. Alternatively, research demonstrates that adolescents who communicate with their mothers regarding peer attitudes toward condom use are more likely to use condoms (Pick & Palos, 1995). A study of Latinas aged 19 to 21 found that both timing and quantity of parent-child sexual communication to be influential on sexual initiation and the use of condoms. Participants who reported good communication patterns with their parents were less likely to have initiated sexual intercourse and more likely to use condoms consistently if sexually active (Hutchinson, 2002). This study also found that only 53% of Latinas reported parental sexual communication prior to first sexual intercourse, underscoring the need for increased parental involvement in sex education and communication within the family setting.

Findings from the NCLR Latino Families HIV/AIDS Needs Assessment confirmed that little or no sexual education or communication occurs within the multiple contexts of families. The overwhelming majority of the participants had not received information from their parents regarding sexuality and reproduction, and female participants were also likely to report no previous knowledge of sex prior to marriage. The participants stated that issues of sexuality are still viewed as taboo and that these issues are very difficult to discuss. In the words of one participant:

*My family didn't teach me anything about it. My mother thought that if I came to the door if a guy came to visit me, that it was prostitution, because only prostitutes do that.*

Another woman from the Needs Assessment defined her role as a woman as not having to “take care of these things.” In her words:

*My mother never taught me to take care of myself. Women never thought about risks. In our culture many of the women don't even know what a condom is.*

Although participants reported receiving little sexual and reproductive education from their parents, the desire among the Needs Assessment participants to better educate their own families and children was great. According to another female participant:

*Our parents didn't teach us about sex. In our culture we don't talk about these things. I want to be different with my children because I don't want them to lack the information I was missing.*

#### **D. Acculturation and HIV/AIDS**

Studies have found acculturation to be strongly related to both health care behavior and individuals' ability to utilize health care resources. Acculturation has also been associated with healthier behaviors, a greater knowledge of health issues, and greater likelihood of seeking treatment (van Servellen, Chang, & Lombardi, 2002). Although access to care and insured status may increase with acculturation, HIV risk may also increase. Studies have shown that acculturation has a negative impact on illicit drug use among adults, pregnant women, and adolescents (Amaro, Whitaker, Coffman, & Heeren, 1990; Gfroerer & Tan, 2003; Vega, Kolody, Hwang, Noble, & Porter, 1997). In addition, high levels of acculturation have been associated with an increased number of sex partners, greater incidence of unprotected sex, and a higher number of unintended pregnancies (Adam, McGuire, Walsh, Basta, & LeCroy, 2005; Ebin et al., 2001; Romo, Berenson, & Segars, 2004). In one particular study, Spanish-speaking youth aged 12 to 18 were found to be the least likely to have initiated sexual intercourse, while English speakers were the most likely to have done so (Adam et al., 2005). Moreover, a study among Mexican-born adolescents found that lower acculturation was associated with older age at sexual initiation and fewer lifetime partners and unintended pregnancies (Kaplan, Erickson, & Juarez-Reyes, 2002). The NCLR Latino Families HIV/AIDS Needs Assessment compared levels of acculturation to the number of sexual partners in the past two years and found that more acculturated participants were more likely to have had a greater number of partners. Despite the relatively small sample size – due to the qualitative nature of the study – this finding was statistically significant at  $p > .05$ .

The impact of acculturation has also been found to have a negative impact on the risk behavior of HIV-positive Latinos. Marks, Cantero, and Simoni (1998) found that increased acculturation was related to engaging in unsafe sex in participants' most recent sexual encounter since testing positive for HIV. Among HIV-positive Latino males, substance use (mainly alcohol) contributed to the risk behavior. Due to the fact that Hispanic women are often reluctant to initiate use of condoms due to cultural expectations, lack of perceived vulnerability to HIV, fear of violence, lack of knowledge, and potential loss of trust or the relationship in its entirety, the cognitive status of the male may dictate whether or not the encounter is protected.

In order to create more effective HIV prevention strategies targeting Latinos, the complex associations between acculturation, relationship status, age, and HIV risk must be better understood. Hirsch et al. (2002) found that differences in relationship expectations exist between older and younger women and that both are at risk for HIV infection due to several factors. In a study of HIV-related risks among Latinas of different levels of acculturation, older Latinas were found to be less likely to use barrier methods or engage in HIV risk reduction behaviors. Although marriage has been traditionally associated with decreased HIV risk, it was found to heighten risk and decrease behavior change (Newcomb et al., 1998), thus indicating the need for targeted HIV strategies for Latino families.

The effects of acculturation on specific sexual practices have been studied to a limited degree. It has been found that condom use was associated with being single, HIV-positive, and a younger age. Oral sex was associated with having experienced anal sex, higher acculturation, time in the U.S., U.S. citizenship, and higher education. Furthermore, anal sex was associated with having noncitizenship status, lower income, and being married, indicating that Latinas with the least economic resources may be at the greatest risk (Vargas Carmona, Romero, & Burns Loeb, 1999). A participant of the NCLR Latino Families HIV/AIDS Needs Assessment confirmed these findings as she shared her experience with her husband:

*I don't like it but he says it's natural. I'm afraid that if I don't do it he will just go somewhere else. Then what would I do?*

Furthermore, research on other health conditions has shown that the common perception that immigrants will become more wary of disease and therefore more careful as they acculturate is not necessarily true. In a study of acculturation and health beliefs regarding tuberculosis (TB) among Mexican immigrants, increased acculturation was found to decrease the perception of the severity of TB (Rodriguez-Reimann, Nicassio, Reimann, Gallegos, & Olmedo, 2004). It is essential that the perceptions of HIV among Latinos of various levels of acculturation be investigated to better guide prevention campaigns and outreach programs.

## **E. Migrant Workers and HIV Risk**

Subpopulation and regional consideration is warranted as Latinos represent diverse groups of persons with distinct origins and the spread of the epidemic varies across Latino subgroups. Specific socioeconomic groups of Latinos in given regions are experiencing increases in HIV infection. For example, HIV prevalence among Mexican migrant workers has been found to be three times as high as the general population with as many as 1% testing positive for the virus. The Commission to Prevent Infant Mortality estimates that 5% of farmworkers are infected with HIV/AIDS (UNIDOS, 2004). In a pilot *promotores de salud* (lay health educators) project in Florida, the Farmworker Justice Fund reported that 11 of 92 farmworkers tested positive for HIV.

Latino migrant workers are at high risk for HIV infection due to many aspects of the migrant experience in the U.S., in addition to other risk factors associated with low-income and minority populations. Migrant workers tend to be young men far from home for long periods of time. The resulting loneliness and disruption of social, familial, and sexual relations experienced by migrant workers may lead to use of commercial sex workers and increase their risk for substance abuse and mental health issues. Further contributors to risk include low-paying, inconsistent, and sometimes dangerous labor; low levels of education, low literacy, and high rates of English non-proficiency; undocumented status; and low access to health and social services.

Many migrant workers also experience inadequate housing, the resulting stress of which has been proven to increase risky sexual activity such as the sharing of sex workers, drinking and/or drug use, and mental illness. In fact, multiple studies show that mental health issues (Organista & Kubo, 2005), substance abuse, and needle-sharing for injections of illegal drugs and vitamins or antibiotics are more common among migrant workers. A survey of 500 predominantly Mexican migrant farmworkers in California found that 28% of men and 16% of women had lifetime rates of diagnosable psychiatric disorders, and a 2000 study found that 9% of the sample had a lifetime prevalence rate of alcohol dependence and 12% had a lifetime prevalence of any substance abuse/dependence disorder (Denner, Organista, Dupree, & Thrush, 2005). In another study, more than half of the participants interviewed had used at least one illicit substance within the 12 months previous to the survey.

This research underscores the risk for HIV infection among Mexican migrants on both sides of the border (Barclay, 2005). In addition, migrant and emerging populations are often living away from their primary residences. Repeated or extended travel away from communities of origin has been associated with HIV infection. When working with mobile populations, additional guidelines require the merging of prevention services, treating each area as if opposite sides of the border were extensions of one community (Family Health International, 2003).

As in other countries with high-traffic border areas and large migrant populations where the spread of disease is more rapid and far-reaching, transmigration of Latinos to and from the U.S. has been shown to increase HIV infection among women and families in their countries of origin. This is particularly true in rural Mexico, wherein 25% of AIDS cases were among men who had traveled to the U.S., compared to only 6% among Mexican urban AIDS cases (Magis-Rodríguez, del Rios-Zolezzi, Valdespino-Gómez, & García-García, 1995). Another study examining the spread of AIDS cases in Mexico found that one-third were from Mexican states with the highest out-migration to the U.S., and that one in ten cases reported having lived in the U.S. (Organista & Kubo, 2005). Among persons with AIDS in two rural areas of Mexico, more than 50% of those in Degollado, Jalisco and 39% of those in El Fuerte, Michoacán had been to the U.S. (Bronfman & Moreno, 1996). Since HIV/AIDS is relatively new in these Latin American communities, HIV prevention, education, and treatment are scarce if nonexistent. One participant in the NCLR Latino Families HIV/AIDS Needs Assessment expressed her concern over this phenomenon:

*They go back and have sex with their wives, and many times they infect their wives. Sometimes, the wife becomes pregnant, and even then they don't get tested because in Mexico it is not very common to get tested for HIV.*

The poignancy of the widely-used phrase “HIV/AIDS knows no borders” is increasingly felt among communities with very few resources with which to battle infection. It is essential that we learn from the early mistakes made in the epidemic in Puerto Rico. There the virus was allowed to escalate considerably prior to the government’s allocation of prevention and management resources. It is critical that these lessons be applied to the underserved in the U.S. before the epidemic is allowed to escalate further. According to research projects currently being conducted along the border and among migrant workers in the U.S., HIV infection is on the verge of a rapid escalation in this population, and the prevalence observed in Mexican migrant workers may eventually be mirrored by the U.S. Latino population overall (Kaiser Family Foundation, 2004b).

The high rates of unprotected sexual activity among multiple partners, an unfortunate reality among migrant communities in all societies, have the potential to significantly increase the spread of HIV/AIDS among Latino migrants. A study of the sexual behaviors of international migrants from Mexico found a statistically significantly higher number of sexual partners and use of injected drugs for nonmedical reasons among both male and female international migrants (Magis-Rodríguez, Gayet, et al., 2004). The same study also found a high use of vitamin B injection among both international migrants and nonimmigrants, which has been found in previous studies (McVea, 1997). Male participants in the NCLR Latino Families HIV/AIDS Needs Assessment confirmed some of these findings:

*Many times when we are drunk we sleep with prostitutes. To tell you the truth, we don't even think about condoms when we are drunk. I never saw this in Mexico, but here we drink together and share needles and this is where the prostitutes come onto the scene.*

Another reported the combination of needle-sharing and tattoos as a risk:

*The problem we have is that most of us often share needles, needles that could be contaminated. Something else that puts us at risk is tattoos. Most of us here have tattoos.*

Organista et al., (1998) found that extramarital sex is especially pronounced among Mexican migrant men, with 27% of married men and 82% of single men reporting multiple sex partners during the past year. These figures are considerably higher than the rates among married and single U.S. Latino men (18% and 60%, respectively). Approximately 10% of the sample reported sex with other males, and 11% had received money for sexual favors. Furthermore, 58% of married men and 85% of single men reported not using condoms with casual and steady partners. Participants reported that 25% of their partners were sex workers, and four-fifths of them stated that they were under the influence during their last sexual encounter. Study participants revealed that, despite few negative attitudes toward condoms and high condom efficacy, they are only sanctioned and promoted to a limited degree. The Needs Assessment further examined HIV/AIDS risk among migrants and confirmed the results of other studies. Female sex workers were reported to frequent residences occupied by multiple males, and HIV-positive Latino male sex workers reported that it was not uncommon to be solicited by married Latino men (Rios-Ellis, 2003). One male participant reported:

*We don't even have to go to look for them (sex workers). They just knock on our door and come in because they know where we live and they know we are lonely.*

Economics, isolation, distance from family, and the stress of life as a migrant were reported by participants of the NCLR Latino Families HIV/AIDS Needs Assessment to significantly increase these behaviors.

## **F. Immigration Status**

Immigrant Latinos also must face ineligibility for health programs, fear of deportation, or inability to achieve U.S. residency and citizenship. Undocumented Latinos are ineligible for almost all publicly-supported health benefits except for limited emergency services. In addition, undocumented Latinos may experience additional barriers to HIV testing due to the recent increase in deportation raids, which have resulted in substantial decreases in clinic and hospital visits and appointments, many for preventive care such as prenatal visits (National Council of La Raza, 2004b).

Even when documented, immigrant Latinos are the least likely to have health insurance and often cannot afford the time missed from work to attempt to access care. Furthermore, many categories of legal immigrants are ineligible for Medicaid and Medicare. Moreover, in the case of certain legal immigrants, their identification as an HIV-positive case or receipt of public benefits could adversely impact their current immigration status, their ability to petition for family members abroad, and/or their eventual transition to U.S. citizenship. Once HIV/AIDS is diagnosed, certain immigrants in the U.S. under color of law are rendered ineligible for legal permanent residency and, therefore, for Medicaid benefits (Morales, 2003). Taken together, these factors undoubtedly deter many immigrant Hispanics from seeking HIV testing or, once diagnosed, from seeking or obtaining treatment.

## G. Prevention, Outreach, and Exposure to HIV Campaigns

Historically, approaches to preventing HIV infection have included reduction of multiple sex partners, promotion of monogamous relationships, abstinence or safer-sex practices (e.g., condom use), and screening for and treating sexually-transmitted infections (Reid, 1992). Unfortunately, just as in underserved countries, these strategies have little relevance for underserved Latinos and other communities with the greatest risk for HIV infection in the U.S. today. Hispanic and African American women, in particular, are gravely neglected by current prevention strategies that target gay men of color and focus only on women who are pregnant, engage in sex work or injection drug use, or experience a combination of these factors. Although women have perhaps the most influential role in educating their families and communities, little is being done to target them as they are often perceived as “low-risk.” Furthermore, traditional prevention strategies primarily focus on individual behavior change. These models fail to acknowledge the many constraints that inhibit safer-sex behaviors. According to Janz and Becker (1984):

These models are limited to accounting for as much of the variance in individuals’ health-related behaviors as can be explained by [only] their attitudes and beliefs. It is clear that other forces influence health actions as well.

One of the major foci of the NCLR Latino Families HIV/AIDS Needs Assessment was to better understand the failure of current HIV/AIDS prevention efforts and messages to impact underserved Hispanic communities, as well as to learn more about how messages could better resonate within these communities. The first two years targeted women exclusively, and both men and women participated in the third year of the assessment. A total of 259 Hispanic women and 63 Hispanic men participated. In an effort to determine the extent of media exposure and recall of HIV prevention messages among at-risk and HIV-positive Latinos, participants were asked to provide information regarding their exposure as well as direct recall of information acquired through media channels. Participants were first asked to recall messages and discuss their perceived target audience and issue. They were then asked to consider the cultural and linguistic relevance of the HIV/AIDS messages for which they reported recall and to provide their recommendations for the development of prevention messages and HIV outreach and educational strategies.

The most glaring finding of the Needs Assessment was the lack of exposure to media messages among participants, and the extent to which HIV prevention was perceived as only pertaining to certain populations, namely gays, IDUs, and sex workers. When participants in the Needs Assessment were asked about their exposure to HIV prevention messages, not one participant could remember seeing a prevention message which targeted Latinos. With the exception of participants in New York City and Puerto Rico, little to no HIV/AIDS-specific recall was detected. The most frequent response could be best summarized by the following statement:

*There are very few commercials that talk about HIV, but I haven’t seen any that target Latinos. I can’t remember any commercials on television or on the radio.*

Participants in virtually every session were in agreement with statements such as:

*There aren’t any commercials directed at Latinos. We don’t have the information we need. We don’t see commercials for Hispanics about HIV.*



Furthermore, Latino Needs Assessment participants differentiated themselves from those of other minority groups, describing a sense of invisibility of Latinos in health media:

*There are no commercials that are directed at Latinos, like there is for Blacks. You don't hear anything special directed to us.*

Although there was little to no recall of HIV prevention messages, several focus group and interview participants did recall pharmaceutical messages targeting the HIV-positive. The following quote exemplifies this finding:

*Take Combivir. Take Retrovir. The ones I see are made by Glaxo. They advertise that if you take these HIV drugs that you will live a better life.*

Participants also reported that messages targeted gays and “(White) Americans” and not Latinos. The fact that Latinos across multiple sites remember HIV/AIDS management media messages and have no recall of HIV prevention messages indicates a failure of the public health system to reach out to those most vulnerable to infection.

The few participants who did remember HIV messages, mainly in New York and Puerto Rico, said that they were in relation to pregnancy, IDU, or condoms. Participants in New York complained that the messages were often in English. A few other sites mentioned having been exposed to messages on other health topics such as cancer. HIV-positive participants stated that awareness would have made a difference in their status. The following is typical of the responses of several HIV participants:

*More orientation would have helped me prevent HIV, because when I did learn about it, I was already positive.*

Furthermore, the perceptions that HIV was just an issue for homosexuals, IDUs, and sex workers resonated throughout the NCLR Latino Families HIV/AIDS Needs Assessment, thus emphasizing the need for inclusive and non-stigmatizing HIV prevention messages. In the words of one HIV-positive woman:

*This disease has been stereotyped. Everybody thought that this disease only affected gay males, prostitutes, and drug addicts. Nobody ever thought about what my husband or boyfriend could be doing.*

Thus, the literature and Summit findings show, and the Needs Assessment participants confirm, that the disproportionately high rates of HIV/AIDS among Hispanics is largely a function of increased transmission of the virus to Latinas through heterosexual contact, and of rapidly rising infection rates of Hispanic youth. Furthermore, both the academic research and participants demonstrate that structural barriers to health care generally and to HIV/AIDS services in particular are serious impediments to reducing the incidence of the disease, and that a broad array of cultural, social, and policy issues also inhibit effective responses. Finally, the failure of current and previous prevention and outreach strategies to effectively target at-risk Latinos is apparent, not only from the disproportionate impact that HIV/AIDS has on Hispanics at a time when such impact is being reduced for most other ethnic groups, but also based on the firsthand impressions of HIV-positive and at-risk Latinos themselves as represented among the Needs Assessment participants.

## VII. PROMISING STRATEGIES

### A. Overview

Notwithstanding the grim picture illustrated above, both the academic research and the real-life observations of affected Hispanics strongly suggest that effective Latino-focused HIV/AIDS prevention and outreach strategies are possible, provided that they are carefully designed to address the cultural, social, and other factors that place this community at disproportionate risk.

The following subsections examine the relatively sparse literature identifying effective approaches for reducing Latino HIV/AIDS infection rates, as well as practices that have demonstrated results in the contexts of other infectious diseases. In addition, inferences drawn from research in related fields are highlighted, and potential approaches that might be applied to the fight against HIV/AIDS are identified. Finally, this white paper draws heavily from the observations and experiences of the actual “target audience” for potential social marketing campaigns and other health interventions – as exemplified by participants in the NCLR Latino Families HIV/AIDS Needs Assessment – to identify promising strategies for development, testing, and dissemination of national HIV prevention messages targeting Latinos.

### B. Family-Centered Paradigm

Developing and delivering culturally- and linguistically-appropriate HIV/AIDS prevention services to Latinos requires an understanding of many different perceptions, attitudes, and behaviors that are deeply influenced by diverse Latino cultures and values. By utilizing the more often than not strong family structure within the Latino community, communication about sex as a means to protect the family unit from this health risk can be emphasized, as can communal support of those who are HIV-positive. The initiation of sexual and reproductive communication within the family setting is difficult, not only for Latino families but for others. However, because sex education is not a fundamental part of school curricula and low-income parents are less likely than their middle-class counterparts to discuss sex with their children, families must be targeted (Zambrana, Cornelius, Sims Boykin, & Salas Lopez, 2004). Furthermore, given the linguistic isolation that many Latino parents experience as their children acculturate (Suro, 1999), this task becomes even more difficult. However, the changing context of risk experienced by a Latino immigrant family may also give rise to opportunity, as parents can be encouraged to become more involved given the need to protect their children from harm in a new environment.

Despite the traditional conservatism of many Latino families, the dynamic strength which exists within many Hispanic families can be a tremendous resource to curbing the disease and improving Latino HIV/AIDS care. Across Latino subpopulations, the family has long been viewed as the most influential factor in their lives as well as central to the health and well-being of individuals (Romero, Robinson, Haydel, Mendoza, & Killen, 2004). As in many cultures, a great deal of information regarding health and behavior is learned within the family. This is perhaps more pronounced within the Latino culture, where individualism is less valued than *familismo*, and family unity is often key to successful adaptation and advancement in the U.S. The strength of *familismo* has been demonstrated through studies which report Latino youth as having greater respect for their parents’ values and ideas when compared to their Anglo counterparts (East, 1998). Families with high degrees of *familismo* are characterized by positive relationships, social support, unity, interdependence in carrying out responsibilities related to daily living, and living in close proximity to extended family members (Romero, Robinson, et al., 2004).

Participants in the NCLR Latino Families HIV/AIDS Needs Assessment found that messages promoting open communication within families on sexuality and the various activities that increase risk for HIV/AIDS were more effective, for example, than negatively-constructed messages that warned against individual practices – such as unprotected sex and IDUs. To be effective, participants asked that HIV education be incorporated into programs that remove the stigma and invite participation based on responsible parenting and/or self-care. One woman recommended that media messages to prevent HIV be family-inclusive. She stated, “It’s a problem that affects the whole family.”

Another woman discussed the need to be inclusive of single-parent families:

*We need information targeting single mothers and divorced women because there are plenty of them in the Latino community. We need to learn how to involve those women in programs because when they are alone it is easy for them to sleep around.*

A family focus also has the potential to influence health-seeking behaviors, including HIV testing and HIV/AIDS management. Latino families are often extended and are not limited to the nuclear paradigm most often reflected in U.S. mainstream society. Research conducted among families of HIV-positive and “at-risk” HIV-negative women in four northeastern U.S. states found that Latinas were more likely than all other Whites and African Americans to have a family member with HIV (21%, 34%, and 49%, respectively) and more likely to have a family wherein more than one person was infected (17%, 25%, and 42%, respectively). Furthermore, Latinas were more likely to know and have extended family members with HIV, thus underlying the close-knit nature of the Latino family and the potential impact of Latinas’ role in both HIV prevention and care (Fiore et al., 2001). This research, although limited to one U.S. region, demonstrates the need for further investigation of the potential impact of family involvement in HIV prevention and management.

The importance of family support among HIV-positive participants in the Needs Assessment was reinforced continuously. When there is a lack of understanding regarding both infection and the transmission of the virus, family reactions can be hurtful; one participant shared her experience:

*Since they found out about my infection, they almost never call. They are afraid I will infect them. When they invited me to their home for Christmas dinner, they served my food on paper plates with plastic utensils.*

Conversely, however, when the family is effectively mobilized, it can provide tremendous support for effective disease management, as another Latina participant noted:

*I give thanks to God for the support of my family. Their understanding and love have helped me greatly in managing my illness.*

### **C. Latina Empowerment as a Component of the Family Focus**

While much more work needs to be done to create effective programs that empower Latinas to initiate sexual conversation and overcome traditional stigma associated with such conversations, early evidence continues to show the effectiveness of utilizing political empowerment as a health education strategy. A recent study of Latina immigrants and refugees shows that participating in political and social events, for example, may increase sexual communication comfort (Gomez, Hernandez, & Faigeles, 1999). On the other hand, participating in smaller, more intensive

activities that focus on HIV prevention may not. Generally, sexual communication comfort can be affected by a program that focuses on empowering Latinas rather than solely focusing on HIV prevention. Gomez et al. (1999) found that participants who attended a mean of nine program sessions of various activity types decreased their beliefs concerning traditional gender roles more significantly than those who attended nine or fewer sessions. In addition, women who attended leadership trainings and volunteer programs were more likely to report a decrease in incidents of coercive or violent behavior from a male sex partner.

Some studies also show that Latina women can have a significant impact on a husband's activities, further supporting efforts to target female empowerment. A CDC-funded study to examine factors associated with condom use in a community-based sample of young Latino men found that relationship factors were more predictive of men's condom use behaviors than were intrapersonal factors. Men were more likely to use condoms with casual sex partners than with their steady partners, and those who were significantly more likely to use condoms reported a high level of participation in decision-making about condom use and lower expectations of negative partner reactions to condom requests. It was also found that condom use was more likely among men with more positive attitudes toward condoms and those with stronger partner condom norms. These findings indicate that men's protective behaviors are influenced by their female sexual partners and the dynamics within the relationship (Harvey et al., 2004).

Empowerment strategies appear to be effective even among the most vulnerable Latina subpopulations. For example, one study of Mexican women migrants found that they would be more ready to assume an active role in AIDS prevention given their increasing positions of authority within the U.S. (Organista et al., 1998). Similarly, Gomez et al. (1999) found that, among participants in an empowerment program targeting immigrant and refugee Latina women which integrates HIV prevention strategies, women who at baseline reported higher levels of comfort with sexual communication were also more likely to report the use of condoms during their most recent sexual encounter. In a study investigating the impact of women's health promotion compared with intensive HIV prevention, both methods were found to positively impact the behaviors of Latinas aged 18 to 35. While the HIV prevention program was effective at promoting safer sex negotiation, the women's health promotion program demonstrated an increased level of HIV testing among participants (Raj et al. 2001). These findings indicate that both health promotion and HIV prevention information should be components in HIV prevention education and outreach programs.

As with the overall family-focused paradigm, these findings from the academic research were confirmed by participants in the Needs Assessment and further discussed during the Summit. Female participants readily spoke of empowerment, either directly or indirectly, and how this played a role in a woman's readiness to absorb education and change life behaviors. In the words of one participant:

*In order for the education to work, we need empowerment. In order to go forward with the education we need to feel empowered. Then with the empowerment we can get an education.*

## D. Reaching Youth Through the Family

Although few interventions regarding sexual education and Latinos have been developed, and even fewer that involve family members, research shows that such interventions can be effective in building parent skills and reducing sexual risk among adolescents. In addition, support for HIV-positive family members can be greatly heightened through a better understanding of the virus as well as compassion among program participants. Sexuality education programs designed to promote the health education role and sexual education skills of the parent have been proven to be more successful than traditional sexual education and abstinence-based programs alone (Nitz, 1999). Moreover, when parents and adolescents are comfortable communicating, adolescents have an increased tendency to reject high-risk behaviors and delay sex (Burgess, Dziegielewski, & Evans Green, 2005).

Increased parental supervision has also been demonstrated to be influential in the formation of sexual self-efficacy, and parents who know of their children's whereabouts and activities and spend time with their children after school are less likely to have sexually-active children (Velez-Pastrana et al. 2005). It is easily understood how some parents, such as low-income parents who work multiple jobs and long hours, could find it difficult to provide such monitoring and thus may have more limited opportunities to promote risk reduction and effectively deliver HIV prevention messages to their teens. However, a study examining the impact of the Parents as Primary Sexuality Educators (PAPSE) program among parents who were relatively disconnected from school, community supports, and family found statistically significant changes in parents' perceived ability in, and frequency of, sexual and reproductive dialogue with their adolescents (Klein et al., 2005). Although the aforementioned study did include a small number of Hispanics (8%), the incorporation of *familismo* is a far too underexploited resource in HIV/AIDS and STI prevention, particularly among families that are Spanish-speaking dominant. The importance of maintaining family bonds and using the strength of parent-child relationships as a vehicle for HIV/AIDS and STI prevention and management programs and strategies cannot be overstated. According to Pick and Palos (1995), the level of communication comfort will enhance the transmission of information and dialogue and benefit all parties involved, indicating the need to educate parent-child or family groups so as to maintain communication while enforcing preventive sexual behaviors.

The potential role of parents in reinforcing sexual behavior represents a critical and often missing link in U.S.-based prevention strategies that emphasize individual behavior as the key to HIV prevention. Several HIV/AIDS researchers have underscored the critical role of the family in HIV prevention and management, particularly involving sexual decision-making, age at first intercourse, number of sexual partners, decisions regarding contraceptive use, and pregnancy (Blake, Simkin, Ledsky, Perkins, & Calabrese, 2001; Hovell et al., 1994; Irwin, 2004; Miller, Benson, & Galbraith, 2001; Wood & Price, 1997). Researchers suggest that parental monitoring does influence adolescent sexual activity, may reduce the risk of HIV transmission, and can affect the content and delivery of HIV prevention messages (Wren, Janz, Carovano, Zimmerman, & Washienko, 1997). Studies have shown that African American and Latino youth with highly-responsive mothers have been found to delay first onset of sexual activity when compared to their peers with mothers who are less responsive (Fasula & Miller, 2006). Adolescents of parents who supervise and/or monitor their teens are less likely to engage in sexual activity (Longmore, Manning, & Giordano, 2001; Ramirez, Zimmerman, & Newcomb, 1998). In addition, high parent-child connectedness has been associated with delay in sexual initiation contributing to decreased teen pregnancy, fewer sexual partners, and better and more frequent use of contraception (Miller et al., 2001). Furthermore, youth from two-parent families are less likely to engage in early sexual

relationships, less likely to become pregnant, and more likely to have abortions if pregnant (Baumeister, Flores, & Marin, 1995; Murry, 1995; Upchurch, Aneshensel, Sucoff, & Levy-Storms, 1999).

Studies have found that culturally- and linguistically-relevant HIV prevention education is effective in facilitating the adoption of preventive behaviors among youth, particularly if combined with strategies that incorporate behavioral theory-based interventions (Kirby et al., 2004; Villarruel, Jemmott, & Jemmott, 2006). In a study of Puerto Rican adolescents, participation in a theoretically-based, culturally- and linguistically-relevant HIV prevention program was effective in reducing episodes of sexual intercourse and number of sexual partners, while increasing both consistency and frequency of condom use. These findings were particularly strong among Spanish-speaking Puerto Rican youth, indicating the need for further evaluation of intervention effectiveness on diverse Latino subpopulations as well as Latinos of various levels of acculturation (Villarruel, Jemmott, & Jemmott, 2006). The potential of testing such strategies among youth and family members will most likely strengthen long-term outcomes.

## E. Addressing *Machismo* in the Family Context

Much like sexual taboos, beliefs and behaviors associated with *machismo* are mutable; in fact, the traditional definition of *machismo* focuses on the male's responsibility to family and honor within society. As a result, HIV/AIDS prevention materials may have the potential to redefine characteristics such as *machismo* which, while normally considered negative, can also be viewed more positively as a male's responsibility to protect and take care of his family (Rodriguez & Gonzales, 1997). *Machismo* was also reported as a barrier to disclosure of HIV status to one's primary partner. One male Needs Assessment participant shared:

*Machismo plays a role in men not disclosing their infection status to their partners. He doesn't care if his wife gets infected because his machismo influences his lack of perceived vulnerability; he cannot admit that he is sick.*

However, in a different family-focused context that emphasizes the man's traditional obligations, the concept *machismo* could be a key, rather than a barrier, to redefined gender roles in the context of HIV/AIDS prevention. In the words of a male Needs Assessment participant:

*The word 'macho' has been distorted over the years. A Mexican man, a macho man, used to refer to that man being the head of the family. It was a positive thing. Now, machismo means violence; a man that beats his wife.*

Furthermore, the scarcity of research on Latino family sexuality must be challenged with new theoretical frameworks that explain the contextual factors affecting health-related behaviors without vilifying culture and stereotyping behavioral manifestations, such as *machismo*, as definitive cultural attributes (Hurtado, 1995). The family-focused approach discussed in this section may provide one such new framework or paradigm.

## F. Culturally-Appropriate Outreach and Education

NCLR Latino Families HIV/AIDS Needs Assessment participants were asked to provide guidance regarding the construction of HIV-related messages, including information on media strategy. Participants reported a need for culturally-relevant Spanish-language messages, the involvement

of HIV-positive Latinos and Latino celebrities, positive messaging, and involvement of men and families in prevention. Some participants stated that talk shows like Univision's *Cristina*, hosted by Cristina Saralegui, were effective in promoting HIV-related knowledge. Participants expressed the need for culturally-appropriate education among Latino families to teach parents how to discuss these issues. One HIV-positive participant summed up the need for greater visibility of Latinos in the HIV/AIDS arena by saying:

*If someone who looked like me had come to me and told me I could be at risk of HIV infection, I wouldn't be infected now.*

Participants at several sites discussed the efficacy of the *telenovela* (soap opera series), wherein an HIV-positive character was portrayed, in educating Latinos about the virus. Although the *novela* approach would dramatize this context to a certain extent, the popularity of *novelas* has helped make Spanish-language television the fastest-growing television market and the most-watched local networks in many urban centers. Furthermore, Latinos tend to watch more television than the general market and prefer to watch it in Spanish (Project for Excellence in Journalism, 2005; Quinones, 2001). Throughout Latin America, the *telenovela* has served as an effective vehicle for targeting health-related messages to underserved communities. Several *telenovelas* have successfully been used to educate viewers regarding sexual responsibility and adolescence, cancer, alcoholism, and a variety of health-related themes (Andaló, 2003).

The *telenovela* is not only watched by individuals but often viewed as a family activity wherein a great deal of dialogue is generated regarding the conflicts and resolutions presented. According to Miguel Sabido, Vice President of the Televisa Network:

The *telenovela* is a communication product of the mass media that is inside the homes of those most needing to be informed. Because of this, we use the capacity for moral reflection of good and bad through this format, and we can demonstrate that this can be done without lowering our ratings.

The *telenovela* approach provides an opportunity to revisit cultural and societal constructs such as *machismo* while providing positive examples of how *machismo* can be positively framed given the context of changing male expectations (Gutmann, 1996).

Participants in the NCLR Latino Families HIV/AIDS Needs Assessment suggested that print advertisements be positioned at laundromats, bus stops, schools, taverns, markets, and dance halls, and that prevention messages be placed on television and radio and before pornographic films. What became apparent throughout the interviews and focus groups at the 14 sites was the need for HIV prevention information that educated and empowered Latinos within the context of HIV risk as it is experienced in their daily lives.

## **G. *Promotores de Salud***

Although a relatively new method of prevention and health education in the U.S., peer education has been used by the World Health Organization and the Pan American Health Organization for decades. Particularly among communities with little access to formal health care and health education, the peer education model can be extremely effective in facilitating the transmission of health information as well as facilitating access to health care. Community health workers (CHWs), peer educators, or health promoters (*promotores*) establish critical links between health care providers and their respective service communities and are trusted members providing informal community-based health-related services. Their functions are multiple and include

outreach and identifying cases, health education, translation, patient transportation, and case management. *Promotores* can also serve as advocates and lobby for health care, center-based child care during business hours, development or strengthening of transportation systems, and cultural sensitivity training for health care staff. They also work with community members and facilitate and encourage appropriate screening and preventive measures (Zuvekas, Nolan, Tumaylle, & Griffin, 1999). In a recent study examining the impact of a *promotor* visit combined with a postcard reminder for annual screening versus a postcard reminder only, the *promotor* visit group experienced a 35% increase in screening over the postcard-only group (Hunter et al. 2004). The personal element in health care outreach was shown to be highly effective in reaching the Latino community.

Studies have shown the *promotores* model to be very effective in assisting with numerous health issues including cardiovascular disease, child abuse, nutrition and food safety, maternal and child health, HIV/AIDS and sexually-transmitted infections, mental health, and facilitating access to health care (Alcalay, Alvarado, Balcazar, Newman, & Huerta, 1999; Balcazar, Alvarado, Luna Hollen, Gonzalez-Cruz, & Pedregon, 2005; Ballew, 1985; Bell, Hillers, & Thomas, 1999; Blumenthal, Eng, & Thomas, 1999; McFarlane, 1996; Serrano, 1997). In addition, peer educators have demonstrated effectiveness with populations of various ages, such as youth and the elderly (Bell et al., 1999; Reininger & Dinh-Zarr, 1999). Moreover, *promotores* have been found to be highly effective in regions with considerable health care and status issues, such as the U.S.-Mexico border (Sanchez-Bane & Moya Guzman, 1999; Williams, 2001).

Often providing the first link to the formal workforce in the United States, *promotores*-based programs offer many low-income Latinos, both men and women, the opportunity to begin to interface with the health and human service sectors. Although few studies have been conducted to examine the transformation of *promotores* into health paraprofessionals and professionals, this work is needed to better understand the role of *promotores* training in the development of culturally- and linguistically-competent health and social service professionals (Baker et al., 1997; Eng, Parker, & Harlan, 1997). Without doubt, *promotores* are beginning to be viewed as an essential part of the health care sector, particularly within organizations committed to providing culturally- and linguistically-relevant care (Witmer, Seifer, Finocchio, Leslie, & O'Neill, 1995). Peer educators have also been found to be effective in networking with faith-based organizations and other community-based organizations (Barnes & Fairbanks, 1997; Eng & Hatch, 1991), and leave skill-sets within the community even after specific project objectives have been completed.

Creative HIV education and prevention strategies, such as peer education programs that provide Latinas, particularly immigrants, with entrance into the formal U.S. health system, are highly promising in the HIV/AIDS context (Reinschmidt, Hunter, Fernandez, Morales, & Lacy-Martinez, 2006). A study of health promoters and barriers to HIV counseling and testing and risk behavior among inner-city Puerto Rican and Dominican Latinas in New York found that preventive role models within women's social networks are very important. Having a greater proportion of network members endorsing safer-sex practices predicts condom use by a woman's main male partner. Furthermore, women who received support from a larger percentage of their social network were more likely to be concerned about HIV prevention and more likely to have undergone HIV testing, thus indicating that social networks not only may sustain existing social norms but could also become vehicles for change. After viewing an educational video, group discussion participation with network members led women to favor safe-sex practices, reject the notion that being married offers protection from HIV infection, increase willingness to talk about condoms with potential partners, and ask potential partners to use condoms to prevent HIV (Ortiz-Torres, Serrano-Garcia, & Torres-Burgos, 2000). The case of the Resource



Sisters/Compañeras Program in Orlando similarly demonstrated that 63% of first-time attendees at peer support meetings remained for the duration of the meeting. The group meeting fostered a sense of community among participants, open dialogue, and mutual support and problem-solving (Lugo, 1996).

Further support for the effectiveness of *promotores*-based programs targeting HIV/AIDS is shown through the Centro San Bonifacio HIV Prevention Program which was found to be highly successful in conducting outreach in a Chicago-based community, increasing HIV-related knowledge, and altering perceptions of HIV risk after participants had been exposed to community health worker trainings (Martin, Camargo, et al., 2005).

Participants in the NCLR Latino Families HIV/AIDS Needs Assessment discussed the need for increasing *promotores*-based programs to serve the Latino community:

*Promotora programs could have people going out in the community and in the homes to give HIV information. There are many topics that people need to be made aware of, like methods of prevention, proper sex hygiene, and sexuality.*

## VIII. RECOMMENDATIONS

### A. Overview

HIV/AIDS prevention programs based on a family-centered approach will do much to eradicate stigma and build on the positive aspects of *machismo*, while encouraging Latina empowerment through more open communication and more open and appropriate family discussion about sexual and reproductive health issues with adolescents and children. It is essential that educational materials are developed which link HIV/AIDS with other issues that impact the socioenvironmental context of HIV risk and risk behavior (economic dependence on male providers, multiple partners, intravenous drug use/sharing needles, unprotected sex, traditional gender roles, family expectations, and poverty) and use culturally- and contextually-appropriate messages to encourage readers to protect themselves and their families by communicating and seeking HIV education, testing, and services.

Until public health professionals are willing to combine efforts to move beyond the alteration of individual behavior within a culturally-competent framework through the creation of long-term socioeconomic and political opportunities for Latinas, we will continue to fail in our HIV prevention efforts. In the words of Hirsch (2003):

*Culture and its programmatic corollary cultural appropriateness have been embraced because they are an easy pill for us to swallow in public health. They suggest that if we capture just the right culturally appropriate perspective, if we could just tell people how to be healthy in the right words, they would listen and all would be well. A social perspective on sexuality, in contrast, might force us more in the direction of political economy.*

Heterosexual risks experienced by Hispanic women must be given voice in HIV/AIDS outreach campaigns; in this context, consideration of sexual behavior and sexual choices as being framed

by many factors given the contexts of poverty and gender issues among Latinos must not be overlooked. According to Gil (1998):

These differences [among Latinas] are in need of study, analysis, interpretation. To be useful, these efforts need involve a description of the contexts in which individuals make decision, as well as how those contexts – interpersonal and social – influence decisions. In this respect, any prevention education program for sexually active Latinas that does not, somehow and eventually, reach their partners concurrently has limited utility.

## B. A Family Focus: The New HIV/AIDS Paradigm

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)

A major, multisite demonstration project incorporating 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, MSM, and sex worker, greater emphasis needs to be placed on designing media campaigns that target the entire Latino family. By focusing on the Latino family, the long-felt stigma associated with the virus can begin to be eliminated. In addition, such models and strategies will do a great deal to engender a supportive family environment for Hispanics living with HIV, which contributes greatly to the social support needed to adhere to HIV/AIDS treatment regimens.

Due to the popularity of the *telenovela* and the number of families who watch these shows together, mini-*telenovelas* would be an ideal way to communicate to the entire family and address HIV/AIDS within a culturally- and linguistically-relevant context. This focus on the family can also provide a functional avenue within which to educate Latinos regarding the harmful effects of related practices, including alcohol and drug abuse, promiscuity, and unsafe sexual practices, and not just HIV prevention strategies.

- **Reducing the stigma through the participation of Latino celebrities and HIV-positive Latinos willing to be part of the media campaign.** In an effort to reduce the stigma associated with HIV, celebrities can participate in the creation of media messages, as can HIV-positive Latinos willing to become involved. Recommendations from participants in the NCLR Latino Families HIV/AIDS Needs Assessment found that messages that did not incite fear, but rather awareness, were desired. Participants stated that they “already have enough to be afraid of” and that focusing on a positive educational image would help them better understand and take control of HIV risks. Furthermore, the fear of the virus would be allayed as the viewers would be exposed to positive images of Latinos living with HIV.
- **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 and, due to the heterogeneous range of Latino subpopulations often residing within one given region, avoid colloquial Spanish of any given subgroup or region. An exception to this recommendation might be when developing materials targeting youth, who often identify with specific word uses. Latino-specific art and pictures should be used to reflect the communities targeted and mere translations of English language materials avoided to the utmost extent possible. In addition, increasing attention should be placed on transcending materials targeting non- or minimally Spanish-speaking Latino indigenous cultures in their respective languages.
- **Linking outreach and prevention activities with community-based organizations (CBOs), educational and religious institutions, and AIDS Service Organizations (ASOs) and creating collaborative projects that mentor new organizations in the development of HIV outreach and education programs.** Many CBOs, although sometimes without an HIV/AIDS prevention and outreach program, are very well established in their respective communities. These organizations can partner with a mentor ASO to create outreach and prevention education networks. To some extent the current competitive funding structure of health dollars in the U.S. discourages collaboration between agencies, but new initiatives, such as various projects administered through the Office of Minority Health, encourage collaboration with other agencies. This is essential for the creation of new models that address Latino needs from a culturally-relevant perspective. Mentoring relationships between 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. Furthermore, because *promotores* often live within the communities they serve, the skill-sets developed are retained in the community, and the peer education programs often provide upward career development to advance education and professional status.
- **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. Furthermore, these agencies often provide an array of services to the populations they serve which can more effectively address the context within which HIV risk most often occurs and do so in a manner that is both culturally and linguistically effective and meaningful.

If, as this white paper suggests, 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.

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