

# White Paper 2011

NCLR-CSULB

¿A Dónde Vamos?

New Directions for Culturally  
Relevant Latino Community  
Involvement in HIV/AIDS Prevention  
and Services Research



## Acknowledgments

The National Council of La Raza (NCLR)—the largest national Hispanic civil rights and advocacy organization in the United States—works to improve opportunities for Hispanic Americans. Through its network of nearly 300 affiliated community-based organizations, NCLR reaches millions of Hispanics each year in 41 states, Puerto Rico, and the District of Columbia. To achieve its mission, NCLR conducts applied research, policy analysis, and advocacy, providing a Latino perspective in five key areas—assets/investments, civil rights/immigration, education, employment and economic status, and health. In addition, it provides capacity building assistance to its affiliates who work at the state and local level to advance opportunities for individuals and families.

Founded in 1968, NCLR is a private, nonprofit, nonpartisan, tax-exempt organization headquartered in Washington, DC. NCLR serves all Hispanic subgroups in all regions of the country and has regional offices in Chicago, Los Angeles, New York, Phoenix, and San Antonio. 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 strives to improve, promote, and advocate for the health and well-being of diverse Latino/Hispanic communities transcending geographic, linguistic, philosophical, religious, cultural, and social contexts. The NCLR-CSULB Center serves as the evaluation arm of the NCLR Institute for Hispanic Health—which works to promote the health and well-being of Hispanic Americans by reducing the incidence, burden, and impact of health problems in this community.

This paper combines a review of the existing literature, an overview of findings from numerous community-based organizations, and data collected by government agencies to provide a state-of-the-art analysis of the growing HIV/AIDS crisis among Latinos in the U.S., as well as corresponding recommendations for Latino involvement in community-based participatory research related to HIV/AIDS prevention and treatment.

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## ¿A Dónde Vamos?

### New Directions for Culturally Relevant Latino Community Involvement in HIV/AIDS Prevention and Services Research



*“The United States will become a place where new HIV infections are rare and when they do occur, every person, regardless of age, gender, race/ethnicity, sexual orientation, gender identity, or socio-economic circumstance, will have unfettered access to high quality, life-extending care, free from stigma and discrimination.”*

*—Vision for the National HIV/AIDS Strategy<sup>1</sup>*

In June 2010, President Barack Obama issued the first national strategy to address the HIV/AIDS epidemic in the United States. The strategic goals are: 1) to reduce the number of new HIV infections; 2) to increase access to care and improve health outcomes for people living with HIV; and 3) to reduce HIV-related disparities and health inequities. An implementation plan with specific steps has been set forth, serving as a call to action, especially for those working with the Latino community. In selecting strategies that will result in the most change, a cognizance of how the epidemic has disproportionately impacted the Latino community and the factors associated with HIV risk are required. Imperative to this effort is the identification of specific areas for improvement and new culturally relevant directions to curb the epidemic and ultimately help realize the HIV/AIDS strategy's goals.

## **I. THE GROWING HIV/AIDS CRISIS AMONG LATINOS IN THE UNITED STATES**

Three decades into the epidemic, HIV/AIDS continues to have a marked and disproportionate effect on Latino\* communities throughout the United States (U.S.) and Puerto Rico. In 2009, although Latinos constituted 16% of the U.S. population, they accounted for approximately 19% of those diagnosed with HIV and 21% of those diagnosed with AIDS in forty states and five U.S.-dependent areas.<sup>2</sup> Furthermore, in 2008, Latino men had twice the rate of HIV infection compared to White men, and Latina women had five times the rate compared to White women.<sup>3</sup> Latinos continue to be more likely (62%) than African Americans (57%) or Whites (56%) to receive HIV testing at the most severe stage of the disease (CD4<200) and to be diagnosed with AIDS within one year of an HIV diagnosis (Latinos 38%; African Americans 32%, Whites 32%).<sup>4</sup> Additionally, HIV testing most often occurs among Latinos after they have become HIV symptomatic,<sup>5</sup> which frequently leads to less effective and more aggressive treatment. In short, Latinos are the last to be tested for HIV and first to develop and die from AIDS. Consequently, they often unknowingly have the potential to infect others in their families and communities.

As the number of Latinos in the U.S. continues to increase, the proportion of Latinos infected with and affected by HIV will continue to increase if effective strategies to reduce HIV/AIDS risk among the Latino population are not developed and implemented.<sup>6</sup> Reasons for the disproportionately high distribution of HIV/AIDS among U.S. Latinos are complex and include macrostructural factors such as poverty, discrimination, and lack of insurance and access to health care. The social and cultural factors that affect this distribution and which must be taken into account include acculturation, traditional values and family dynamics, gender roles, and lack of access to culturally and linguistically relevant HIV/AIDS prevention, testing programs, and health care. Thus, the ability to effectively intervene and reduce HIV/AIDS disparities must account for these various complexities inherent to the lives of Latinos in the U.S.

The overriding objective of this white paper is threefold: 1) to provide an overview of the growing HIV/AIDS crisis among Latinos in the U.S. by reviewing pertinent HIV/AIDS data across diverse Latino subgroups; 2) to provide a contextual understanding of the Latino HIV/AIDS crisis that includes social, cultural, and structural-environmental factors; and 3) to present corresponding recommendations for preventing and treating HIV and AIDS, respectively, through contextualized community-based research and service provision in partnership with the Latino community.

### **A. The Geographic Dispersion of Latinos and HIV/AIDS**

Although the nine states with the largest, most established Latino populations continue to be California, Texas, Florida, New York, Illinois, Arizona, Colorado, New Mexico, and New Jersey,<sup>7</sup> Latino populations more than doubled in the southeastern and eastern states of South Carolina, Alabama, Tennessee, Kentucky, Arkansas, North Carolina, Mississippi, and Maryland between 2000 and 2010,<sup>8</sup> constituting new growth communities of immigrant Latinos.

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

HIV/AIDS is spreading rapidly through the southeastern U.S., particularly in the Deep South<sup>†</sup> where Latino HIV infection and AIDS cases are rising at an alarming rate.<sup>9</sup>

Structural factors contributing to the spread of HIV/AIDS in the Deep South are high rates of poverty and a lack of health care infrastructure.<sup>10</sup> Here, two million Latinos face severe barriers to health care and preventive services, and these states are further restricting Latinos' access to HIV/AIDS prevention and care by excluding immigrants from government health-promotion efforts.<sup>11</sup> Furthermore, HIV/AIDS prevention and service organizations have significant shortages of bilingual service providers, while at the same time distrust of health care providers is growing among Latinos who face anti-immigrant discrimination.<sup>12</sup>

### **B. Latino HIV/AIDS Cases by Country of Origin**

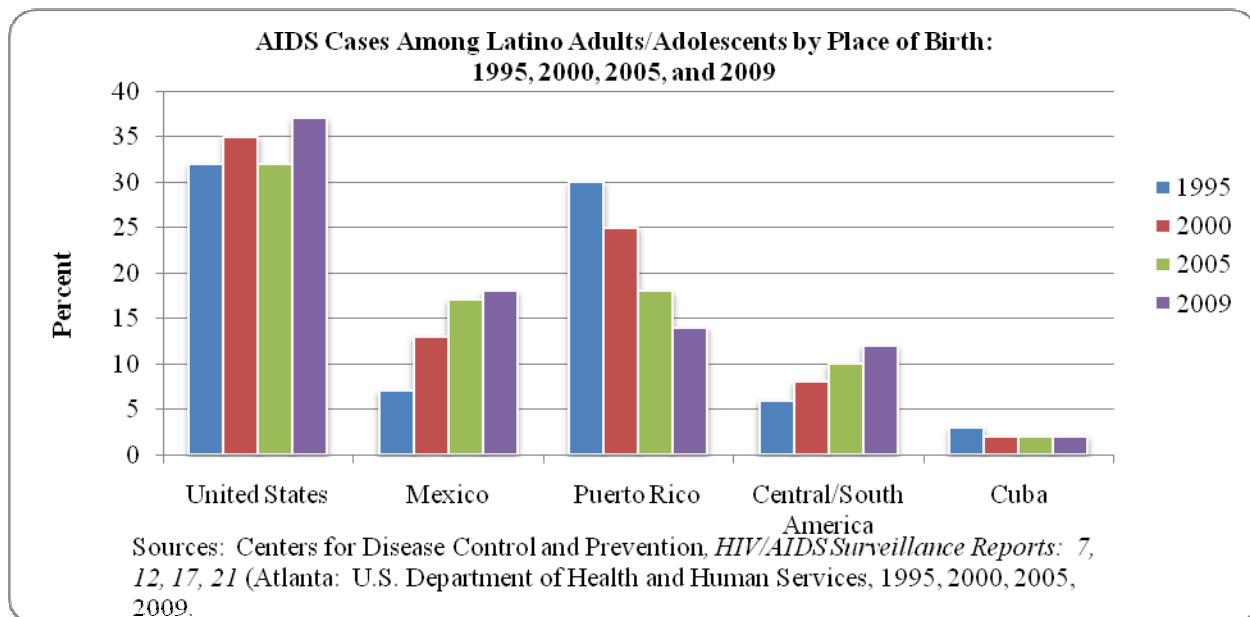
While a recent study of 24,313 HIV-infected Hispanics found that 61% were born outside the U.S.,<sup>13</sup> U.S.-born Hispanics continue to have higher numbers of cases of AIDS than those born in Mexico, Puerto Rico, Central and South America, or Cuba (Figure 1).<sup>14</sup> However, from 1995 to 2009, AIDS cases among Mexican-born Latinos more than doubled from 7% to 18%. Similarly, cases have doubled for Central and South American-born Latinos from 6% to 12%, most likely due to the linguistic isolation experienced by these groups, limited access to HIV prevention, testing, and treatment programs, and an overall lack of access to health care.<sup>15</sup> The rate of AIDS cases among Cuban-born Latinos decreased slightly from 3% to 2%, and decreased dramatically for Puerto Rican-born Latinos, from 30% to 14%. The decline in AIDS cases in Puerto Rico is primarily due to health care reform and the use of highly active antiretroviral therapy,<sup>16</sup> while the overall low rates among Cuban Americans correlate with their high socioeconomic status (SES) relative to other Latino groups.

Research indicates differences in Latino HIV/AIDS characteristics related to place of birth in addition to differences between cultural subgroups.<sup>17</sup> For example, upon seeking care, foreign-born Latinos have lower CD4 counts compared to U.S.-born Latinos, with Mexican-born having a shorter HIV-to-AIDS interval than U.S.-born Latinos.<sup>18</sup> There is also evidence that large proportions of HIV-positive Latino men born in Puerto Rico acquire HIV from injection drug use (IDU) compared to other Latino subpopulations.<sup>19</sup>

### **FIGURE 1**

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<sup>†</sup> The Deep South is defined as those states (Alabama, Georgia, Louisiana, Mississippi, North Carolina, and South Carolina) that historically promoted slavery and had primary agricultural bases in cotton.<sup>9</sup>



### C. Latino Groups and Subgroups Most Affected by HIV/AIDS

Latinos are the largest foreign-born population in the U.S., accounting for 53.1% of all foreign-born inhabitants.<sup>20</sup> Among Latinos, Mexico is the leading country of birth with a ratio of six to one to the next highest country. Studies have reported that Latinos, compared to non-Latino Whites, have a higher percentage of previously undiagnosed HIV infection, experience delays in receiving HIV test results, and have AIDS-defining conditions at the time of diagnosis.<sup>21</sup> In the recently released HIV incidence estimates from the Centers for Disease Control and Prevention (CDC), Blacks and Latinos experienced the most impact of the epidemic between 2006 and 2009.<sup>22</sup> Furthermore, Latino males advanced from the fourth to the third most impacted population in the United States. While significant gaps remain in data documenting the incidence of HIV/AIDS within the Latino community, available research indicates that HIV/AIDS affects Latinos in all regions of the country, and that Latino subgroups are disproportionately impacted. For example, men who have sex with men (MSM) have the highest rates of HIV infection, followed by transgender Latinos; however, heterosexual transmission continues to increase, specifically affecting Latina women and youth. Below is a review of HIV risk in these specific Latino groups, with an emphasis on the multiple contexts of HIV risk.

#### 1. Latino Men Who Have Sex with Men (MSM) and Women (MSMW)

In 2009, Latino MSM represented 71% of the reported HIV infections in Latino men.<sup>23</sup> If the categories of Latino MSM and Latino MSM who also report injection drug use are combined, they account for three-quarters of the HIV infections reported in Latino men for 2009 alone.<sup>24</sup> Data collected from the 40 states with name-based confidential HIV testing since 2006 demonstrate that Latino males have a rate of HIV infection that is over three times that of white males.<sup>25</sup> Among Latino MSM, 43% occurred in those under age thirty.<sup>26</sup> Latino MSM represent the population most severely affected by HIV and the only risk group in which new HIV infections have been increasing steadily since the early 1990s.<sup>27</sup> In the U.S., MSM have consistently comprised the largest percentage of persons diagnosed with AIDS and persons with an AIDS diagnosis who have died.<sup>28</sup>

Studies show that both Latino men and women are most likely to be infected with HIV as a result of sexual contact with men.<sup>29</sup> Latinos have also been reported to have the highest rates of unprotected male-to-male sexual contact.<sup>30</sup> Unprotected male-to-male sexual contact is an

especially significant problem among Latino immigrant men because acculturation and socialization into the U.S. have been reported to be important determinants of sexual risk behaviors.<sup>31</sup> Compared to their counterparts, Latino immigrant men with greater acculturation are more likely to report a higher number of sexual partners and substance abuse that cognitively impairs their ability to practice safer sex.<sup>32</sup>

Certain geographic regions are affected by higher HIV risk profiles due to poverty, inequality of health care access, cultural norms, and other factors. For example, research has provided additional information about the contextual HIV-related risk behaviors and prevalence of HIV among the Latino MSM population in the San Diego–Tijuana border region.<sup>33</sup> In a recent study, nearly one-fifth of participants from Tijuana (20.3%) and one-fourth from San Diego (27.8%) indicated either not having access to or not utilizing health care. Almost half of men living with HIV from San Diego and three in ten of those with HIV from Tijuana reported never having been tested for HIV prior to their diagnosis. The lack of health care, transience of the border population, economic hardship, and homophobia, among other factors, intertwine to exacerbate the HIV epidemic on the California–Tijuana border, impacting both women and men and placing them at high risk for HIV infection. A greater proportion of MSM from Tijuana reported lifetime and recent sexual relations with female partners (MSMW) compared to those from San Diego. The authors of a recent study have reported that men from Tijuana may have been more likely to have had sex with women in response to cultural inhibitors of public identification as gay.<sup>34</sup>

As the U.S. continues to target at-risk populations, it is vital that strategies targeting Latino MSM be culturally and contextually appropriate, including factors such as the lack of open identification with homosexuality and high rate of relationships with women. The synergistic effects of xenophobia, homophobia, economic discrimination, and religious and cultural norms may render a Latino male unable to incorporate HIV prevention as it intertwines with the multiple identities of immigrant, Latino, and gay, among others. A participant in a recent National Alliance of State and Territorial AIDS Directors (NASTAD) publication entitled “*A Través de Nuestros Ojos*” (“Through Our Eyes”) illuminated this dilemma by stating, “It’s either you have to give up your Latino identity and embrace the White gay culture, or you just stay Latino and stay closeted. I think that middle ground never existed to express not only your ‘gayness’ but your ‘Latinoness.’ You can’t separate the two. They’re both equally important.”<sup>35</sup> Similarly, a study concerning existing HIV-prevention services for the Latino MSM community in the Denver metro area<sup>36</sup> found that Latino MSM reported being isolated from the mainstream Latino or MSM communities due to their language, culture, widespread diversity in terms of countries and region of origin, education status, and health literacy. Participants reported feeling marginalized and perceived great levels of stigma stemming from multiple and compounding factors. The study also found that: 1) Latino sexual-behavior issues related to HIV were not being addressed by any local organization; 2) there were high levels of organizational mistrust; 3) many barriers existed to prevention-service use such as *machismo* and Latino community-specific homophobia and homonegativity; and 4) health providers and organizations lacked cultural sensitivity.

The combined force of structural barriers, lack of access to prevention and testing, and discrimination compounded by homophobia and homonegativity in both mainstream and Latino cultures undoubtedly impacts Latino MSM’s and MSMW’s willingness to test for HIV. Research among Latino MSM demonstrates the negative associations with HIV testing; although 39% acknowledged having been exposed to HIV risk through sexual encounters, 11% reported

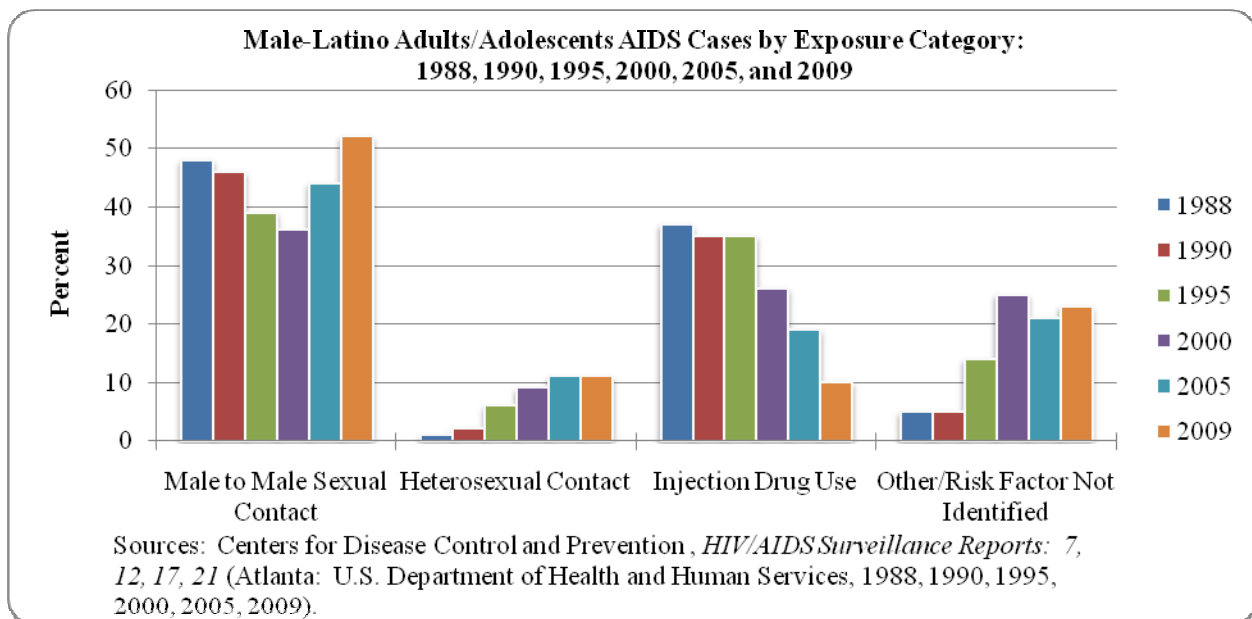


not wanting to know their HIV status.<sup>37</sup> Latino men’s exposure to homonegativity, combined with their engagement in behaviors that are highly stigmatized, may render the act of testing an admission of having engaged in stigmatized sexual behavior.<sup>38</sup>

## 2. Heterosexual Latino Males

As can be seen in Figure 2,<sup>39</sup> Latino AIDS cases due to heterosexual contact increased from 1% to 11% between 1988 and 2009. Although it is the least-reported exposure category, HIV acquisition via heterosexual contact is a reality for Latino males. Due to the stigma associated with IDU and MSM categories and the resulting discomfort with being classified as such, there is an assumption that many of the cases that are reported may in fact not result from heterosexual transmission. However, given that for many underserved populations throughout the world heterosexual transmission is often one of the major or the major transmission risk factor, efforts must be made to further clarify and emphasize the risk of heterosexual transmission among Latino males and its impact on women. Attention must be given to the CDC surveillance methodology for men as well as women,<sup>40</sup> and the increase from 5% to 23% as the “Other/risk factor not reported or identified” category may be indicative of an increase in heterosexual transmission. Hence HIV risk in Latino male heterosexuals is not as well understood as it is for heterosexual Latinas.

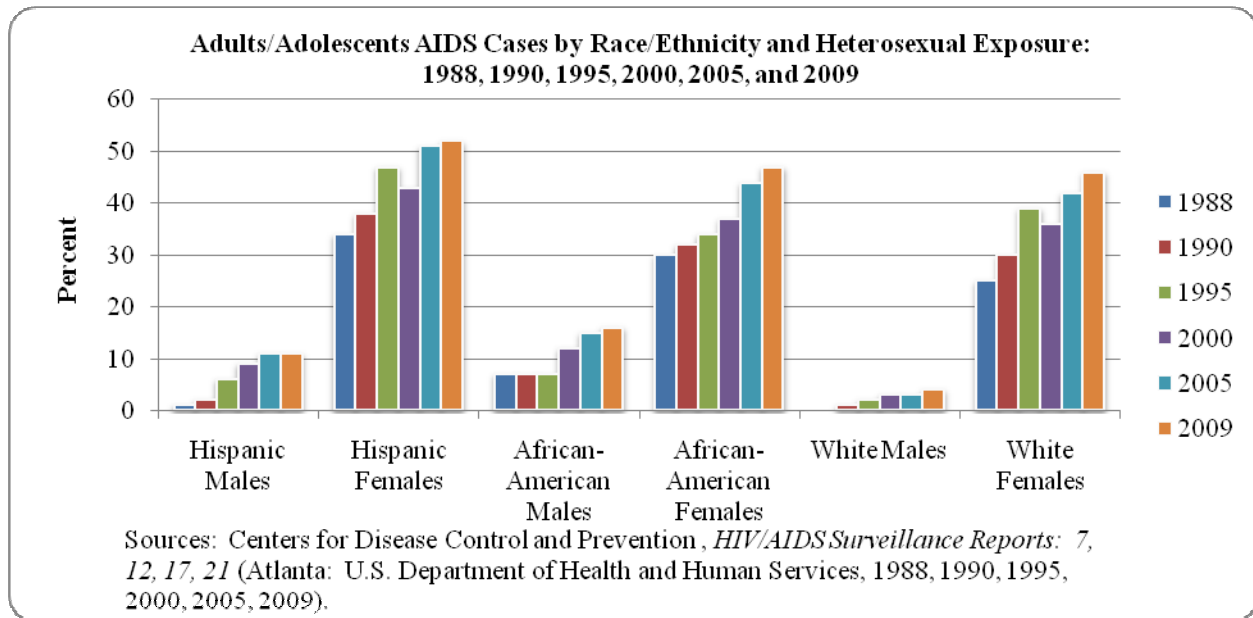
**FIGURE 2**



## 3. Heterosexual Latinas

In 2009, over 50% of Latina women diagnosed with AIDS were infected through heterosexual contact. Between 1998 and 2009, heterosexually acquired AIDS among Hispanic women increased from 34% to 52% (Figure 3).<sup>41</sup> When compared to White women in 2009, Latinas had five times the AIDS rates and accounted for 18% of new AIDS diagnoses among women.<sup>42</sup> Consequently, HIV has become a major cause of death among women, especially among women from racial and ethnic populations.<sup>43,44</sup>

**FIGURE 3**



**Gendered associated risk.** Latinas experience risk factors that contribute to HIV infection similar to their male counterparts; however, they also vary in perceived risk and susceptibility, cultural norms (gender/male interactions), and lack of access to care due to socioeconomic and legal statuses.<sup>45</sup> These variations relate to a unique aspect of Latina risk—the finding that marriage has been cited as the largest risk factor for HIV infection among Mexican women.<sup>46</sup> Hispanic women who are married or live with their partners generally report feeling less susceptible than those who live alone and perceive themselves as not having any chance of HIV infection.<sup>47</sup> In relationships, strongly defined gender roles supported by traditional Latino culture can lead to expectations for appropriate male and female sexual behavior, resulting in male promiscuity and female tolerance of such, thus being important factors in understanding Latino sexual risk behavior. Studies have also documented that negative manifestations of traditional gender roles may contribute to HIV risk. These cultural characteristics have been linked to women’s submission to unprotected sex within their relationships, while males engage in unprotected sexual behavior and have multiple sexual partners.<sup>48</sup> The resulting unacceptability of and inability to communicate effectively about the sexual health risks involved thus leads to unwelcome sexual pressure from male partners, which may confer added risk for women to experience unwanted sexual encounters and/or unprotected sex.<sup>49</sup> Studies of older inner-city Latinos have shown that women were less likely to have had sex with a condom and more likely to identify *machismo* and lack of perceived HIV risk as prospective barriers to condom use.<sup>50</sup> Furthermore, dependence on male partners for income, family support, and security inhibits women from asserting themselves and requesting the use of condoms.

Homophobia, which is prevalent in Latino culture, also increases Latinas risk of HIV infection. Evidence indicates that many HIV infected MSM also have sex with women<sup>51</sup> and have low disclosure rates with female partners regarding their sexual behaviors with other men



the processes by which distal causal factors, such as gender inequality, can lead to unprotected sex at the individual level by linking economic dependency of women on men, male dominance, and the threat or actual incidence of violence against women. This model provides the realm of prevention research with a lens from which to more comprehensively conceptualize behavioral risk by considering its multi-level context. It acknowledges that there are several influential factors that contribute to risk and that warrant inclusion in intervention and prevention research and services.

**FIGURE 5 Causal Pathways Linking Gender Inequality to HIV Risk**



#### 4. Latino Transgenders

The term transgender refers to a diverse group of people, including male-to-female (MTF) or transgender women, female-to-male (FTM) or transgender men, bi-gender (i.e., persons who identify with both male and female characteristics), and individuals who may or may not cross-dress, undergo sex reassignment surgeries, and/or access hormone therapy.<sup>57</sup> Although there have been very few studies and no national surveillance on transgenders, the scant existing research has consistently reported that transgenders are at especially high risk for HIV infection,<sup>58</sup> with prevalence rates among MTF transgender-identified persons ranging from 11% to 78%, with an average of about 35%.<sup>59</sup> Racial and ethnic differences in HIV seroprevalence among MTF transgenders have been reported in studies conducted in San Francisco and Los Angeles where African Americans showed the highest HIV seroprevalence (44%–63%), followed by Latinas (26%–29%), Whites (16%–22%), and Asian/Pacific Islanders (4%–27%).<sup>60</sup>

Although their risk is among the highest, very little HIV-prevention education and research has targeted this population. Not all government agencies provide an official transgender classification when reporting HIV and AIDS risk profiles, thus failing to highlight transgender HIV transmission—missing HIV rates that would identify them as a high-risk population warranting specialized research and intervention efforts. Until recently, the impact of the HIV/AIDS epidemic on the transgender community has been largely overlooked as epidemiologically; they are included within the statistics of men who have sex with men.<sup>61</sup>

Studies of MTF transgender individuals have relied on small convenience samples that lack the power to determine independent predictors of HIV infection.<sup>62</sup> Moreover, few national studies have quantitatively assessed HIV risk among FTM transgenders to date.<sup>63</sup> In a systematic review of existing studies, Herbst et al. (2007)<sup>64</sup> found a high prevalence of HIV infection and risk behaviors among MTF transgenders (27%–48%) but low prevalence rates and risk taking among FTM transgenders. The lack of acknowledgement and focus on transgender populations has serious health implications because several studies have identified a high prevalence of HIV infection and risky sexual behaviors, particularly within Latino communities. Because this population is often ostracized due to xenophobia among Latino immigrants, religious beliefs, as well as traditional cultural views regarding gender, designing effective HIV-prevention interventions will be challenging. Furthermore, the role that misogyny plays in the lives of MTF transgenders and how it compounds with the aforementioned factors to facilitate HIV risk has not been investigated. The structural and social factors leading to multiple marginalities for transgender Latinos incite multiple factors leading to high risk of HIV infection in this unique group of Latinos.

A recent study evaluated risk factors for HIV/sexually transmitted infections (STIs) among 517 MTF transgenders aged nineteen to fifty-nine years from the New York metropolitan area.<sup>65</sup> Results showed extremely high prevalence rates of HIV/STIs among Latino MTF transgenders. Similarly, a recent study that focused on MTF transgenders in Puerto Rico found that participants reported a great need for basic health and social services, and experienced alienation from social networks.<sup>66</sup> The study concludes that it is important to work towards the acceptance of transgenders by understanding: 1) the ways in which they define, construct, and manifest their gender identities and sexualities; 2) the factors that make them socially and structurally vulnerable; and 3) the attitudes and beliefs that place them at risk for HIV/AIDS infection.<sup>67</sup> The high incidence of risky sexual health behaviors, HIV infection, rape, recent violence against, and murders of transgenders, particularly Latina MTF in the U.S. and Puerto Rico, underscores not only the synergy of racism, misogyny, and xenophobia within the U.S.,<sup>68</sup> but also the urgent need for public health interventions and a broader civil rights campaign to advocate on behalf of transgender health, overall and within the Latino community in particular.

**Transgender sex work and HIV risk.** Female sex workers (FSW) and MTF transgender populations experience multiple risk factors which can result in elevated levels of HIV infection. Some of these include: stigmatized social status, economic instability, racism, chemical use and dependency, high rates of sexual and physical abuse, and mental health issues.<sup>69</sup> In Los Angeles County (LAC), transgender women are estimated to have the highest HIV risk of any risk group, and HIV risk appears to be highest in MTF transgenders who report sex work. In an LAC-based study, MTF transgenders reported sex work as their main source of income due to employment discrimination and lack of family support.<sup>70</sup> This alludes to the importance of understanding the significant role that discrimination, on multiple levels, plays in their inability to engage in lawful employment, and how these factors synergistically compel MTF transgenders to survival sex work, which in turn exacerbates related violence and high risk for HIV and STIs.

## **5. Migrant Workers**

Just as the largest proportion of immigrants in the U.S. are of Mexican origin, the migrant laborers that work in various sectors of industry vital to the U.S. are also predominantly Mexican. Not surprisingly, Latino migrant working men (including the day-laborer

subpopulation) are at risk for HIV infection due to many aspects of the migrant experience in the U.S.,<sup>71</sup> including poverty, discrimination, racism, and lack of access to health care.<sup>72</sup> Migrant workers tend to be young men with very low incomes and educational attainment, leading to low literacy and high rates of English nonproficiency.<sup>73</sup> They are away from home for extended periods of time, which may result in a disruption of social relations, and feelings of isolation and loneliness resulting in stress and depression.<sup>74</sup> These factors have been shown to increase the consumption of alcohol,<sup>75</sup> illicit drug use, and sex with commercial sex workers,<sup>76</sup> putting them at high risk for HIV.

Further, Latino MSM who migrate to the U.S. are reported to be at significantly high risk for HIV infection due to similar factors such as poverty, social isolation, limited knowledge of STIs, and opportunities arising in a freer sexual environment.<sup>77</sup> One study reported that early Latino migrant MSM were frequent users of public cruising locales because they did not have to speak English, engage in culturally unfamiliar social interactions, or spend money in order to find partners.<sup>78</sup> In a binational study of male and female Mexican migrants to California in 2004–2005, the authors found HIV risk behaviors related to context (more sexual partners, substance abuse) and individual protective behaviors such as more condom use during vaginal sex and greater HIV testing.<sup>79</sup> A qualitative study by Sowell, Holtz, and Velasquez (2008) found that men migrating to the United States are at high risk of acquiring HIV, and potentially spreading it to their families and loved ones, due to social isolation, lack of knowledge/denial, *machismo*, powerlessness, and survival needs.<sup>80</sup>

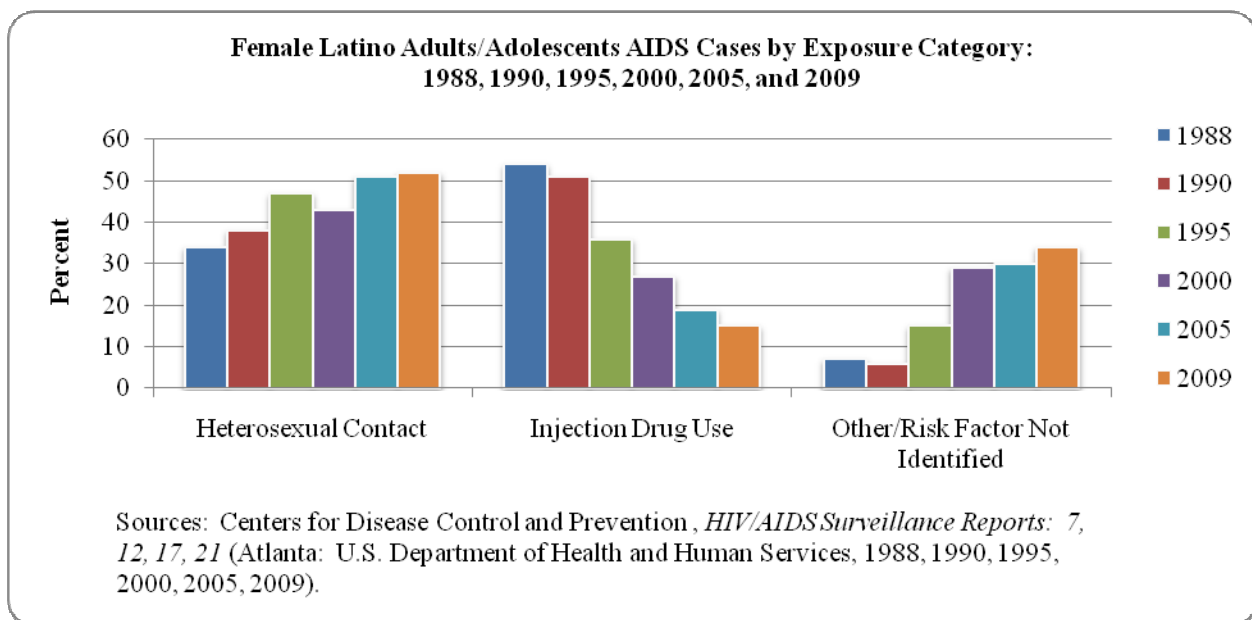
#### **D. Current Gaps in Latino Surveillance Data**

Heterosexual Latinas and transgenders (specifically MTFs) are particularly susceptible to underrepresentation in CDC surveillance data due to misclassification in reporting heterosexual HIV transmission. CDC's current methodology for HIV/AIDS surveillance data collection underestimates the mode of transmission for heterosexual women in general.<sup>81</sup> This surveillance data is, in effect, masking the true rates of heterosexual HIV infection for Latinas. This underrepresentation results from the fact that for Latinas who are reporting heterosexual HIV infection, subsequent classification of their infection is likely to be misidentified as "Other/risk factor not reported or identified" due to the CDC's current established hierarchy of HIV risk classification (see Figure 6).<sup>82</sup> Additionally, Hispanic women may be underrepresented in CDC surveillance data due to sociocultural factors such as sexual silence and culturally dictated scripts that disempower them. These factors further reduce the likelihood of their knowledge of their partner's HIV status or sexual behaviors outside their relationships,<sup>83</sup> in turn decreasing the perceived need to be tested for HIV.

The statistical methods employed by the CDC to reclassify "missing" risk-factor information assume that: 1) the distribution of risk factors among cases initially submitted with "no risk reported" have not changed during the period in which they have been calculated; 2) the cases reclassified as "no risk reported" are representative of all no risk reported cases; and 3) the cases that are reported as "no risk identified" are occurring randomly; that is to say that there are no real patterns to explain these missing risk factors. In response to this dilemma, in 2007, the Council of State and Territorial Epidemiologists called on the CDC to add a new heterosexual HIV-transmission category, "Presumed Heterosexual," to its HIV/AIDS case-report form to improve surveillance-data accuracy.<sup>84</sup> However, an HIV-infected woman's transmission category is "heterosexual" only if she says that she had sex with a male that she knows has HIV. If she doesn't know, the provider does not report it to surveillance, it's not documented in the

chart, or she doesn't want to disclose (perhaps due to stigma, embarrassment, and/or denial), then she is defined as "no risk identified." The fact that Hispanic females' "Other/risk factor not reported or identified" has risen nearly fivefold from 7% to 34% between 1988 and 2009 (Figure 3) indicates the need for revised categories that will more accurately capture heterosexual and MTF transgender cases. It is hard to imagine that this dramatic increase in HIV cases is occurring randomly. The ascertainment and reporting of HIV risk factors needs to improve significantly in order to account for the risk factors that are behind such drastic increases in reported HIV infection cases among Latinas. The reliance on statistical methods used to adjust for "missing risk factor information" may be severely limiting our understanding of HIV transmission patterns.

**FIGURE 6**



Another significant gap in surveillance data that may disproportionately affect Latinos is the minimum time requirement before reporting name-based HIV data. Only areas with mature or confidential name-based HIV infection reporting systems are included in CDC HIV surveillance reports.<sup>85</sup> Currently ten states and the District of Columbia are not included in surveillance data, excluding slightly more than one-third (33.4%) of the U.S. Latino population (Table 1).<sup>86</sup> As of 2012, data for all fifty states and the District of Columbia are expected to be mature and included, but given the aforementioned considerations, significant changes in reporting categories are needed if we are to capture true rates of infection and fully understand the impact on diverse Latino groups/subgroups.

**TABLE 1. Latino representation\* in the 10 non-name-based HIV reporting states and the District of Columbia: 2009**

State/District	Total Population	Latino Population	% State Population	% Total U.S. Latino Population
California	36,961,664	13,675,816	37.0	28.19
Delaware	885,122	63,729	7.2	0.13
District of Columbia	599,657	52,770	8.8	0.11
Hawaii	1,295,178	116,566	9.0	0.24
Maryland	5,699,478	410,362	7.2	0.84
Massachusetts	6,593,587	580,236	8.8	1.20
Montana	974,989	30,225	3.1	0.06
Oregon	3,825,657	428,474	11.2	0.88
Rhode Island	1,053,209	127,438	12.1	0.26
Vermont	621,760	9,326	1.5	0.02
Washington	6,664,195	686,415	10.3	1.41
<b>TOTAL</b>	NA	NA	NA	33.34%

\* Population data were taken from the U.S. Census Bureau's 2009 figures to serve as a best match for 2009 HIV/AIDS data from CDC.

HIV/AIDS among Latinos may also be underreported because the name-based reporting requirement may discourage many Latinos from taking the HIV test for fear of compromised confidentiality and concerns over immigration status, employment, and other discrimination.<sup>87</sup> While additional data are needed in order to completely understand the extent to which name requirements deter Hispanics from taking an HIV test, an accurate picture of HIV/AIDS' impact on the community will only be available once all data are included and correctly categorized.

## **II. UNDERSTANDING THE DISPROPORTIONATELY HIGH IMPACT OF HIV/AIDS ON LATINOS IN THE U.S.**

Factors related to the disproportionately high rate of HIV/AIDS in U.S. Latinos are multilevel and complex, and include structural-environmental, social and cultural, as well as situational factors that produce and reproduce health and risk. Although the Latino population is extremely diverse, most of its members share common factors that may place them at increased risk for HIV/AIDS, including the usual social determinants of health—high rates of poverty, discrimination, limited educational and occupational opportunities—and those related to their immigration status—immigration-related policies, migration-related mobility and isolation from family and country of origin, and rigid gender- and age-role expectations. Latinos also face many language and cultural barriers to HIV prevention, testing, and treatment, which often result in a poor understanding among health care professionals of Latino-specific needs. Lastly, male migrant workers face migration-related risk factors and may also play a unique role in spreading HIV/AIDS within Latino communities both in the U.S. and in their countries of origin.<sup>88</sup> The purpose of this section is to convey an understanding of HIV/AIDS among U.S. Latinos by emphasizing the context of risk within multilevel social, cultural, and structural-environmental factors.

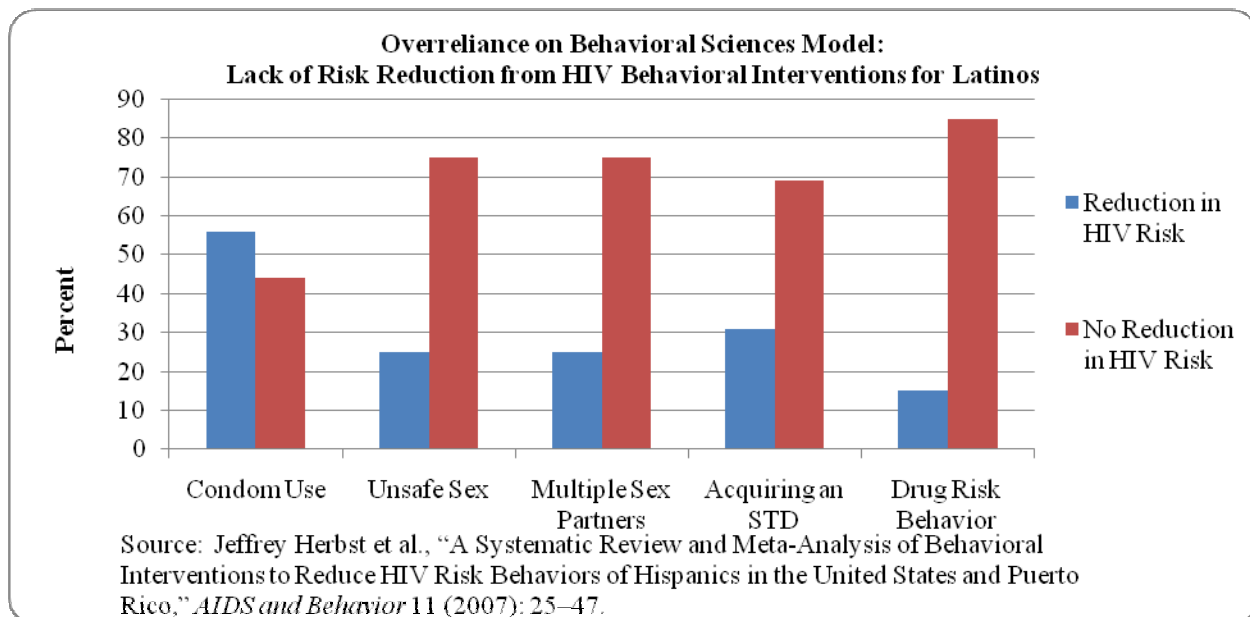


### **A. Addressing the Social–Environmental Context of HIV Risk**

Although HIV-prevention information has emphasized individual behavior change, we know that many socio-environmental factors also impact Latinos' HIV risk, including poverty and discrimination,<sup>89</sup> lack of educational and occupational opportunities,<sup>90</sup> immigration status,<sup>91</sup> and housing.<sup>92</sup> Moreover, socioeconomic circumstances may contribute to a sense of resignation and powerlessness towards issues such as health and self-care practices.<sup>93</sup> The importance of understanding the context of risk is punctuated in a statement by Dr. Jonathan Mermin, director of CDC's Division of HIV/AIDS Prevention: "We can't look at HIV in isolation from the environment in which people live."<sup>94</sup>

The results of a systematic review and meta-analysis of the twenty most rigorous behavioral interventions for Latinos in the U.S. and Puerto Rico, published between 1988 and 2005, appears to answer the question of how well Latino-specific behavioral prevention interventions work, or perhaps how limited they are.<sup>95</sup> While the results of the review revealed consistent reductions in unprotected sex (25%), multiple sex partners (25%), injection drug use (17%), sharing cotton/cookers (27%), incident STDs (31%), as well as an increase in condom use (56%; Figure 7),<sup>96</sup> the review also begs the question: is this as good as it gets for behavioral prevention interventions with Latinos? That is, given the immense labor and expense of implementing behavioral interventions, does the overall reduction in risk of about 26% found by Herbst et al. (2007) suggest a level of diminishing returns? According to Organista (2007),<sup>97</sup> if the context of behavioral risk is not understood, targeted, and modified, we may not be able to exceed the overall 26% risk-reduction rate reported by Herbst et al. To put it another way, we may not be able to decrease the overall 74% "lack of reduction in risk" revealed by Herbst et al.'s review of behavioral prevention interventions with Latinos. Hence, we must begin to contextualize behavioral risk for HIV for various Latino groups in various risky situations, environments, and social locations. By addressing the contextual factors influencing behavioral risk, we can continue to decrease risk in Latinos and other populations. Further, as treatment for HIV/AIDS has become increasingly effective, national prevention efforts have focused more on identifying the HIV positives and extremely high-risk individuals to ensure their treatment, and have focused less on primary prevention and HIV/AIDS education. Although these treatment efforts are both commendable and understandable given the advancements and effectiveness of biomedical treatment, the need for less costly primary-prevention efforts remains, and hence the glaring need to identify the specific contexts that contribute to HIV risk and risk behavior.

### **FIGURE 7**



## 1. Socioeconomic Status and Poverty

Low educational attainment is a marker of socioeconomic status that correlates strongly with higher death rates from many conditions, including HIV.<sup>98</sup> In an unprecedented study of age-standardized (25–64 years), race/ethnicity-specific death rates from all causes (using U.S. National Mortality Data from 2001), the authors found that 39% of all causes of death among Hispanic males and 30% among Hispanic females would not have occurred in this age range if these individuals would have had access to higher levels of education.<sup>99</sup> Moreover, death due to HIV infection was one of the most extreme differences, in relative terms, found to result from lower education.<sup>100</sup>

A strong association exists between HIV infection and poverty.<sup>101</sup> Indeed, a CDC analysis shows that poverty is the single most important demographic factor associated with HIV infection among inner-city heterosexuals, with poverty shown to be a more influential factor than the severe racial disparities that characterize the overall U.S. epidemic.<sup>102</sup> In 2009, 25.3% of Latinos were living below the poverty level in the U.S. Furthermore, Latinos' income level in 2009 was lower than all other racial/ethnic groups after African Americans, and Latinos were the most likely to have no health insurance.<sup>103</sup> The poor frequently have low levels of education and decreasing access to risk-reduction information, which is particularly exacerbated among monolingual Spanish or indigenous Latin American language speakers. Moreover, the poor may, in an attempt to meet immediate survival needs, seek income and other resources through activities that place them at higher risk for infection.<sup>104</sup> A study conducted by Diaz et al. (2001) found a strong association between poverty and psychological distress, which increased the propensity for participation in high-sexual-risk situations (e.g., sex under the influence of alcohol or drugs; sex to relieve depression and loneliness).<sup>105</sup>

One in five children living in the U.S. is Hispanic.<sup>106</sup> The low socioeconomic status of many Hispanic youth, coupled with cultural stigma around sex and gender roles, is likely to contribute to behaviors that increase risk for contracting HIV. Low-income Hispanic adolescents report higher intentions to have sex, earlier sexual initiation, more sexual partners, and lower use of contraception, including condoms.<sup>107</sup> Low socioeconomic status could increase the risk of

HIV among Latino youth due to factors including limited access to quality health care and less opportunity for quality time with parents due to long work hours, and/or by contributing to disenfranchisement, which has been demonstrated to increase risky sexual behavior.

## **2. Immigration, Acculturative Stress, and HIV Risk**

The continuous flow of Latinos immigrating to the U.S. has many implications for vulnerability to psychosocial and health problems, including HIV, given that immigration issues tend to interact with the SES and poverty factors noted above. The stress of stigma and related discrimination resulting from being an immigrant and/or undocumented Latino needs to be better understood in relation to HIV risk and prevention, particularly in today's political climate. How Latinos cope with stigma and discrimination warrants further study as a critical component of the context of risk experienced by Latino communities nationwide.<sup>108</sup>

With regard to migration-related stress, Apostolopoulos et al. (2006) used ethnographic methods to assess how individual and environmental factors intertwine, rendering Mexican farm workers vulnerable to STI/HIV risks in both Arizona and South Carolina.<sup>109</sup> The primary stressors noted were isolation or separation from family, friends, and associated social support networks, transience (unpredictable work and housing/homelessness, substandard housing), poverty, and rigid work demands.

The interface of Hispanics' values and norms with those of the dominant culture or various subcultures they encounter in the U.S. has been shown to shape risk of HIV infection, both positively and negatively. Greater acculturation into the U.S. mainstream has been associated with the adoption of health-protective practices among Hispanics, including communicating with partners about sexual safety and disclosing positive HIV serostatus<sup>110</sup> and use of health care services.<sup>111</sup> One study found that more acculturated teens reported higher levels of confidence and 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 unplanned pregnancy, STIs, and HIV.<sup>112</sup> In contrast, studies have suggested that higher levels of acculturation indicate a greater likelihood of having STIs and more sexual risk taking among Latina teens.<sup>113</sup> Studies of less-assimilated Latino male and female adolescents have shown that they are significantly less likely to have had sex than their more assimilated peers<sup>114</sup> and more likely to maintain their religiosity, leading to reduced levels of sexual behavior.<sup>115</sup> The above underscores how the association between acculturation and risk appears to operate differently for different subgroups of Latinos.

## **B. Cultural Factors Associated with HIV Risk**

### **1. Language**

More than one in ten U.S. residents now speaks Spanish at home, the second most commonly spoken language in the U.S. after English.<sup>116</sup> Among these residents, approximately half report an ability to speak English less than "very well."<sup>117</sup> In a study of 45,076 Spanish- and English-speaking Hispanic adults in twenty-three states (representing 90% of the U.S. Hispanic population), researchers found that Spanish-speaking Latinos have far worse health status, less access to care, and less preventive care when compared to their English-speaking counterparts. The study showed that 39% vs. 17% reported being in fair or poor health, 55% vs. 23% were uninsured, and 58% vs. 29% reported not having a personal physician, for Spanish vs. English-speaking participants, respectively.<sup>118</sup> Moreover, adjustment for demographic and

socioeconomic factors did not mitigate the influence of language on these health indicators, indicating that language compounds vulnerability, and underscoring the need for language-specific HIV prevention and testing information and risk-reduction interventions.

## **2. Religion, HIV Stigma, and Cultural Taboos**

Religion is thought to be a protective factor in that it discourages multiple sexual partners and encourages periods of abstinence. However, it is also a risk factor associated with intolerance towards homosexuality<sup>119</sup> and beliefs against contraception. For Latina women whose primary risk factor is sex with their primary partner, religion may not function as a protective factor as women are often prescribed a submissive function in terms of their ability to control their sexual role in marriage. In a national needs assessment of Latinas and HIV/AIDS, the majority of married participants were found to perceive sex as a *deber* (duty) as opposed to a *placer* (pleasure) and part of the integral role of a wife.<sup>120</sup> In a cross-racial study of youth and sexual activity, Tolma et al. (2008) noted an association between religion and abstinence among Hispanic youth but concluded “there is insufficient empirical evidence to describe the relationship between religiosity and abstinence.”<sup>121</sup> In a recent study with a nationally representative data set of Hispanics, youth who regarded religion as important (e.g., attended religious services at least once a week) and who had traditional attitudes about sexuality had fewer sexual partners and an older age of sexual debut.<sup>122</sup> Also, a cross-sectional study of sexually active Latino adolescents found that religiosity positively predicted females’ recent condom use above and beyond factors such as *familismo* and gender roles.<sup>123</sup> However, the authors indicated that other aspects of religiosity may lead to helplessness and the belief that efforts to protect oneself from HIV are in vain. Moreover, an additional study showed that religion heightened risk taking for male-to-female transgender youth participants.<sup>124</sup> Hence, whether religiosity functions as a factor that contributes to protection or risk may depend on the age, gender, and sexual orientation of the person, thus warranting further study.

As in other cultures, homonegativity, transnegativity, taboos regarding premarital sexuality, sexual orientation, homophobia and transphobia, injection drug use, and extramarital relationships are prominent in Latino communities. For many Latino communities, responding effectively to HIV/AIDS has meant having to admit yet another threat to a long list of problems that already results in precarious survival. Although effective HIV-prevention programs for Latino communities are those that are responsive to taboo issues such as HIV stigma and its compounding factors, few existing interventions have been developed by and with Latino communities and community-based researchers.

Stigma, unfortunately a common human reaction to any disease or state that could be construed as “different,” undermines public and private efforts to combat the discrimination relating to HIV/AIDS (AIDS stigma), people living with HIV or AIDS, HIV risk behavior, and the epidemic itself. Stigma negatively affects preventive behaviors and the quality of care given to persons living with HIV. Furthermore, stigma impacts the treatment that people living with HIV receive in their respective communities, families, and from their partners.<sup>125</sup> The use of substances and the practice of sexual risk behavior may function as maladaptive coping strategies in response to that stress.<sup>126</sup> Therefore, decreasing HIV/AIDS-related stigma is a vital step in stemming the epidemic.<sup>127</sup>

## **3. Family Relations and Latino Youth**

Latino youth are disproportionately affected by HIV/AIDS. Although Latino youth represented

15% of the teen population in 2007, Latino youth aged thirteen to nineteen represented 21% of AIDS diagnoses among teens, while Latino young adults aged twenty to twenty-four accounted for 20% of new AIDS diagnoses.<sup>128</sup> Latino females aged thirteen to twenty-four accounted for 18% of youth living with HIV infection while males accounted for 20%.<sup>129</sup> Furthermore, according to data from the 2009 Youth Risk Behavior Surveillance System, Latino high school youth were more likely to have engaged in sexual intercourse when compared to all U.S. high school students (49% and 46%, respectively) and were the least likely to have used a condom at most recent intercourse when compared to their White and African American counterparts (55%, 61%, and 63%, respectively).<sup>130</sup> These higher rates of sexual risk behaviors may partially explain why Hispanic youth are the second most likely racial/ethnic group to contract HIV/AIDS.<sup>131</sup> Although the HIV infection rates have declined for youth since the beginning of the epidemic, the rate of decline among Hispanics/Latinos has been slower than among non-Latino Whites.<sup>132</sup>

Research has shown that Latino parents can have a major influence in shaping the sexual attitudes and contraceptive behavior of adolescents.<sup>133</sup> One study found that parent–child communication, specifically the communication between mothers and daughters, has proven to be influential in the reduction of sexual-risk behaviors among adolescent girls.<sup>134</sup> Other studies have emphasized the quality as opposed to the frequency of mother–daughter interactions as protective against risky sexual activity among White, African American, and Hispanic adolescent females.<sup>135</sup> Furthermore, adolescent females who reported less frequent communication about sexual topics with their parents reported fewer discussions with partners about STIs and HIV/AIDS, less frequent condom use, and also reported lower self-efficacy to negotiate safer sex or refuse an unsafe sexual encounter.<sup>136</sup> There is an increasing awareness of the effect that culturally driven gender roles, patterns of partner and parent–adolescent communication, and traditional family interactions have on HIV/AIDS and sexual health risk among the U.S. Latino community.<sup>137</sup>

#### **4. Cultural Values and Roles**

Despite the importance of family and the degree to which familism is valued across Latino cultures, studies have shown that Latino parents experience difficulty discussing sexuality and contraception with their children<sup>138</sup> or view sexual health as a topic that should not be discussed due to cultural traditions and beliefs. Yet programs that build upon Hispanic cultural expectations of parents as family leaders, educators, and authority figures have been found effective in mitigating unsafe sexual behaviors.<sup>139</sup> For example, an experimental intervention was recently conducted with two attention-control conditions in a sample of 266 eighth-grade adolescents and their primary caregivers.<sup>140</sup> The intervention focused on Latino-specific factors, including the idea of *respeto* (respect), indicating parental authority and the role of parents as leaders and teachers within the family. Results revealed that adolescents in the experimental condition were less likely to report unsafe sex at last intercourse than those in one control condition. In addition, none of the adolescents in the experimental condition reported contracting an STI, compared to six of the 165 adolescents in the two control conditions. Results suggested that Latino adolescents can benefit from an intervention in which parents act as change agents and in which family functioning is improved and sexual-risk dialogue is sanctioned within a culturally relevant framework. Hence, Latino-specific interventions must overcome cultural barriers and encourage families to engage in open communication about sexual topics, as

research has illustrated the benefits of these methods. The key is to address these barriers in a culturally sensitive and appropriate manner, utilizing the cultural assets of the community.

***Familismo and Respeto.*** As in many cultures, a great deal of information regarding health and behavior is learned within Latino families, and *familismo* (familism), a cultural value emphasizing the strength of family unity and the degree to which a person experiences family attachment, is a significant tenet across Latino subpopulations.<sup>141</sup> *Familismo* is more pronounced within Latino cultures, where individualism is less valued and family unity is often perceived as key to successful adaptation and advancement in the United States. *Respeto*, defined as respect for one's elder relatives and persons of authority, is also highly valued within traditional Latino families. Within the contexts of *familismo* and *respeto*, Latino parents have the potential to positively impact the sexual health behaviors of their children. For example, parents may call on the idea of family unity to promote a team effort towards protective and healthy behaviors among the whole family.

Research has also demonstrated generational similarities and differences among Mexican women regarding their perspectives on male–female relationships and marriage. While older women valued *respeto* and obligation within their marriages, younger Latinas tended to prefer companionate marriage,<sup>‡</sup> which included less rigid gender roles and valued *confianza* (trust).<sup>142</sup> Although women of different generations viewed their relationships and expectations quite distinctly, both generations were found to be reluctant to acknowledge infidelity of, or to suggest the use of condoms to, their male partners. Suggestion of condoms could be interpreted as a *falta de respeto* (lacking respect) or to imply infidelity on behalf of either partner, thus weakening their position in the relationship. This illustrates how cultural values may serve to increase risk, as Latinas may not ask their husbands to use condoms for fear of showing disrespect.

***Machismo and Marianismo.*** Certain characteristics associated with traditional gender roles have been reported to create an imbalance of power in sexual relationships.<sup>143</sup> These include elements of *machismo*, described as negative male characteristics which can include violence, overbearing control, sexual aggression, male dominance, and physical strength; and *marianismo*, described as female characteristics such as being sexually chaste, passive, and not discussing sexual topics. This imbalance in power may be of great consequence to sexual-health risk behaviors and attitudes. Research indicates that HIV risk is increased by these negative facets of *machismo* and *marianismo*, as they are linked to increased unprotected sexual encounters and multiple sexual partners among men.<sup>144</sup> However, the negative portrayal of *machismo* does not facilitate the incorporation of its potentially positive aspects, such as protection of family, which could be effectively integrated into HIV prevention and testing efforts to incite men to test and use condoms. Likewise, *marianismo* encompasses a similar protective element, where it is the mother's duty to care for the family. Emphasizing sexual risk responsibility as a key responsibility of women may serve to increase their openness to sexual discussion with children and HIV testing, and these behaviors may then support their families' health.

Clearly, cultural values play a pivotal role in HIV risk promotion and protection as well as hold the potential to be harnessed to intervene in risk. Research that increases comprehension of the complexity of the relationships and interactions among cultural values and HIV risk behaviors needs to be conducted. This in-depth understanding will allow for effective

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<sup>‡</sup> A proposed form of marriage in which legalized birth control would be practiced, the divorce of childless couples would be permitted, and neither party would have any financial or economic claim on the other.<sup>141</sup>

integration of important cultural values into prevention and treatment strategies to reduce HIV risk among Latinos, creating specific interventions for this population which are truly culturally relevant.

### **C. Structural Factors and HIV Risk**

As noted above, proximal behavioral risk factors are often produced, reproduced, and exacerbated by distal causal structural factors such as formal and informal institutions, policies, norms, and values. While challenging, we need to study and describe the pathways between macro structural factors and micro risk factors. Below are a few important examples.

#### **1. Lack of Health Insurance**

Individuals who are uninsured are more likely to be unaware of their HIV status until late in their HIV disease progression, and are unlikely to be able to pay for expensive treatment regimens or unaware of the federally funded Ryan White HIV/AIDS Program<sup>145</sup> that provides HIV care to uninsured and underinsured individuals.<sup>146</sup> Latinos have historically been more likely to be uninsured than any other racial or ethnic group in the U.S., and under the current economic recession, Hispanic-Americans' uninsured rate rose to 32.4%—approximately 16 million people.<sup>147</sup> The largest increases in the uninsured between 2008 and 2009 were among working, adult, U.S.-born Latino citizens. It is important to note that when workers lose employment-based insurance, there is often a ripple effect as dependents also become uninsured. Lack of insurance and subsequent health care access is most alarming among undocumented Latino immigrants and their children as they comprise 17%<sup>148</sup> of the estimated 46 million Americans who lack health insurance.<sup>149</sup> According to a recent analysis conducted by the Pew Hispanic Center, six in ten Hispanic adults living in the United States who are not citizens or legal permanent residents lack health insurance.<sup>150</sup> The Pew Hispanic Center also reports that the share of uninsured among this group (60%) was much higher than the share of uninsured among Latino adults who are legal permanent residents or citizens (28%), or among the adult population of the United States (17%).<sup>151</sup>

Considering that Latinos are under- or uninsured, behaviorally based community HIV-prevention interventions are more readily accessible to the Mexican immigrant population than institutionalized health care programs. Furthermore, given the geographic dispersion of HIV/AIDS and the high rates along the U.S.–Mexico border, prevention efforts must involve Latino community-based organizations and community leaders if they are to serve Latino public health interests and be optimally effective at stemming the tide of infection among underserved Latino communities. Programs such as the “*Soy*” and “*Tú No Me Conoces*” campaigns provide examples of community integration through social marketing campaigns to increase HIV prevention, outreach, and testing.<sup>152</sup> The “*Soy*” campaign, a partnership between Univision and the Kaiser Family Foundation, broadcasts short real-life testimonials of HIV-positive individuals and affected family members regarding their life experiences, thus personalizing and normalizing the epidemic and giving it a Latino-specific face. The “*Tú No Me Conoces*” campaign combined Spanish-language radio, print media, a Web site, and a toll-free HIV-testing referral hotline for an eight-week period to increase HIV/AIDS awareness and testing. Findings demonstrated an increase in HIV testing along the U.S.–Mexico border, with 28% of testers specifically identifying the campaign messages as the factors that motivated them to test. Both campaigns have demonstrated an ability to incite concern, personalization, and motivation in Latino communities to test for HIV. Furthermore, these campaigns have provided greater insight into

the types of culturally relevant messaging and social-media campaigns that are most effective in targeting Latino communities.

## 2. Obstacles to HIV Testing

In the U.S. today, individuals who are living with HIV but are unaware of their status are more likely to transmit HIV to others compared to individuals who are aware of being HIV-positive.<sup>153</sup> The HIV/AIDS epidemic can be lessened substantially by increasing the proportion of HIV-positive persons who are aware of their status.<sup>154</sup> In 2006, the CDC issued HIV-testing recommendations that call for routine HIV screening in the health care setting for all patients between the ages of thirteen and sixty-four years.<sup>155</sup> Yet one of the consequences of the high level of the uninsured among the Latino population is the lack of access to the health care system, where HIV testing is supposed to be offered. Population-wide studies indicate that Latinos are more likely than Whites to be “late testers” for HIV.<sup>156</sup> A recent study showed that immigration status was significantly associated with delayed HIV presentation among Latinos.<sup>157</sup> While the twenty-year ban on allowing HIV-infected persons to enter the U.S. has been repealed, a large number of Latinos may be unwilling to test for HIV for fear of jeopardizing their future residency status.<sup>158</sup> While recent studies have not found immigration status to be a significant factor for not testing for HIV,<sup>159</sup> the authors note that residents with those concerns may simply not consent to participate in research for the same reason. Latinos have also been found to be less likely to have their HIV-seropositive status detected early in its infection (greater than five years between the first reported HIV-positive test and an AIDS diagnosis) when compared to non-Latino Whites.<sup>160</sup>

Research indicates that Latinos avoid seeking testing, counseling, or treatment if infected due to lack of perception of HIV risk and fear of embarrassment, rejection, and stigma.<sup>161</sup> Levy et al. (2007) found that for Latinos, especially immigrant Latinos, lack of knowledge of HIV risk contributed to delayed HIV testing.<sup>162</sup> Latinos tested for HIV because of clinical presentation and not because they perceived themselves at risk for HIV. The prevalence of HIV stigma in the Latino community has further demonstrated its contribution to low rates of HIV testing. A national population survey found that 36% percent of Latino participants would be “very” or “somewhat” concerned that people would think less of them if they found out they had been tested for HIV regardless of the test result.<sup>163</sup> When asked if, in general, they felt there was prejudice and discrimination against people living with HIV/AIDS in the United States today, 85% of Latinos responded “yes.” Although some would hypothesize that education may increase positive attitudes regarding HIV testing, Latinos with more education were found to be more likely to fear being stigmatized for HIV issues than those with less education.

The high mobility of migrant workers and their lack of access to healthcare and HIV testing mean that HIV-infection rates will continue to increase. Structural and environmental factors associated with migration, such as long separations from family, loss of social and familial support networks, and isolation may contribute to an increase in risky behaviors (illicit drug use, alcohol abuse, sex with casual partners, and commercial sex workers), making Latino migrants greatly vulnerable to HIV infection and low testing.<sup>164</sup> Furthermore, what migrant men call desperation or *desesperación*, stemming from social isolation, discrimination, economic hardship, undocumented status, and other factors, appears to render members of this subgroup more likely to engage in drinking and chemical use and sexual-risk behaviors with men and commercial sex workers.<sup>165</sup>

Late HIV detection has negative implications for individual morbidity and mortality as



well as for public health. Failure to test early for HIV can result in a delay in accessing treatment for those infected, while increasing the risk of transmission to others. The benefits of early HIV detection are significant, including a wider range of treatment options for the individual, a more brisk lowering of the viral load, and a lowering risk of medication side effects. Additional benefit may be conferred across the population, potentially slowing new infections.<sup>166</sup> Novel HIV-testing strategies are imperative in order to identify HIV infection at an earlier stage and offer early entry into treatment. A recent study examined whether offering HIV testing with screening for other conditions would increase HIV testing among Latino men who frequent gay bars. This study showed that Latino men were more likely to test for HIV when it was bundled with other tests.<sup>167</sup> This bundling may serve to reduce stigma associated with HIV testing, and thus a promising strategy to increase testing in this group.

### **3. Obstacles to HIV Treatment**

A great number of HIV-positive Latinos have little or no experience with health care systems in the U.S. which is potentiated by the high number of uninsured among this population. Many HIV-positive Latinos may be unaware of the safety net that the Ryan White HIV/AIDS Program provides to individuals who do not have sufficient resources to pay for HIV-related care (e.g., HIV care providers, AIDS Drug Assistance Program). This lack of health care access and utilization is a critical barrier to HIV treatment for this population.

Latino clients from Central and South America are mostly accustomed to a system that involves receiving personal attention quickly, minimal recordkeeping, limited laboratory testing, and symptom-based treatments.<sup>168</sup> Furthermore, medical guidelines in Mexico require the physician to spend considerable time discussing health issues with the patient prior to examining the patient in the examination room.<sup>169</sup> The formalized health care systems in the United States thus may be perceived as alienating, impersonal, intrusive, and cumbersome. Some immigrants who have U.S. health insurance still return to Mexico for health care because services are less expensive and the style of treatment is more culturally familiar and cognizant of Latino communication values.<sup>170</sup> Organizational barriers that impede Latinos' access to and use of HIV care include: policies and practices that limit the availability, acceptability, or affordability of HIV care and supportive services; limited clinic hours; lack of client privacy and case coordination; lack of Spanish and Latin American indigenous-language health care providers and materials; and confusing, unwelcoming facilities.<sup>171</sup>

The lack of basic linguistic and cultural competence or the necessary skills to communicate effectively with low-literacy clients or clients with limited English proficiency are also great barriers to HIV/AIDS treatment among the Latino population. Other important structural barriers impeding adequate access to HIV/AIDS treatment include the lack of: eligibility for publicly funded medical and supportive services for undocumented immigrants; funding for Latino-centered HIV medical care and supportive services; organizational capacity to provide comprehensive, colocated HIV services; and care coordination across providers.<sup>172</sup>

A recent study identified the following key strategies that health care providers could use to reach out to HIV-positive Latinos in order to link them to HIV care and help them remain in treatment: the use of bilingual, bicultural providers and Spanish-language materials, and addressing barriers such as fear of disclosure of their HIV status and lack of understanding of HIV.<sup>173</sup> Furthermore, research has also underscored the potential impact that could be made by community health workers in HIV counseling and testing as well as linkage to care and treatment through community services.<sup>174</sup>

### **III. THE NEED TO ADDRESS THE CONTEXT OF HIV/AIDS PREVENTION, TREATMENT, AND RESEARCH IN PARTNERSHIP WITH THE LATINO COMMUNITY**

Despite the fact that Latinos have been disproportionately affected by HIV/AIDS, few Latino-specific initiatives have been developed and supported to address the multiple contexts of risk experienced by distinct at-risk Latino groups described above. Detailed programmatic strategies are needed to address the divergent cultural, social, economic, and other structural risk factors experienced by diverse Latino groups, and such efforts need to be developed, implemented, and evaluated in partnership with Latino communities. However, Latino community involvement is hampered by the lack of integration of Hispanic communities in the advancement of prevention efforts. In a recent survey of its membership, the National Latino AIDS Action Network (NLAAN) asked its members to name what they believed should be the top three from the nine efforts of the 2011 HIV/AIDS national policy recommendations. According to NLAAN members, the top three priorities should be: 1) increasing funding for Latino-specific outreach, education, and prevention (54.5%); 2) increasing Latino-specific prevention interventions (50.6%); and 3) improving inclusion of Latino community members in planning, implementation, and evaluation (42.9%). Moreover, 63.8% stated that national efforts had not addressed the need for Latino-specific homegrown interventions.

Few Latinos and Latino-specific organizations have been asked to contribute to research strategies and programmatic recommendations. Rather, Latino organizations are often relegated to adapting and modifying programs solicited through grant mechanisms that have been developed for other populations. While it is worthwhile to explore adapting evidence-based prevention programs to Latino populations, it is also equally if not more important to develop and evaluate homegrown Latino prevention efforts. Such strategies could be successful in addressing the multiple and specific contexts of risk uniquely experienced by Latinos. Furthermore, Latino community involvement would help determine how differing risk profiles can be effectively addressed by integrating key cultural values, community members, and population-specific components for diverse Latino risk groups. This section describes how HIV/AIDS prevention and treatment efforts can be improved by integrating salient Latino values and community assets, including lay community helpers and paraprofessionals.

#### **A. Integrating Salient Latino Cultural Values into HIV/AIDS Prevention and Treatment Strategies**

The fact that approximately two-thirds (65.2%) of Latinos living in the U.S. are foreign born illustrates the importance of considering the cultural influences that may impact the health behaviors of Latinos, and their health outcomes.<sup>175</sup> Cultural influences such as traditionally accepted gender roles and the importance of family have been shown to impact the health behaviors of Latinos across a number of studies.<sup>176</sup> Research has demonstrated that *familismo* is an important cultural value and belief among Latinos.<sup>177</sup> However, to date, few investigations have examined how such values of reciprocity and family support relate to health outcomes, particularly with respect to HIV prevention. Other identified cultural factors such as *confianza* can also prove useful in uncovering ways to prevent Latinos from engaging in HIV risk behaviors. *Confianza* refers to a sense of trust and intimacy within one's interpersonal relationships<sup>178</sup> and is considered to be an intrinsic Latino cultural characteristic that is present in

many aspects of daily life.<sup>179</sup> It is not unusual to hear individuals describe their relationships in terms of their sense of *confianza*. It has been hypothesized that individuals who adhere to *confianza* may make decisions on the basis of advice from a *persona de confianza* (a trusted person).<sup>180</sup> Thus, *confianza* may be of great use in HIV prevention and treatment efforts among the Latino community.

An additional, potentially important Latino cultural factor which may be utilized to help build culturally specific prevention and treatment efforts is *respeto*. Young children are taught to respect their elders and greet adults and persons of authority courteously. There is admiration for an older adult's life experience and a generalized perception that their wisdom holds significant value.<sup>181</sup> Interactions occur within a hierarchical structure that is clearly mediated by age, gender, and status. *Respeto* and *autorespeto* (self-respect) may thus be utilized to influence the behavior of younger populations through HIV-prevention efforts that address the risk factors to which this population is exposed.

One particularly successful example of prevention intervention that integrates core Latino values is *¡Cuidate!* (Take Care of Yourself), a small-group intervention designed to reduce HIV sexual risk among Latino youth. The intervention consists of six sixty-minute modules delivered to small, mixed-gender groups. *¡Cuidate!* incorporates salient aspects of Latino culture, including *familismo*, *machismo*, and *marianismo* in their varying forms. For example, the positive aspects of *machismo* (e.g., protector of the family) can be incorporated into HIV-prevention efforts instead of the typical negative portrayals, depicting this cultural factor in a positive light. *Machismo* can then be used to frame abstinence and condom use as culturally accepted and an effective way to prevent STIs, including HIV, and protect family members from infection.<sup>182</sup> Additionally, through the integration of role-playing, videos, music, interactive games, and hands-on practice, *¡Cuidate!* addresses the building of HIV knowledge, understanding vulnerability to HIV infection, identifying attitudes and beliefs about HIV and safe sex, increasing self-efficacy and skills for correct condom use, as well as learning developmentally appropriate negotiation of abstinence and safer sex practices.

Furthermore, an approach congruent with Latino participants' beliefs and expectations facilitates the development of *confianza*. This strategy is consistent with acknowledgement of the traditional role of Latinas, who are typically charged with general caretaking and the health of their families. Particular strategies comprise culturally sensitive assertiveness training that introduces requests for condom use with qualifiers such as "*con todo respeto*," ("with all due respect"), acknowledging the status differences between men and women as well as the importance of *respeto* as a core cultural value and its fundamental role in sexual relations. HIV/AIDS prevention programs should include the prerequisite of training HIV educators in Latino culture and countering resistance or anger from males.<sup>183</sup> If possible, these HIV educators should come from the Latino communities engaged in the prevention efforts.

## **B. Integrating Community Assets into HIV/AIDS Prevention, Treatment, and Research**

Latinos and their respective communities are traditionally much more tightly knit and community focused than their Western counterparts.<sup>184</sup> The lack of Latino-centered HIV-prevention efforts, combined with the individual-focused behavior-change efforts most often created to prevent HIV in the U.S., have not harnessed the potential of collectivism within Latino communities. In fact, interventions used to ameliorate both health- and education-related disparities within diverse Latino communities often focus on deficits found within Latino risk

profiles. However, these approaches often ignore positive Latino cultural traits and practices and fail to consider how they may be used to benefit HIV-prevention efforts.

Future work should assess Latino-specific community strengths, particularly in hard-hit geographic regions such as those previously discussed, as well as along the U.S.–Mexico border, to determine how Latino communities could best incorporate and harness their cultural and network strengths in HIV prevention and testing efforts. Several studies have indicated that despite the stigma associated with HIV/AIDS, Latino community members involved as organizational volunteers experienced an increase in self-esteem, sense of empowerment, and safer-sex behaviors.<sup>185</sup>

### **The Special Role of *Promotores de Salud* or Community Health Workers**

According to the Health Resource Services Administration (HRSA), community health workers (CHWs) or *promotores de salud* are defined as:

lay members of communities who work either for pay or as volunteers in association with the local health care system in both urban and rural environments and usually share ethnicity, language, socioeconomic status and life experiences with the community members they serve. They have been identified by many titles such as community health advisors, lay health advocates, *promotores(as)*, outreach educators, community health representatives, peer health promoters, and peer health educators. CHWs offer interpretation and translation services, provide culturally appropriate health education and information, assist people in receiving the care they need, give informal counseling and guidance on health behaviors, advocate for individual and community health needs, and provide some direct services such as first aid and blood pressure screening.<sup>186</sup>

Recognized as members and leaders within their respective communities, *promotores de salud* have close connections with the people they serve and have great potential to increase access to care and testing among linguistically isolated and underserved communities, reduce health care costs and provider and patient frustration, improve health care by facilitating communication and continuity of care, and help the underserved better understand the complexity of the U.S. health care system.<sup>187</sup> *Promotores de salud* can also facilitate skills acquisition through role-playing to help male and female clients apply new, forthcoming prevention behaviors. Community health workers can often bridge the gap between underserved Latinos and health care services, enabling Latinos to overcome barriers such as transportation, lack of knowledge regarding where to go for care, lack of condition-specific knowledge, doubt about the need for screening and care, and social support.<sup>188</sup> As the role of *promotores de salud* continues to evolve, they will undoubtedly play an increasingly important role in the health care and disease prevention of individuals who have little experience with the U.S. health care system.

Although the Affordable Care Act (ACA) is projected to ameliorate some of the disparities in Latinos' access to health insurance, the current act as it stands excludes undocumented people.<sup>189</sup> HIV/AIDS-related *promotores* efforts have proven to be effective in targeting the general Latino population by conducting culturally and linguistically relevant HIV/AIDS education as well as testing outreach.<sup>190</sup> In terms of prevention-related outcomes, a recent *promotores*, community-based participatory research intervention found that *promotores*-driven *charlas* (educational conversations) were found to increase HIV knowledge as well as

augment the level of HIV prevention and sexual risk-related conversations held within the households of participants ninety days post intervention.<sup>191</sup> These findings indicate that *promotores* can be effective in “normalizing” HIV risk, despite having to use dialogue regarding sexual risk and HIV prevention that may not have been traditionally, culturally, or religiously sanctioned prior to the participants’ *charla* experiences.

Studies have also demonstrated that *promotores* are effective in conducting door-to-door, rapid HIV testing among Latino immigrants, underscoring their ability to build rapport and trust when conducting outreach to recent immigrant populations with a high percentage of undocumented residents.<sup>192</sup> Moreover, several *promotores*-based HIV/AIDS-specific studies have shown that *promotores* are effective in both rural and urban settings, with both gay and heterosexual populations, and with persons of wide age ranges. *Promotores* engaging in HIV prevention in an urban setting were found to be particularly effective at increasing perceptions of HIV risk among those with lower levels of formal education, while increasing HIV/AIDS-related knowledge.<sup>193</sup> The Healthy Women Project, carried out on the U.S.–Mexico border, found that *promotores*’ efforts increase HIV testing, prevention knowledge, and word of mouth regarding the need to test for HIV among non-study participant peers.<sup>194</sup>

Community health-worker programs can also be adapted to meet the needs of various populations and frameworks. A study using the Popular Opinion Leader Intervention, called Young Latino *Promotores*, was adapted to meet the needs of two diverse migrant communities. Despite high participant mobility, results showed that participants’ HIV knowledge increased and that they were more likely to use condoms when engaging in anal sex.<sup>195</sup> Finally, the *Promovisión* program, through its *promotores* networks, was found to increase community stakeholder capacity for collaboration, and to facilitate the creation and sustainability of HIV-prevention community coalitions through surveying *promotores* in four states to assess the potential role of community-based organizations (CBOs) in HIV prevention.<sup>196</sup>

## C. Needed Research Directions

### 1. Creating Mixed-Language, Family-Based Strategies for HIV Prevention and Testing

Strategies for HIV prevention that have taken cultural aspects of the Latino family into account have been shown to be effective in addressing risk factors that are particular to this population.<sup>197</sup> Intervention efforts which address acculturation into U.S. norms through the use of family communication have proven to be successful among Latino families.<sup>198</sup> Indeed, several cross-sectional studies indicate that Latino youth who communicated with their parents about sex decreased their sexual activity and pregnancy rates and engaged in more responsible sexual behaviors.<sup>199</sup> Research indicates that Latino adolescents and their parents desire open discussions of sexual issues, but that communication is often difficult.<sup>200</sup> A recent family-based, HIV-prevention intervention effort among 100 Latino parents and their adolescents showed that parents and adolescents were often relieved to be discussing the topic of sexual health. Participants reported understanding that engaging in such skills-based activities provided useful factual information for the health of their families.<sup>201</sup> Furthermore, two interventions working with intergenerational Hispanic-female family dyads and small groups have shown increases in female-centered and overall family dialogue regarding HIV and sexual risk, augmenting HIV knowledge and bolstering participants’ intention to test.<sup>202</sup>

Indeed, there is evidence that interventions that allow for discussion of issues such as sexual decision making, sexually transmitted infections, and encouragement of the delay of

initiation of sex or abstinence can be helpful in HIV prevention among the Latino community.<sup>203</sup> Recent research has shown that family-based strategies for HIV prevention must consider Latino cultural issues such as acculturation and mixed-language communication. Further research is needed to investigate how the strong family unity that exists among many Latino families can serve to foster open communication that is inclusive of both the Latino and American cultural values and languages in order to best prevent the spread of HIV infection among this population. Furthermore, family-based HIV-prevention education can facilitate a greater understanding of the harmful effects of homophobia and homonegativity and begin to eradicate the sexual stigma that often accompanies HIV risk and dialogue.<sup>204</sup>

## **2. The Need to Measure Cultural Characteristics and Impact in HIV Prevention**

Cultural groups are more receptive to health-behavior interventions when the intervention components reflect their cultural realities and avoid mismatches stemming from language preference and use, discrepant values and attitudes, and contextual characteristics such as delivery method.<sup>205</sup> A review of Latino behavioral HIV-prevention intervention studies published since the late eighties found that the most successful intervention studies addressed cultural factors and were developed to specifically target the population of interest.<sup>206</sup> These findings show the need for research that identifies and measures the specific Latino cultural factors to be integrated into interventions.

Research must be conducted to empirically develop measurements of cultural values which can assist prevention scientists in understanding the ways in which specific Latino cultural factors influence the emergence of HIV-infection risk behaviors. In order to utilize cultural values in HIV interventions, new and empirically valid measures relevant to HIV-risk behavior must be developed, tested, and evaluated within the context of demographic, psychosocial, and behavioral constructs. Further, the ability to validly measure these values allows for quantification of the impact of the specific mediators of HIV-related behavioral change, thus increasing understanding of their role in HIV prevention. Application of HIV-relevant cultural values could facilitate the application of cultural relevance beyond mere linguistics. As many Latinos receive the majority of their care at community clinics and health centers, these measurement instruments must be easily administrable in these settings. This would provide researchers and practitioners a greater understanding of how Latino cultural factors may be scientifically employed to minimize the occurrence of HIV among the Latino population.

## **3. Culturally Appropriate Biomedical Approaches to HIV Treatment and Prevention**

Advances in biomedical approaches to HIV treatment and prevention have demonstrated great promise in preventing HIV infection among HIV serodiscordant couples and other high-risk populations. Several newer promising biomedical approaches include antiretroviral therapy (ART), pre-exposure prophylaxis (PrEP), post-exposure prophylaxis (PEP), male circumcision, microbicides, and HIV vaccine research efforts.<sup>207</sup> If these approaches are to effectively stem the epidemic within Latino communities they must be combined with structural-environmental solutions that address the various aforementioned contexts of risk experienced by diverse Latino populations, the environments in which they live, and risky situations that they frequently encounter. Furthermore, these approaches require urgent formative research in partnership with the Latino community in order to develop culturally relevant approaches.

**ART.** Antiretroviral medications have greatly improved health and survival outcomes among HIV-infected persons with access to medications.<sup>208</sup> Additionally, recent findings

support the notion of treatment as prevention. Based on findings from the HIV Prevention Trials Network 052, initiation of ART use by HIV-infected individuals significantly reduces the risk of HIV transmission to their HIV-negative partners by 96%.<sup>209</sup> Most of the newer regimens, specifically those recommended by the U.S. Department of Health and Human Services (DHHS),<sup>210</sup> are simpler and more tolerable. However, a recent study indicated that Latinos receiving ART had significantly greater increases in glucose levels and insulin resistance and fat redistribution when compared to African Americans and Whites.<sup>211</sup> Although this was a small study, Latinos' high risk of diabetes compared to Whites and higher rate of death from diabetes than the general population warrants further investigation into the effects of ART on Latinos' specific health risks.<sup>212</sup> Further investigation of potential interactions between Latino ethnicity and pharmacologic effects of ART is warranted. Community involvement is essential for encouraging Latinos on ART to participate in research investigating the influence of comorbid conditions such as diabetes and other chronic diseases prevalent among the Latino population.

**PrEP and PEP.** HIV PrEP and PEP are biomedical prevention strategies that use antiretrovirals to prevent HIV infection. The *Iniciativa PrEx* (PrEP Initiative) assessed the effectiveness and safety of daily oral tenofovir (TDF)/emtricitabine (FTC), a fixed-dose combination of two nucleotide reverse transcriptase inhibitors in one pill, for the prevention of HIV acquisition in high-risk MSM. A double-blind, randomized, controlled trial was conducted comparing oral tenofovir (n = 1,251) with a placebo (n = 1,248) in sexually active, HIV-negative adult MSM in Latin America (82%), U.S. (9%), Thailand (5%), and South Africa (4%). Based on three-year follow-up findings, oral PrEP taken before exposure provided a minimum 44% reduction in new HIV infections among MSMs and transgender MTFs engaged in high-risk exposure.<sup>213</sup> Greater efficacy was observed among individuals with greater PrEP adherence.

PrEP efficacy was recently reinforced through two other studies. The Partners PrEP Study trial of 4,758 HIV discordant couples from Kenya and Uganda found that daily oral tenofovir reduced HIV transmission by 62%; transmission was reduced by 73%, with the TDF/FTC combination.<sup>214</sup> The Botswana TDF2 trial 2 in 1,219 heterosexual men and women from the general population demonstrated a 63% reduction in HIV transmission among persons in the TDF/FTC group.<sup>215</sup> In both the Partners PrEP and TDF2 studies, treatment adherence was at least 84%.

Findings from a PrEP study conducted with women at high sexual risk were not as promising. The global FEM-PrEP study was terminated early because daily oral PrEP did not appear to be efficacious for women.<sup>216</sup> It is speculated that poor adherence may be a factor in this trial since other PrEP studies on MSM and heterosexuals with high adherence demonstrate the protective effects of oral PrEP.

PrEP studies to date not only highlight encouraging biomedical prevention strategies but also elucidate the need to tailor strategies with population subgroups and different locations. Although some preliminary findings demonstrate efficacy, PrEP studies need to be replicated among other populations, such as Latinos living in the United States, to determine both effectiveness as well as community readiness and adaptation to new prevention methods.

Early in the epidemic, the U.S. Public Health Service established guidelines for the management of persons occupationally exposed to HIV.<sup>217</sup> Fairly recently, the DHHS established recommendations for nonoccupational exposures.<sup>218</sup> The DHHS Working Group on nonoccupational PEP recommends the use of PEP for persons seeking care within seventy-two hours after nonoccupational exposure to blood, genital secretions, or other potentially infected bodily fluids of a person known to be HIV-positive.

Although there is increasing awareness of PEP as a common exposure strategy to reduce HIV transmission, locating nonoccupational PEP services within seventy-two hours may be difficult, even within an HIV epicenter such as Los Angeles County.<sup>219</sup> Barriers to the utilization of these treatments include a limited number of facilities with these resources, lack of emergency department readiness for medication administration, and difficulty with follow-up, particularly with underserved and mobile populations including uninsured patients who lack an HIV diagnosis and are therefore not eligible for federally funded drug assistance programs.<sup>220</sup>

Structural factors such as health care access will limit availability of PEP and other medical prevention modes for many Latinos who do not have access to care, leaving them at risk of contracting HIV. Both forms of prophylaxis provide a significant reduction in the probability of HIV infection. Challenges faced will include medical personnel and institutional readiness to provide culturally and linguistically relevant instruction and transition to follow-up care for Latinos. Additionally, strides to promote community awareness, readiness to take and access to the medication, as well as work to eradicate homophobia and transphobia will be needed to facilitate community acceptance of these modes of HIV prevention.

**Male circumcision.** Male circumcision, the partial or full removal of the foreskin of the penis, is a long-term prevention strategy that has been shown to decrease the transmission of HIV. The risk of HIV transmission appears to be greater with uncircumcised males because of biological features such as the foreskin's inner mucosal layer having a higher density of HIV target cells; the greater chance for viral survival between the foreskin and penis; and the greater chance of foreskin tearing, introducing HIV portals of entry and exit.<sup>221</sup> Two randomized clinical trials conducted on African men have shown the protective effect of male circumcision in HIV acquisition with a 60% decrease in HIV transmission in men who were circumcised compared to uncircumcised men.<sup>222</sup> However, in a randomized clinical trial in Uganda, a male partner's circumcision provided no protective effect to women.<sup>223</sup> Given the environmental, economic, and health care access issues faced by many African nations, studies on the reduction of risk gained by circumcision among U.S. residents are needed to warrant full adaptation of the practice.

Latinos in the U.S. have one of the lowest male circumcision prevalence rates among all ethnic groups, ranging from 10% to 40%.<sup>224</sup> A study among south Florida Latinos was conducted to investigate how likely Latinos are to accept neonatal circumcision. The results showed that 85% of the 100 Latino participants were willing to circumcise their future sons if the circumcision was offered free of charge, in a hospital, and within thirty days of birth.<sup>225</sup> Although the majority of participants were foreign born, most of them had been in the U.S. for several years, and therefore acculturation may have influenced their beliefs about circumcision. The barriers found to influence expecting Latino parents regarding circumcision were cost, lack of support by health care providers, and cultural tradition. Additional research within the Latino community is needed to explore in greater detail the associations between different factors (e.g., country of origin, time in the U.S., acculturation scores, income) and how they relate to neonatal male circumcision.

Moreover, there is debate about the effects of male circumcision on male sexual pleasure and penile sensitivity. A study of forty-two young adult males who underwent elective circumcision showed no difference in sexual function before and after male circumcision. The only statistically significant difference was an increase in the average time needed to ejaculate, but this was not found to be a problem among the participants.<sup>226</sup> The benefits of male circumcision are decreased risk of penile carcinoma, HIV infection, urinary tract infections, and



ulcerative sexually transmitted diseases.<sup>227</sup> Finally, circumcision as a biomedical prevention intervention will result in diminishing returns if the environmental, cultural, social, and situational contexts of sexual risk on the part of circumcised men are not considered.

**Microbicides.** Microbicides are another form of antiretroviral prophylaxis that has shown promising results in reducing HIV infection. Microbicides are gel-like products that can be applied to the vagina or rectum with the intention of reducing the acquisition of STIs, including HIV. A 2004 trial conducted by the Centre for the AIDS Program of Research in South Africa (CAPRISA) assessed the effectiveness and safety of a vaginal gel formulation of tenofovir, a nucleotide reverse transcriptase inhibitor, for the prevention of HIV acquisition in women.<sup>228</sup> A double-blind, randomized controlled trial was conducted comparing tenofovir gel (n = 445 women) with placebo gel (n = 444 women) in sexually active, HIV-negative eighteen- to forty-year-old women in urban and rural South Africa. In high adherers (gel adherence >80%), HIV incidence was 54% lower (p = 0.025) in the tenofovir gel study arm. In intermediate adherers (gel adherence 50% to 80%) and low adherers (gel adherence <50%), the HIV incidence reduction was 38% and 28%, respectively. Coitally related tenofovir gel use was found to be safe.

Given these findings and FEM-PrEP's demonstration of no efficacy with oral PrEP, the tenofovir gel could potentially fill an important HIV-prevention gap, especially for women unable to successfully negotiate mutual monogamy or condom use. Due to issues associated with modesty, lack of knowledge regarding sexual and reproductive anatomy, and cultural and religious stigma related to acknowledgement of sexual risk and contraception, considerable community-based participatory research and interventions are warranted if all Latinas, regardless of acculturation and language use, are to be prepared to fully utilize the potential benefits of microbicides once these gels reach the market.

**HIV vaccine research trials.** While Latinos are disproportionately impacted by HIV/AIDS, they are underrepresented in HIV/AIDS medical research in the United States.<sup>229</sup> A recent study showed that mistrust and fear of government emerged as important themes related to reluctance to participate in HIV vaccine trials. Specific concerns regarding trial participation included fear of vaccine-induced HIV infection, physical side effects, stigma, and false-induced HIV-positive test results and their social repercussions.<sup>230</sup> The authors concluded that for HIV vaccine trials to be successful among Latinos, they should address mistrust and fear of government-sponsored HIV/AIDS medical research, increase access to and convenience of clinical trials, address fear of vaccine-induced infection, combat HIV/AIDS stigma, and raise awareness of the relevance of HIV/AIDS in Latino communities.<sup>231</sup>

#### **4. Culturally Responsive Health Care**

The importance of the medical service sector's recognition of the multiple and complex contexts of Latino HIV risk and prevention, barriers to testing, and treatment adherence cannot be overstated. The integration of national and local social-media campaigns, community health workers, and *promotores* interventions is necessary if we are to "normalize" biomedical approaches to HIV prevention and AIDS treatment within Latino communities nationwide. The integration of efforts to work with immigration and law enforcement as well as public health officials is also necessary to ensure that Latino immigrants are aware of the risks and offered testing, prevention, and treatment at each service and enforcement sector.

With regards to Latinos, the National HIV/AIDS Strategy for the U.S. seeks to increase the proportion of HIV-diagnosed Latinos with undetectable viral load by 20% by 2015.

Additionally, it aims to target Latino communities with HIV-prevention efforts that are culturally appropriate and available to acculturated and non-acculturated Latino populations. For example, the CDC plans to launch an evidence-based social-marketing campaign targeting the Latino community and to collaborate with national Latino organizations on HIV-prevention efforts by the end of 2011. However, for such efforts to achieve maximum dissemination and success, they will need to be developed in collaboration with Latino communities in order to more thoroughly consider multilevel contextual factors.

#### **IV. RECOMMENDATIONS**

Thirty years into the epidemic, while other groups have reduced infection rates, Latinos continue to be disproportionately affected by HIV/AIDS—proportions that gradually and alarmingly increase each year. The integration of Latino communities and families into community-based participatory research efforts and the development of HIV/AIDS-prevention programs will provide communities with the knowledge, skills, and resources necessary to protect themselves, their families, and their respective communities while making use of the strong social-support networks characteristic of Latin American and Caribbean cultures in the fight against HIV/AIDS. It is essential that research efforts, social-media campaigns, and educational materials are developed to link HIV/AIDS with other issues that impact the social and environmental contexts of HIV risk among Latinos. Strategies that move beyond individual behavior and delve into the structural and environmental factors that contribute to risk are necessary in order to create effective community-based HIV/AIDS-prevention resources that offer sustainable and lasting solutions linked within a broader context of social justice.

The Latino population is resilient and replete with thriving networks to facilitate survival and success, despite the many barriers members of Hispanic communities face on a daily basis. This is evident in the phenomenon known as the “Hispanic Paradox.” This paradox refers to the fact that despite multiple risk factors for poor health outcomes, the age-adjusted death rate is consistently lower for Hispanics than all other race/ethnic groups, except for Asians and Pacific Islanders.<sup>232</sup> This endurance is often attributed to the strengths and assets of the Latino community and culture. Family unity, cultural values, and solid social networks and traditions provide the public health arena with an array of opportunities through which to engage and involve Latino communities in HIV/AIDS prevention efforts. The following conclusions and recommendations are grouped into three sections: 1) structural; 2) social and cultural; and 3) biomedical.

##### **A. Structurally Oriented Recommendations**

How we as a nation define and measure HIV/AIDS-related risk and prevalence data are structural factors that determine resource allocations. Current HIV/AIDS data related to Latinos could be improved by the recommendations below.

##### **1. Improve Data on Impact of HIV/AIDS on Latinos**

Latinos will continue to drive the nation’s growth and changes in geographic/regional population demographics. Given the youth of the Latino population—with a median age of 27.3 years compared to 36.8 years for the total U.S. population<sup>233</sup>—and its actual and potential contributions to our nation’s productivity, a better understanding of Latino-specific disease burden and lost prevention opportunities is warranted. While great strides have been made to incorporate data from Puerto Rico into the national surveillance system and to urge states to

engage in name-based reporting, HIV-specific data still do not reflect a full third of the Latino population in the U.S. The impact of incomplete data regarding HIV/AIDS has grave repercussions on the allocation of resources and the accuracy of research efforts needed to incite community awareness and community-based research and HIV-prevention intervention efforts. To achieve more accurate and full representation of the impact of HIV/AIDS on diverse groups of Latinos, data reporting and intervention allocations should:

■ **Include a “Presumed Heterosexual” risk population category to more accurately portray the effects of heterosexual risk on Latinos**, particularly women of color who may not know the risk profiles of their partners. Although women represent an increasing proportion of those who test for HIV, many women suffer domestic violence, gender-based discrimination, and sexual abuse situations, sometimes compounded by undocumented status, that do not provide them with the leverage necessary to query their partners regarding their HIV status and sexual and IDU risk histories. Epidemiologic data have indicated that many HIV-positive Latinas have had only one sexual partner, often their husbands, and do not fit the risk profiles established early in the history of the HIV/AIDS epidemic. A more accurate portrayal of heterosexual infections is necessary if we are to curb the epidemic among Latinos, particularly impoverished people of color.

■ **Publish HIV data for all U.S. Hispanics in all states.** The CDC must work with state and local partners to quickly ensure that all Latinos are represented in the published surveillance data to ensure a more complete portrayal of the impact of HIV in all states and territories by 2012, the year of the next International AIDS Conference.

■ **Track changes in state and region-specific HIV/AIDS cases among Latinos** to create a system whereby resources for HIV/AIDS prevention, outreach, testing, and services can be quickly allocated.

■ **Include “Transgender Male-to-Female” and “Female-to-Male” classifications in all HIV/AIDS surveillance-reporting measures.** The CDC must work with state and local partners to quickly ensure that transgender cases are accurately reflected in the national data profiles, particularly given the extremely high rate of infection among male-to-female transgenders and the extreme risk of rape and violence to this population that exacerbates HIV-infection risk. Accurate data reporting requires the immediate discontinuation of the practice of categorizing transgender as MSM. Research should also be conducted to assess any issues or barriers to self-reporting transgender status, such as perception as male or female vs. transgender and stigma associated with transgender identification.

## **B. Socially and Culturally Oriented Recommendations**

### **1. Promote HIV/AIDS Prevention and Service Strategies Responsive to Latino Cultural Values and Experiences**

Academic research as well as National Council of La Raza-specific *promotores* and social-media efforts, combined with the work of other national and regional Latino-focused community-based HIV/AIDS agencies, point to the need for culturally and linguistically relevant HIV/AIDS prevention. These efforts must include the principles of community-based participatory research

to guide Hispanic-focused HIV/AIDS prevention, outreach, and education. Programs should underscore the strength of Latino social networks and families and include the following themes and messages:

■ **Integrate salient cultural values** to construct prevention efforts regarding the growing risk of HIV among Latino families. These efforts should enhance the resilience of Hispanic communities, encourage respectful communication between parents and youth, and decrease the incidence of domestic violence in relationships. The integration of cultural values with Spanish and Latin American indigenous language HIV/AIDS-prevention message development will resonate with underserved Latino communities and help increase overall awareness regarding the need to protect oneself and one's family and to engage in HIV testing.

■ **Enhance sexual risk communication in Latino families and communities**, thus culturally sanctioning sexual risk communication within Hispanic families and relationships, and removing taboos associated with protective sexual communication and behaviors.

■ **Challenge homophobia and transphobia within Latino families and communities in a culturally relevant manner.** This will better allow Latino youth with diverse genders and sexual orientations to gain acceptance and nurturance within their families and communities, thus leading to, and reinforcing, HIV-protective behaviors and diminishing violence toward LGBT community members.

■ **Emphasize the positive aspects of traditional gender roles**, focusing on the responsibility of Latino males to protect their partners and their families by communicating about their risk behaviors and using condoms, and the responsibility of Latina females to keep an open sexual dialogue with their families and to get tested as important strategies in taking care of her family. These approaches will provide the potential for framing "*machismo*" and "*marianismo*" with a positive and proactive lens.

■ **Promote awareness among and facilitate the empowerment of Latino youth** regarding both their growing risk for contracting the virus as well as the need to use condoms and build developmentally appropriate sexual-negotiation skills. Furthermore, educate youth regarding the gender and privilege issues related to the factors motivating sexual behavior, create testing incentives motivating youth to be screened for HIV, and develop contemporary interventions that correspond with the identities of being both Latino and young.

■ **Develop and evaluate culturally and linguistically relevant media campaigns targeting the Latino family and community.** Media campaigns engaging and educating Hispanics in HIV testing, decreasing homophobia and transphobia, and normalizing acknowledgement of HIV/AIDS and sexual risk are needed if we are to stem the tide of the epidemic among the youngest and fastest growing demographic in our nation. Promote the fact that many Latinos at risk for HIV have the misconception that 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 Latino families, utilizing relevant cultural values to improve message recognition and resonation. By focusing on the Latino family, the long-felt stigma associated with the virus can begin to be eliminated, as this changes the stereotypical

ideas around HIV and conveys the fact that those living with HIV are just like them. In addition, such models and strategies will do a great deal to engender a supportive family environment for Hispanics living with, and at high risk for HIV, which contributes greatly to the social support needed to adhere to HIV/AIDS prevention and treatment regimens. 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, avoidance of colloquial Spanish of any given subgroup or region is a necessity. Materials designed for youth may use both colloquial English and Spanish when necessary to resonate with young people who were raised in the U.S.

## **2. Conduct Contextually Oriented Research in Partnership with Latino Communities**

■ **Promote Latino-specific community-based participatory research in HIV/AIDS** that unites Latino-serving community-based organizations, AIDS service organizations, Latino community leaders, and Latino-focused academic researchers to facilitate culturally relevant HIV/AIDS intervention development and careful evaluation of outcomes. These opportunities can be used to mentor new organizations in the development of HIV prevention, outreach, and testing efforts. Many CBOs and ASOs are well established, recognized, trusted, and utilized by underserved Latino community members. They are often entrenched in the daily struggles of providing HIV/AIDS-related care that spans the difficulties that underserved and underinsured HIV-positive Latinos manage on a daily basis. Although these organizations often have critical insights that could help shape effective national research and intervention paradigms, their work is rarely reflected in the scientific realm of “peer-reviewed” journals and major conference presentations. By creating partnerships between researchers and Latino-serving institutions, new research paradigms that incorporate structural-environmental models to decrease Latino HIV risk can potentially compete for funding. This, in turn, will increase attention from the academic and medical communities, and improve and accelerate wide dissemination of effective interventions. Mentoring relationships between organizations allow for creative endeavors that can in turn provide services to other institutions such as those of an educational and/or religious nature. In this vein, training of community leaders and CBO staff to participate in the peer-review process would facilitate a broader lens from which to view contemporary HIV/AIDS research and prevention efforts.

■ **Fund, promote, support, and evaluate *promotores*-based HIV/AIDS research and intervention programs.** *Promotores* programs have been widely used throughout developing countries and provide underserved and often linguistically isolated communities with needed health-related information. The evolution of *promotoría* in the U.S. has clearly demonstrated the potential for *promotores* involvement in community-based participatory research efforts, via efficacious intervention results and positive evaluations related to their involvement.

*Promotores* resonate with the most underserved Latinos from diverse Latino communities and can provide 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 within the community. This can lead to peer education and research programs that provide upward career development to advance education and professional status, while filling critical voids in public health research and interventions for programs seeking to meet the needs of linguistically isolated populations.

■ **Allocate funds for HIV/AIDS prevention research efforts that are premised upon community-based participatory research methods to address structural-environmental issues placing Latinos at risk.** Clearly the behavioral risk-factor model has not reached the level of expected success because of its over-emphasis on behavior change, often without addressing contextual factors associated with societal barriers and the at-risk individual's environment. If lasting and sustained HIV/AIDS prevention and treatment efforts are to be achieved, considerable resources must be allocated to community-based participatory research efforts that address the multiple contexts of HIV/AIDS risk at multiple levels among diverse groups of Latinos.

■ **Increase funds for HIV/AIDS-prevention efforts in collaboration with Mexico, along the U.S.–Mexico border, and with Central and South American and Caribbean countries.** The steady rise of AIDS cases among Latinos born in Mexico and Central and South America warrants immediate attention. This is particularly relevant given that Mexicans and Mexican Americans represent 64%, Central Americans 8%, and South Americans 6% of the U.S. Hispanic population, respectively, thus representing nearly eight out of ten Latinos overall. Among Latinos of Mexican heritage, 40% are foreign born, while the proportion of foreign-born individuals from Central and South America is even higher (67% and 70%, respectively).<sup>234</sup> According to the U.S. Census Bureau, Latinos make up 53% of all foreign-born U.S. residents, with Mexicans being the largest single foreign country of birth, representing 30% of all foreign-born individuals.<sup>235</sup> Epidemiologic data indicate that infection is most likely to occur within the U.S. among immigrants, pointing to the lack of culturally and linguistically relevant outreach targeting Spanish and indigenous language-speaking populations.

### **C. Promote Formative Research Efforts to Enhance Latino Community Engagement in Recent Biomedical HIV Prevention and AIDS Treatment Approaches**

Although a number of medical interventions are being developed to prevent HIV infection, little has been done to determine the potential responsiveness of diverse groups of Latinos, particularly the Spanish speaking. Latino-specific community readiness for biomedical prevention interventions such as PrEP, PEP, microbicides, and HIV vaccine trials remains unknown. Furthermore, little has been done to identify issues that might interfere with treatment adherence among distinct groups of HIV-positive Latinos. In an effort to ensure that Latino communities fully benefit from, and engage in, upcoming prevention and treatment initiatives, formative qualitative research should assess specific barriers to medically based prevention as well as HIV treatment. There are specific needs to:

■ **Conduct focus groups and key informant interviews to enhance understanding of barriers and facilitators to PrEP, PEP, and vaccine trials** among diverse groups of Latinos with an emphasis on Latino MSM, MSMW, transgender MTF, and Latina women. Without knowledge of existing beliefs, attitudes, and factors that could facilitate access to these prevention mechanisms, Latinos will continue to be underserved and underrepresented among those receiving needed prevention just as they have with health care overall.

■ **Enhance understanding of barriers and facilitators to microbicide use among diverse groups of Hispanic women and their communities.** In preparation for microbicides, needs assessments associated with readiness are essential. Public health outreach, intervention, and

social-marketing specialists need to know gaps in Latino community knowledge, as well as perceptions and beliefs that may interfere with the use of microbicides. For example, we must determine the extent to which Latina immigrants are versed in the anatomical knowledge needed to ensure proper insertion and placement. Furthermore, culturally and linguistically relevant campaigns are needed to help Hispanic men and women learn about the specific risks associated with multiple sex partners to ensure widespread community acceptance of microbicides as part of a culturally sanctioned sexual health repertoire that reinforces correct vaginal and anal application.

■ **Learn more about barriers to medical regimen adherence among diverse Latino HIV-positive groups** so as to better address these barriers and medication side effects through message delivery. If HIV-positive Latinos are to experience a high quality of life, a greater understanding of potential barriers to treatment adherence (including potential ethnopharmacological considerations) must be gained and integrated into treatment protocols. Taboos associated with HIV treatment must be addressed so that HIV-positive Latinos are able to openly store, carry, and take their medications as needed and cultural assets and social support systems can be integrated into treatment to reinforce adherence and management.

## **V. CONCLUSION**

Our nation's future economic prosperity and quality of life depends on a healthy and thriving Latino population, the largest and youngest minority group in the U.S. By 2050 nearly one in three individuals in the U.S. will be of Hispanic descent, underscoring the need to make decreasing rates of HIV infection among Latinos a national priority now. The development of HIV prevention and outreach and AIDS-management strategies based on Latino-specific, community-based participatory research methods will ensure that HIV/AIDS prevention activities, interventions, and treatments resonate with Latino communities and subgroups nationwide. This cultural congruence is imperative to increase program efficacy and participation of Latinos. We must ensure through these efforts that no Latinos, regardless of gender, sexual orientation, immigration status, or risk profile, have to compromise their Latino identity when seeking prevention information, testing, or treatment.

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