

Integrando Nuestra Visión: **HIV/AIDS Prevention and Treatment** through a Latino Lens of Community- Engaged Theory, Research, and Practice

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Founded in 1968, NCLR is a private, nonprofit, nonpartisan, tax-exempt organization headquartered in Washington, DC, serving all Hispanic subgroups in all regions of the country. It has regional offices in Chicago, Los Angeles, New York, Phoenix, and San Antonio and state operations throughout the nation.

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INTEGRANDO NUESTRA VISIÓN:

HIV/AIDS PREVENTION AND TREATMENT THROUGH A LATINO LENS
OF COMMUNITY-ENGAGED THEORY, RESEARCH, AND PRACTICE

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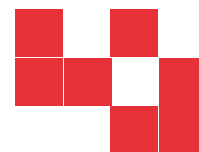
ACKNOWLEDGMENTS

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 the Hispanic community, largely through community health worker programs (*promotores de salud*) based in cities throughout the United States and Puerto Rico at NCLR's Affiliate Network of community-based organizations.

This paper combines a review of the existing literature, an overview of findings from community-based participatory research conducted at numerous community-based organizations, information from the Latino forum at the International AIDS Conference in Washington, DC, 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.

The paper was authored by Dr. Britt Rios-Ellis, professor and director of the NCLR/CSULB Center; Dr. Kurt C. Organista, professor at the School of Social Welfare at the University of California, Berkeley; Dr. Davida Becker, postdoctoral fellow at the Keck School of Medicine of the University of Southern California; Dr. Lilia Espinoza, assistant professor of Health Science at California State University, Fullerton; and Drs. Mara Bird and Gino Galvez, and Mayra Rascón, MPH, research associates at the NCLR/CSULB Center. The authors would like to thank Rita Heng and Monica Aguilar, MPH, graduate research assistants at the NCLR/CSULB Center, for their assistance in reviewing the literature. We also would like to thank the HIV/AIDS researchers, community-based and private organizations, and government contributors for research, statistics, and findings that contributed to the conceptualization of this paper. Our appreciation goes to Maria Victoria Rojas, the NCLR/CSULB Center graphic artist, for her preparation of the graphs and diagrams in this report, as well as Susan Wampler, editor at NCLR/CSULB Center; Alejandra Gepp, senior director of the Institute of Hispanic Health, NCLR; and Karen Nava Lazarte, director of Graphics and Publications, NCLR—all of whom assisted in preparing this document for publication.

The opinions expressed in this paper are solely those of the authors and not of any of our funders.



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*¹

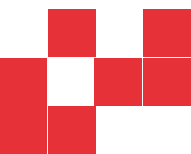
But my time in Juarez and El Paso with Marco, Oscar, Jose, and the other *compañeros* [was] not all about illness, death, and hardships. While we took our community work very seriously, we enjoyed it fully, or at least I did. The work became part of our own lives as it took over our evenings and weekends. It became a part of our friendships and our gayness. The camaraderie even among strangers filled our souls, gave us energy to do more than we were doing already, and ignited our creativity.

—*Jesus Ramirez-Valles*²

In this revision of the 2011 white paper on HIV/AIDS and Latinos,* the third in a series, the authors have chosen to approach this complex topic by addressing the multilevel contexts of HIV/AIDS within Latino communities. This approach to such a challenging health disparity enables us to better integrate Latino community and family systems to ensure that Latino cultural capital, resilience, creativity, and other community assets are central to the evolving HIV/AIDS prevention and treatment research paradigm. Only by integrating a Latino lens through which to develop and implement prevention and treatment strategies will our current scientific HIV/AIDS paradigm become powerful enough to promote greater health and social equity within our nation's largest and fastest growing minority population.

The goals of this white paper are to: 1) theorize about the multilevel causes and contexts of HIV/AIDS in Latino communities; 2) use national HIV surveillance data to describe the breadth and depth of the pandemic, particularly now that all fifty states are included in the national HIV/AIDS surveillance database; 3) provide a selective review and critique of state-of-the-art prevention and treatment research through a Latino lens that promotes cutting-edge work that integrates community and family systems, cultural capital, creativity, resilience, and other cultural assets into our nation's HIV/AIDS research paradigm; and 4) provide a series of recommendations ranging from project-specific improvements to ways of enhancing the HIV/AIDS research enterprise by infusing a Latino perspective. The paper concludes by briefly summarizing and distilling essential elements regarding how integration of a Latino lens will facilitate optimal and sustainable progress toward curbing the pandemic, especially during a period of shrinking resources. Furthermore, we seek to compel researchers and policymakers to recognize that HIV/AIDS, as it affects Latinos and other underserved populations, is a multilevel health disparity that requires multilevel solutions.

*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.

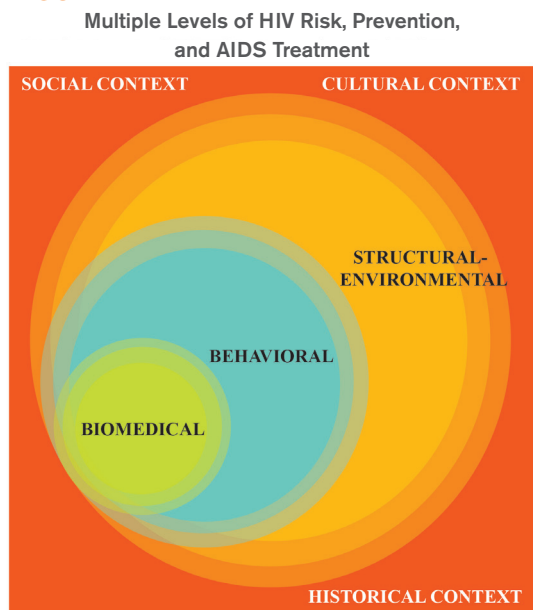


I. THE DISPROPORTIONATE IMPACT OF HIV/AIDS ON LATINOS IN THE U.S. THROUGH A LATINO LENS OF COMMUNITY ENGAGEMENT

More than thirty years into the HIV/AIDS pandemic, pausing to reflect on our progress—and at times the lack thereof—is essential if we are to reinvigorate our efforts to tackle this biopsychosocial disease. To catalyze such reflection, a short series of bold questions and statements is presented here that compels us to consider the multiple dimensions of this complex health disparity.

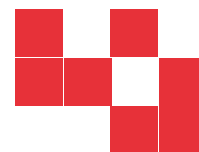
- Is HIV homophobic, racist, sexist, transphobic? Or does the virus mirror stigma and discrimination in the United States by exploiting the fault lines of inequality that separate different groups and exposing them to varying degrees of vulnerability to disparities in socioeconomic status (SES), health, and well-being?
- HIV/AIDS is a health disparity that over-affects minority groups along the lines of sexual orientation, racial and ethnic minority status, gender and gender identity, and SES. As such, it is as much a social problem as a biomedical or behavioral problem and requires social solutions beyond biomedical and behavioral interventions.
- HIV/AIDS over-affects people whose group memberships have exposed them to stigma and discrimination, historically and today, resulting in social disadvantage and a heightened vulnerability to psychosocial and health problems.
- Conquering HIV/AIDS requires social, cultural, and structural-environmental understanding and sustained solutions to contextual problems that have been associated with health disparities throughout our nation's history.

FIGURE 1



Sources: Kurt Organista, "The Urgent Need for Structural-Environmental Models of HIV Risk and Prevention in Latino Communities" (presentation to staff from the Office of National AIDS Policy, Long Beach, CA, February 13, 2013); and Britt Rios-Ellis, personal communication among authors, May 20, 2013.

Factors related to the disproportionately high rate of HIV/AIDS in U.S. Latinos—now representing 16.7% of the U.S. population³—are multilevel and complex, and include structural-environmental, social, cultural, and situational factors that produce and reproduce health disparities. Although the Latino population is extremely diverse, most of its members experience common factors that may place them at increased risk for HIV/AIDS, including the usual social determinants of health: high rates of poverty, stigma and discrimination, and limited educational and occupational opportunities, as well as those related to their immigration status, such as broken immigration policies, migration-related mobility and isolation from family and country of origin, rigid gender and age-role expectations, and the spread of HIV/AIDS back to sending communities in Latin America via male migrant workers marginalized by current national policies regulating the flow of labor migration in the U.S.⁴ Latinos also face 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. Latinos also often reside in densely populated urban areas where HIV and AIDS are typically concentrated,⁵ rendering place-based prevention and treatment strategies increasingly imperative. The purpose of this section is to convey an understanding of HIV/AIDS among U.S. Latinos through a Latino lens that emphasizes the context of risk within multilevel social, cultural, and structural-environmental factors.

A. Addressing the Social-Environmental Context of HIV Risk

Whereas HIV prevention continues to emphasize biomedical solutions augmented by individual behavior-change strategies, HIV risk for Latinos occurs within a much larger social-environmental context that includes poverty and discrimination,⁶ lack of educational and occupational opportunities,⁷ frequent undocumented immigration status,⁸ and inadequate housing.⁹ For too many, socioeconomic disparities make health and self-care practices quite challenging.¹⁰ The importance of understanding the multilevel context of risk is punctuated in a statement by Dr. Jonathan Mermin, director of the Centers for Disease Control and Prevention (CDC)'s Division of HIV/AIDS Prevention, who said, "We can't look at HIV in isolation from the environment in which people live."¹¹

While poverty can contribute to a sense of resignation and powerlessness toward health and self-care practices, there is growing recognition that those challenged by poverty often exhibit impressive resilience and health behaviors that are innovative, creative, and warrant integration into contemporary HIV/AIDS research frameworks. As opposed to focusing solely on SES-associated deficits, researchers are becoming cognizant of the resilience developed in challenging circumstances and how it can be utilized to promote healthy community development, including adherence to HIV/AIDS prevention and treatment protocols. The integration of Latino community and cultural assets into our prevention efforts will enable us to transcend limitations that are built into one-dimensional biomedical or behavioral approaches that seem to have reached diminishing returns, as illustrated below.

Limitations of behavioral interventions. A systematic review and meta-analysis of the twenty most rigorous behavioral interventions for Latinos in the U.S. and Puerto Rico, documented in studies published between 1988 and 2005, illustrate the positive yet diminishing returns of Latino-specific behavioral prevention interventions.¹² That is, while the review reveals consistent reductions in unprotected sex (25%), multiple sex partners (25%), injection-drug use (IDU) (17%), sharing drug-injection equipment (27%), and incidence of sexually transmitted diseases (STDs) (31%), as well as an increase in condom use (56%; Figure 2),¹³ it ultimately raises 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.¹⁴ suggest a level of diminishing returns? According to Organista,¹⁵ if the social, cultural, and community context of behavioral risk is not better understood and strategically incorporated, we may not be able to exceed the overall 26% risk-reduction rate. 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. in their review of behavioral prevention interventions with Latinos. Hence, we must begin to contextualize behavioral risk for HIV among Latino groups in various risky situations, environments, and social locations. Thus it is time to creatively enhance primary prevention efforts in Latino communities rather than de-emphasizing them simply because treatment for AIDS has become increasingly effective under controlled research conditions. That is, while it makes sense to promote national prevention efforts that focus on identifying the HIV seropositive and extremely high-risk individuals to ensure their treatment, this process should not occur at the expense of equally urgent primary prevention and HIV/AIDS education—especially if the latter integrates and capitalizes on Latino community and cultural assets.

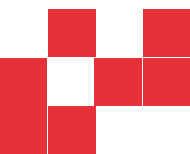
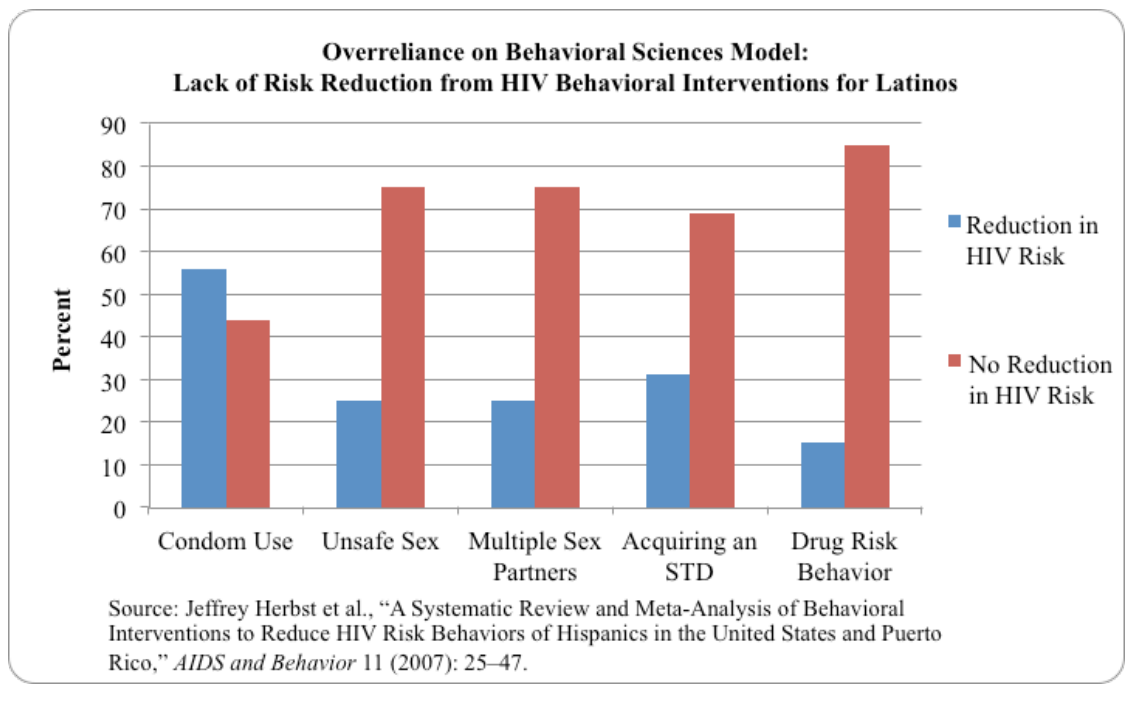


FIGURE 2

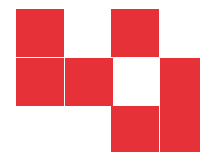


1. Socioeconomic Status and Poverty

Although poverty within underserved communities is increasingly recognized as a contextual risk factor for HIV/AIDS and other health disparities, it is becoming equally important to recognize the underlying resilience and adaptability of individuals who have managed impoverished situations. Such recognition facilitates the researcher's and health care professional's ability to better understand how such coping strategies or community activities can be employed to optimize care and prevention in under-resourced environments.

A strong association exists between HIV and poverty.¹⁶ Indeed, a CDC analysis shows that poverty is the single most important demographic factor associated with HIV among inner-city heterosexuals, and is more influential than the severe racial disparities that characterize the overall U.S. epidemic.¹⁷ In 2011, nearly a quarter of Latinos were living below the poverty line, with incomes lower than all other racial/ethnic groups except Blacks and Native Americans.¹⁸ Latinos were the group most likely to have no health insurance, with 40.7% reporting no health insurance in 2011.¹⁹ Although evaluation of health status and disease vulnerability is intrinsically tied to poverty, researchers are sorely lacking a lens that allows for integration of cultural and resiliency-based wealth. As opposed to utilizing what could be termed the *pobrecito* [poor thing] approach to evaluating Latino health disparities, it is essential for researchers and interventions to begin recognizing, integrating, and optimizing cultural capital and assets to ensure sustained efficacy long after program funding has expired.

Low educational attainment is a marker of SES that correlates strongly with higher death rates from many conditions, including HIV.²⁰ 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.²¹ Moreover, death due to HIV was one of the most extreme differences, in relative terms, found to result from lower education.²² Lower SES decreases access to risk-reduction information, which is particularly exacerbated among monolingual Spanish or indigenous Latin American-language speakers. Moreover, in an attempt to meet immediate survival needs, the poor may seek income and other resources through activities that place them at higher risk for HIV, or simply succumb to vulnerable states of dislocation.²³ A study conducted by Diaz et al. found a strong association between poverty and what they called *social oppressors* that increased psychological distress in Latino men who have sex with men (MSM), as well as the propensity for participation in high-risk sexual situations (e.g., sex under the influence of alcohol or drugs; sex to relieve depression and loneliness).²⁴

One in five children living in the U.S. is Hispanic.²⁵ The low SES 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.²⁶ Low SES 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 disempowerment, which has been demonstrated to increase risky sexual behavior. Such circumstances are exacerbated for immigrant Latinos in general and the undocumented in particular.

2. Immigration, Acculturative Stress, HIV Vulnerability, and Resilience

The continuous flow of Latinos immigrating to the U.S. has several implications for vulnerability to psychosocial and health problems, including HIV, given the frequent interaction between immigration issues, SES, and poverty 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 charged political climate. How Latinos cope with stigma and discrimination, on both the individual and community level, warrants further study as a critical component of the context of risk experienced by Latino communities nationwide.²⁷

With regard to migration-related stress, Apostolopoulos et al. used ethnographic methods to assess how individual and environmental factors intertwine, rendering Mexican farm workers vulnerable to sexually transmitted infections (STI)/HIV risks in both Arizona and South Carolina.²⁸ The primary stressors noted by these migrant men 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, 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 serostatus²⁹ and use of health care services.³⁰ 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 with less acculturated teens, suggesting a higher motivation to use contraception and thus avoid unplanned pregnancy, STIs, and HIV.³¹ 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.³² 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

peers³³ and more likely to maintain their religiosity, leading to reduced levels of sexual behavior.³⁴ The above underscores both risks inherent in acculturation for Latinos but also what appear to be protective cultural values and practices that we need to understand better in order to reinforce and utilize in disease-prevention and health-promotion campaigns.

B. Cultural Factors and HIV Vulnerability

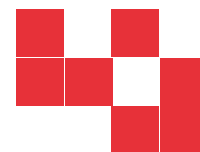
1. Language

Language has long been an obvious cultural factor to consider in Latino disease prevention, and recent data continue to underscore this need. More than one in ten U.S. residents now speaks Spanish at home, making it the second most commonly spoken language after English.³⁵ Among these residents, approximately half report an ability to speak English less than “very well.”³⁶ In a study of 45,076 Spanish- and English-speaking Hispanic adults in twenty-three states, researchers found that Spanish-speaking Latinos have far worse health status, less access to care, and less preventive care when compared with their English-speaking counterparts. The study showed that 39% versus 17% reported being in fair or poor health, 55% versus 23% were uninsured, and 58% versus 29% reported not having a personal physician, for Spanish- versus English-speaking participants, respectively.³⁷ 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 AIDS treatment information and risk-reduction interventions.

2. Religion, Cultural Taboos, and HIV Stigma

Role of women. Religion is thought to be a protective factor in that it discourages multiple sexual partners and encourages periods of abstinence and sexual conservatism. At the same time, religion has frequently been associated with intolerance toward homosexuality³⁸ and beliefs against contraception. For Latinas whose principal risk factor is sex with their primary male partners, religion may function less as a protective factor because women are often prescribed submissive functions 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.³⁹ While gendered HIV prevention with Latinas that considers power differentials, sexual health, economic hardship, domestic violence, etc., has been described, little focus on the role of religion (e.g., Catholicism) has occurred.⁴⁰ Although challenging, such consideration could begin with dialogues among clergy, women, researchers, etc.

Youth. In a cross-racial study of youth and sexual activity, Tolma et al. 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.”⁴¹ In a contemporary 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.⁴² 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* [familism] and gender roles.⁴³ 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. Mixed findings on the role of religion in Latino youth warrant more research that engages both religious and family systems in exploring this important cultural factor in the age of AIDS.



Sexual orientation. As in other cultures, homophobia and transphobia (i.e., stigma and discrimination against transgendered people) are prominent in Latino communities and religious institutions. 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 to explore and address the dilemma of lesbian, gay, bisexual, transgender, and queer (LGBTQ) Latinos and religious institutions. Preliminary qualitative research indicates that many LGBTQ believe church attendance is integral to their spiritual health but often change their dress or sit away from their partners during church services so as not to be identified as gay, lesbian, or transgendered.⁴⁴ HIV-positive individuals attributed their spiritual practices to their ability to maintain their health. These findings underscore the difficulties associated with maintaining one's religious practices, which are associated with spiritual health, and one's sexual or gender orientation, leaving little space for religious integration for LGBTQ populations. 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.

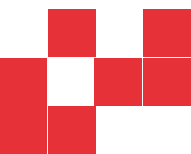
Stigma. Despite the support provided by some religious institutions in Latino communities, stigma related to sexual-minority status represents a formidable impediment to HIV prevention that must be addressed. Stigma is a common human reaction to any disease or state construed as "different." Stigma undermines public and private efforts to combat discrimination relating to HIV/AIDS, 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, and can also affect a person's general context of well-being (e.g., through denial of employment).⁴⁵ Furthermore, stigma affects the treatment that people living with HIV receive in their respective communities and families, and from their partners.⁴⁶ The use of substances and the practice of risky sexual behavior may function as maladaptive coping strategies in response to that stress.⁴⁷ Therefore, decreasing HIV/AIDS-related stigma is a vital step in stemming the epidemic, and religious institutions need to be included in such efforts.⁴⁸

3. Latino Family Systems and HIV Vulnerability and Prevention

Social and cultural factors that render Latinos more vulnerable to HIV risk as described above affect Latino youth in developmentally sensitive ways that need to be understood to inform prevention efforts. For example, 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.⁴⁹ Such an intervention focus is urgently needed as the data on HIV risk among Latino youth convey.

Latino youth represented 21% of the teen population in 2011, and Hispanics age 13–19 represented 21% of AIDS diagnoses among teens, while Latino young adults age 20–24 (20% of the U.S. young adult population) accounted for 18% of new AIDS diagnoses.⁵⁰ At the end of 2010, Latino females age 13–24 accounted for 18% of youth living with HIV, while males accounted for 19%.⁵¹ According to data from the 2009 Youth Risk Behavior Surveillance System, Latino high school youth were more likely to have engaged in sexual intercourse compared with 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 with their White and Black counterparts (55%, 61%, and 63%, respectively).⁵² 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.⁵³

Research has shown that Latino parents can have a major influence in shaping the sexual attitudes and contraceptive behavior of adolescents.⁵⁴ One study found that parent–child communication,



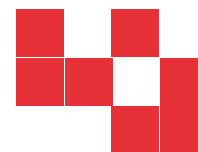
specifically the communication between mothers and daughters, has proven to be influential in the reduction of risky sexual behaviors among adolescent girls.⁵⁵ Other studies have emphasized the quality as opposed to the frequency of mother–daughter interactions as protective against risky sexual activity among White, Black, and Hispanic adolescent females.⁵⁶ Furthermore, adolescent females who reported less-frequent communication about sexual topics with parents also reported fewer discussions with partners about STIs and HIV/AIDS, less frequent condom use, and lower self-efficacy to negotiate safer sex or refuse an unsafe sexual encounter.⁵⁷

While the majority of research on family factors and HIV risk has focused on heterosexual Latino youth, a growing body of research has revealed that family can play a major role in shaping sexual risk behaviors and HIV-testing behaviors in other populations, including gay and bisexual men and migrants. The need to belong and to be accepted by family was found to be related to HIV sexual risk-taking behaviors of Latino MSM in several studies.⁵⁸ In one qualitative study with Mexican American MSM in Dallas, men reported that they engaged in protective sex behaviors out of respect for their family. As one participant commented, *“I definitely think that my close bond with my family helps me to stay [HIV] negative. My family totally supports a gay, safe lifestyle. They support safe sex. I don’t want to let them down.”*⁵⁹ Other research with lesbian, gay, and bisexual youth found that family rejection of youth sexual orientation in adolescence was associated with unprotected intercourse, as well as other negative health outcomes, and that Latino men reported the highest number of negative family reactions to their sexual orientation in adolescence of all groups studied.⁶⁰ A recent literature review examining parental influences on the health of lesbian, gay, or bisexual youth recommended more research to understand parental influences on sexual behaviors and more focus on positive parental influences, as the majority of past studies have focused on negative influences.⁶¹

A recent study of Latino migrant men in a new receiving community that examined HIV/STI risk behavior found that drug use and high mobility were associated with sexual risks, and that having family in one’s household was a protective factor.⁶² Another study with men of Mexican descent living in the Midwest found stronger HIV-testing intentions among men who perceived the HIV test to have benefits to their family and community.⁶³

4. Cultural Values, Norms, and Roles

Despite the importance of family and the degree to which *familismo*—a cultural value emphasizing the strength of family unity and the degree to which a person experiences family attachment—is valued across Latino cultures, studies have shown that Latino parents experience difficulty discussing sexuality and contraception with their children⁶⁴ 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.⁶⁵ For example, an experimental intervention was conducted with two attention-control conditions in a sample of 266 eighth-grade adolescents and their primary caregivers.⁶⁶ 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 from their last intercourse than those in one control condition. In addition, none of the adolescents in the experimental condition reported contracting an STI, compared with 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 need to involve family systems in challenging cultural obstacles by encouraging families to engage in open communication about sexual topics and by building upon cultural assets such as core Latino values, including *familismo* and *respeto*.



Familismo and respeto. As in many cultures, a great deal of information regarding health and behavior is learned within Latino families, and *familismo* is a significant tenet across Latino subpopulations.⁶⁷ *Familismo* is pronounced within Latino cultures, where individualism is less valued and family unity is often perceived as key to successful adaptation and advancement in the U.S. *Respeto*, defined as respect for one's elder relatives and persons of authority, is also highly valued within traditional Latino families. Given the influence of *familismo* and *respeto*, Latino parents have the potential to positively affect the sexual-health behaviors of their children in ways not previously considered.

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,^{†68} which included less rigid gender roles, and valued *confianza* [trust].⁶⁹ 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* [lack of 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, because Latinas may not ask their husbands to use condoms for fear of showing disrespect.

Cultural values may also shape the experiences of HIV-positive Latinos. A study from the mid-1990s that examined nondisclosure of HIV serostatus among HIV-positive Latinos and Whites found that Spanish-speaking Latinos were more likely than English-speaking Latinos or Whites to withhold their HIV-positive serostatus from significant others, particularly family members. This nondisclosure was related to a desire to prevent family members from worrying, which was stronger for Latinos than Whites.⁷⁰ Traditional cultural values such as *familismo* and *simpatía*, a cultural value that supports harmonious interpersonal interactions, may present barriers preventing HIV-positive Latinos from seeking support from their social networks in times of need.⁷¹ Given the publication date of this study, the need to understand how familism can support treatment adherence in the era of antiretroviral therapy (ART) is warranted if we are to invert the pyramid.

Machismo and marianismo. Certain characteristics associated with traditional gender roles have been reported to create an imbalance of power in sexual relationships.⁷² These include elements of *machismo*, described as negative male characteristics that 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*, because they are linked to increased unprotected sexual encounters and multiple sexual partners among men.⁷³ 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 efforts to encourage men to get tested and to use condoms. Scholars have developed more sophisticated measures of *machismo* that incorporate both positive and negative elements.⁷⁴ In a recent study with HIV-positive Latino men in Los Angeles, researchers found both positive and negative aspects of *machismo* were associated with adherence to HIV medication. Negative aspects of *machismo* were associated with lower odds of HIV-medication adherence (or = 0.56, 95% CI: 0.36–0.88), while positive aspects were associated with higher odds of adherence (or = 1.86, 95% CI: 1.17–2.98).⁷⁵ *Marianismo* encompasses a similar protective element, wherein it is the mother's duty to care for the family. Emphasizing sexual

[†]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.



risk as a key health responsibility of parents may serve to increase openness to sexual discussion with children as well as HIV testing, and these behaviors may then support their families' health.

C. Structural Factors and HIV Risk

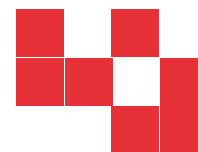
The aforementioned discussion of Latino-relevant social and cultural factors lays a foundation for a structural-environmental perspective in which proximal behavioral risk factors are viewed as produced and reproduced by distal causal-structural factors, consisting of formal and informal institutions, policies, norms, and values that produce and reproduce risky environments. While challenging, such a perspective helps us theorize and describe the pathways between distal structural-environmental factors and proximal risk factors at the individual level. The advantage of theorizing such pathways for different Latino groups is that it can reveal multiple levels of risk and potential prevention-intervention sites (e.g., not simply at the behavioral level but also at community and policy levels). Below are a few salient examples of Latino-relevant structural factors that exacerbate HIV and other psychosocial and health disparities.

1. Lack of Health Insurance and Implications of the Patient Protection and Affordable Care Act of 2010 (ACA)

Lack of health insurance—disproportionately high for Latinos—is one of the most compelling structural markers of several health disparities, including HIV/AIDS. Research shows that uninsured individuals are more likely to be unaware of their HIV status until late in their HIV disease progression, cannot afford expensive treatment regimens, and are unaware of the federally funded Ryan White HIV/AIDS Program,⁷⁶ which provides HIV care to uninsured and underinsured individuals.⁷⁷ 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, the uninsured rate for Latinos under the age of 65 rose to 33%—making Latinos more than twice as likely as their non-Hispanic counterparts to be uninsured.⁷⁸ Furthermore, among the uninsured, Latinos (40%) were more likely than non-Hispanics (12%) to have never been insured.⁷⁹ Although U.S. health insurance historically is more likely to be tied to employment, for Latinos this is not the case.

Despite regular immigration, the largest increases in the uninsured between 2008 and 2009 were among working, adult, U.S.-born Latinos. It is important to note that when workers lose employment-based insurance there is often a ripple effect, as dependents also become uninsured. Of course, lack of insurance and subsequent lack of health care access are most alarming among undocumented Latino immigrants and their children, who comprise 17%⁸⁰ of the estimated 46 million Americans who lack health insurance.⁸¹ Hispanics (17%) were less likely than non-Latinos (32%) to be uninsured as a result of loss of, or change in, employment.⁸² According to a recent analysis conducted by the Pew Hispanic Center, six in ten Hispanic adults living in the U.S. who are not citizens or legal permanent residents lack health insurance.⁸³ 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%).⁸⁴

Although the Patient Protection and Affordable Care Act of 2010 (ACA) will facilitate health insurance for millions of Latinos, fourteen states have opted out of participating in the health care exchange programs, including Alabama, Alaska, Georgia, Idaho, Louisiana, Maine, Mississippi, North Carolina, Oklahoma, Pennsylvania, South Carolina, South Dakota, Texas, and Wisconsin.⁸⁵ A total



of 13,451,982 Latinos reside in these fourteen states, many of whom—despite citizenship and gainful employment—will remain uninsured. Another five states— Kansas, Nebraska, Utah, Virginia, and Wyoming—are leaning toward not participating. An additional 1,507,843 Latinos reside in the states leaning toward not participating in the ACA exchange. Thus, nearly fifteen million Latinos reside in states in which ACA exchanges will likely remain unavailable. Furthermore, the vast majority of the fourteen states whose legislative officials have opted out of the ACA are among those with the fastest-growing Hispanic populations, including South Carolina and Alabama, which experienced Latino population growth from 2000 to 2010 of 147.9% and 144.8%, respectively. In fact, of the fourteen states opting out of the ACA, twelve experienced Latino population growth ranging from 73% to 147.9%.⁸⁶

Considering that Latinos are under- or uninsured, and hence lack access to institutionalized health care programs, creative campaigns that incorporate cultural values and assets such as *personalismo* [a personalized approach to communication], and *familismo* are urgently needed. 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. For example, campaigns such as *Soy* [I Am] and *Tú No Me Conoces* [You Don’t Know Me] illustrate effective messaging to increase HIV prevention, outreach, and testing.⁸⁷ 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 website, 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 get tested. Both campaigns instilled concern, personalization, and motivation in Latino communities to test for HIV.

2. Obstacles to HIV Testing

Lack of health care. Despite the promise of the above culturally competent campaigns, they comprise but one of many multilevel approaches to decrease HIV risk by promoting HIV testing in those with low access to health care. 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 with individuals who know they are HIV-positive.⁸⁸ The HIV/AIDS epidemic would be lessened substantially by increasing the proportion of HIV-positive persons who are aware of their status.⁸⁹ In 2006, the CDC issued HIV-testing recommendations that call for routine HIV screening for all patients age 13–64.⁹⁰ 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. Approximately half of Latinos (53%) age 18–64 report ever having been tested for HIV.⁹¹ Population-wide studies indicate that Latinos are more likely than Whites to be “late testers” for HIV.⁹² According to CDC data, 36% of Latinos were tested for HIV late in their illness, meaning that they were diagnosed with AIDS within one year of testing positive.⁹³ Further, a study showed that immigration status was significantly associated with delayed HIV presentation among Latinos.⁹⁴ While the twenty-year ban on allowing HIV-positive persons to enter the U.S. has been repealed, a large number of Latino immigrants may be unwilling to test for HIV for fear of jeopardizing their future residency status.⁹⁵ While recent studies have not found immigration status to be a significant factor for not testing for HIV,⁹⁶ 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 on (greater than five years between the first reported HIV-positive test and an AIDS diagnosis) when compared



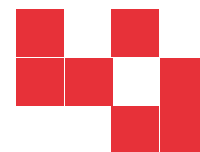
with non-Latino Whites.⁹⁷ A study with 247 immigrant Latinos receiving health department outreach services in Baltimore examined factors associated with previous HIV testing. Surprisingly, self-perceived HIV risk was not associated with actual HIV risk behaviors or with HIV testing. Factors positively associated with prior HIV testing were knowledge of HIV transmission modes and the fact that an HIV-positive individual may appear healthy. The authors emphasize that these findings highlight the importance of not limiting HIV testing among immigrant Latinos to those who have self-perceived risk for HIV.⁹⁸ Another study that examined the correlates of voluntary counseling and testing for HIV in a population of 135 middle-aged and older Latinas in South Florida found that the strongest predictor was health-provider endorsement of testing, followed by having a clinic as a regular source of health care,⁹⁹ highlighting the important role that health-system factors play in HIV testing.

Stigma. Anti-stigma campaigns are badly needed in Latino communities. Research indicates that Latinos avoid seeking testing, counseling, or treatment, due to lack of perception of HIV risk and fear of embarrassment, rejection, and stigma.¹⁰⁰ Language barriers, perceived cost of HIV-testing services, and fears of deportation are also cultural and structural impediments to testing.¹⁰¹ Levy et al. found that for Latinos, especially immigrants, lack of knowledge of HIV risk contributed to delayed HIV testing.¹⁰² Latinos often test for HIV because of clinical presentation versus perceiving themselves to be at risk for HIV, and more frequently present with AIDS, opportunistic infections, or other co-infections compared with Whites or Blacks.¹⁰³ Regarding stigma, a national survey found that 36% 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.¹⁰⁴ When asked whether, 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.”

Migration. The high mobility of migrant workers and their lack of access to health care and HIV testing mean that STI and HIV-positive 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, and sex with casual partners and commercial sex workers), making Latino migrants greatly vulnerable to HIV and low testing.¹⁰⁵ Furthermore, what migrant men call *desesperación* [desperation] 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 risky sexual behaviors with men and commercial sex workers.¹⁰⁶

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 who are HIV-positive, 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 lowered risk of medication side effects. Additional benefits may be conferred across the population, potentially slowing new cases of HIV.¹⁰⁷ Novel HIV-testing strategies are imperative in order to identify HIV-positive status at an earlier stage and offer early entry into treatment. For example, one 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 some subgroups of Latino men were more likely to test for HIV when it was bundled with other medical tests.¹⁰⁸ This bundling may serve to reduce stigma associated with HIV testing, and thus provide a promising strategy to increase testing in this group.

Hombres Sanos [Healthy Men] used a social marketing approach to increase HIV testing and condom use in the population of heterosexually identified Latino men, including heterosexual men who have sex with both men and women (MSMW) in North San Diego County. The campaign promoted a general health exam for men that included HIV/STI risk assessment, testing, and counseling along with a battery of other tests for high-prevalence conditions with lower stigma levels, such as diabetes



and hypertension. This health exam was made available to men on a sliding-fee scale, from bilingual and bicultural staff at a local community clinic, with transportation provided for those in need. Both condom use and the general health exam were promoted in the community using a variety of media. An evaluation following the effort found that participants exposed to the campaign reported increases in condom use when having sex and increased likelihood of making an appointment to receive the general health exam, and that the campaign appeared to have been particularly effective in the MSMW population.¹⁰⁹ Many obstacles to HIV testing also apply to HIV/AIDS treatment for Latinos in need.

3. Obstacles to HIV Treatment

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.¹¹⁰ Furthermore, medical guidelines in Mexico require the physician to spend considerable time discussing health issues with the patient prior to the physical examination.¹¹¹ The formalized health care systems in the U.S. 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.¹¹² 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-speaking health care providers and materials; and confusing, unwelcoming facilities.¹¹³

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 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, co-located HIV services; and care coordination across providers.¹¹⁴

Data indicate that while 80% of HIV-positive Latinos are diagnosed and two-thirds are linked into care, only 37% remain in regular care, only a third are prescribed ART, and only 26% are virally suppressed. The percentage of HIV-positive Latinos who are virally suppressed is lower than the percentage among HIV-positive Whites (30%).¹¹⁵ Additional studies have also found HIV-positive Latinos have lower retention in HIV care compared with other populations. For example, a recent study with HIV-positive young MSM found lower retention in HIV care among Latino MSM compared with Black MSM.¹¹⁶

One study with 470 HIV-positive Latinos on the U.S.–Mexico border examined barriers associated with delayed entry into HIV care. The researchers found that the primary barriers were at the structural and systems levels, including the cost of medications and services. Cultural barriers were not found to be major factors contributing to delays in entering HIV care.¹¹⁷ Another study that examined retention in HIV care among HIV-positive Latino and Black MSM and women found that disclosure of HIV status to a greater number of social-network members was associated with



higher retention in care. Additionally, greater stigma of homosexuality was associated with poorer retention in care among Latino MSM.¹¹⁸ Other research has found that the quality of patient-provider relationships can be a factor contributing to engagement and retention in HIV care, as well as HIV-medication adherence.¹¹⁹ In a qualitative study with undocumented HIV-positive Latino immigrants, HIV stigma and structural barriers associated with being an undocumented immigrant were found to be factors that interfered with entry into and retention in HIV care.¹²⁰

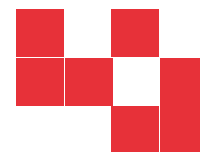
Researchers have also tested novel strategies to increase engagement and retention in HIV care among HIV-positive Latinos. One study found that case management at a clinic improved retention in care among HIV-positive Black and Latino MSM age 18–24.¹²¹ Another initiative used a social-marketing approach to improve engagement and retention in care among young MSM of color in North Carolina.¹²² Other interventions found to be effective at improving retention in HIV primary care include: peer navigation, reducing structural- and systems-level barriers, including peers as part of the health care team, displaying posters and brochures in waiting rooms to promote retention, asking medical providers to present brief messages to patients, and having clinics stay in closer contact with patients over time.¹²³ While few interventions currently target HIV-positive Latinos, the studies reviewed above support future efforts that utilize medical staff, campaigns, community health workers, social networks, and peers to decrease barriers ranging from stigma and homophobia at the cultural level to decreasing financial obstacles and lack of documentation at the structural level.

II. THE GROWING VULNERABILITY OF LATINOS IN THE UNITED STATES TO HIV/AIDS

More than thirty years into the epidemic, HIV/AIDS continues to exact a toll on populations most vulnerable to stigma, discrimination, and social and economic dislocation. The disproportionate impact on Latino communities is evident throughout the U.S. and Puerto Rico. In 2011, although Latinos constituted 16.7% of the U.S. population, they accounted for 22% of the total estimated number of diagnoses of HIV and AIDS among adults and adolescents in the fifty states, including the District of Columbia, and six U.S.-dependent areas.¹²⁴ In 2011, the estimated rate (per 100,000 population) of diagnoses of HIV among Latino males was three times the rate of diagnoses of HIV among White male counterparts (43.4 and 14.5, respectively). Further, Latina females had four times the rate of HIV diagnoses compared with White females (7.9 and 2.0, respectively).¹²⁵

Latinos also continue to be more likely (62%) than Blacks (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%; Blacks 32%; Whites 32%).¹²⁶ Sadly, HIV testing most often occurs among Latinos after they have become HIV symptomatic,¹²⁷ which frequently leads to less effective and more aggressive treatment. In short, Latinos are the last to be tested for HIV and the first to develop and die from AIDS. Consequently, they often unknowingly have the potential to transmit HIV to others in their families and communities.

As the number of Latinos in the U.S. continues to increase, diagnoses of HIV among Latinos in comparison with Native Americans, Asians, Pacific Islanders, and Whites will remain disproportionately high unless effective strategies to reduce HIV/AIDS risk among the Latino population are developed and implemented.¹²⁸ Reasons for the disproportionately high distribution of HIV/AIDS among U.S.



Latinos are complex and include macrostructural factors such as poverty, discrimination, lack of health insurance, and lack of access to medical care. Social and cultural factors that affect rates of HIV/AIDS, 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 our ability to effectively intervene and reduce HIV/AIDS disparities must engage with the various complexities that frame the lives of Latinos in the U.S.

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,¹²⁹ 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 2010,¹³⁰ constituting “new growth” communities of immigrant Latinos. HIV/AIDS is spreading through the southeastern U.S., particularly in the Deep South[†] where HIV and AIDS cases among Latinos are rising at a steady rate.¹³¹

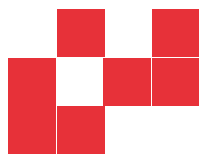
Structural factors contributing to the spread of HIV/AIDS in the Deep South are high rates of poverty, geographic and transportation barriers, and a lack of health care infrastructure.¹³² Here, two million Latinos face severe barriers to health care and preventive services, and these states are further restricting Latinos’ access to HIV/AIDS prevention and care by excluding immigrants from government health-promotion efforts.¹³³ Furthermore, HIV/AIDS prevention and service organizations have significant shortages of bilingual service providers, while distrust of health care providers is growing among Latinos who face anti-immigrant discrimination.¹³⁴ As such, the need for Latino community-engaged efforts is paramount; illustrations are provided in Section III.

B. Latino HIV/AIDS Cases by Country of Origin

A recent study of 24,313 HIV-positive Hispanics found that 61% were born outside the U.S.¹³⁵ While 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 3),¹³⁶ data from the CDC indicate that from 1995 to 2011, AIDS cases among Mexican-born Latinos more than doubled from 7% to 17%. 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.¹³⁷ 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 11%. The decline in AIDS cases in Puerto Rico is primarily due to health care reform on the island and the use of highly active antiretroviral therapy (HAART),¹³⁸ while the overall low rates among Cuban Americans correlate with their historically high 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.¹³⁹ For example, upon seeking care, foreign-born Latinos have lower CD4 counts compared with U.S.-born Latinos, with the Mexican-born having a shorter HIV-to-AIDS interval than U.S.-born Latinos.¹⁴⁰ There is also evidence that large proportions

[†]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.

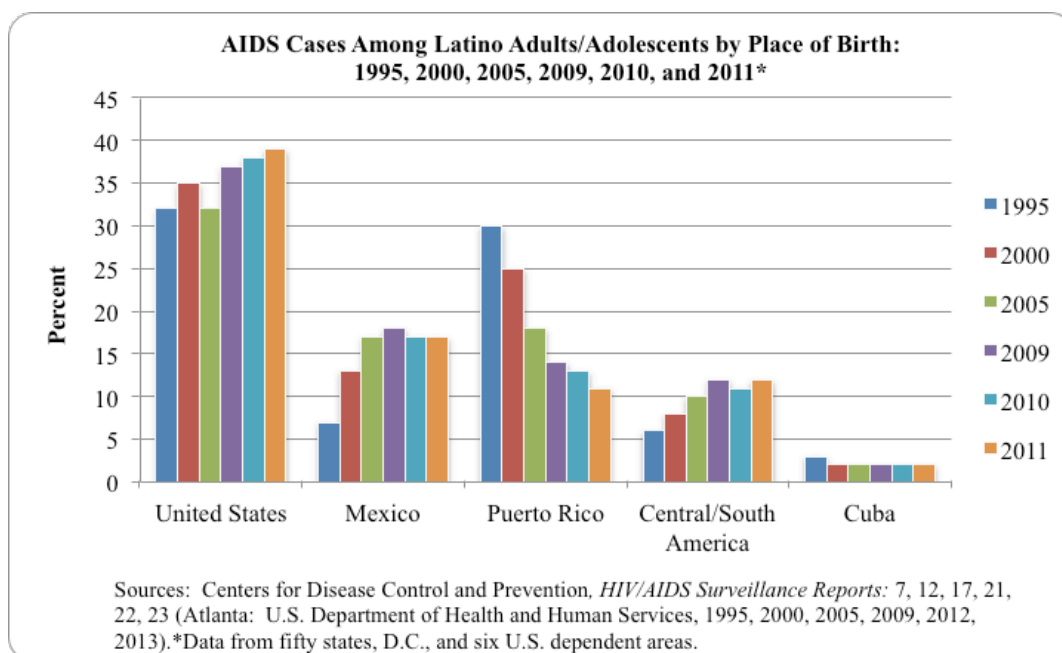


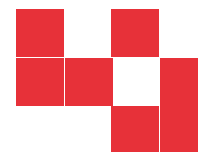
of HIV-positive Latino men born in Puerto Rico acquire HIV from IDU compared with other Latino subpopulations.¹⁴¹ The high rate of IDU in Puerto Rico and among Puerto Ricans in the mainland U.S. is a significant health concern. Puerto Ricans with high rates of substance use are at high risk for the health consequences associated with IDU.¹⁴²

Substance use, IDU, and HIV contribute largely to the health disparities that exist between Hispanics and other groups. In general, estimates of Hispanic IDU are higher than estimates for non-Hispanic Whites.¹⁴³ In 2011, transmission of HIV via IDU accounted for 5.1% of all HIV diagnoses among adult and adolescent Hispanics.¹⁴⁴ An examination of gender differences indicates that women drug users may be at a particularly higher risk of contracting HIV than males. Specifically with regard to IDU, data from the CDC indicate that differences in HIV diagnoses exist between Latino males and females (4.6% versus 7.7%, respectively) and AIDS diagnoses (8.6% versus 13%, respectively).¹⁴⁵

Several studies have indicated that substance use is relatively high among LGBTQ persons and is related to risky sexual behavior.¹⁴⁶ In one study of 3,492 Latino MSM, participants reported using multiple substances during sex in the past six months, which included alcohol (43%), marijuana (28%), cocaine (9%), amphetamines (9%), and amyl nitrates (8%).¹⁴⁷ Among a sample of 171 Latino MSM, 49% reported use of club drugs (e.g., cocaine, crystal methamphetamines, ketamine, volatile nitrites) in the past six months, which was positively associated with HIV-positive status, having unprotected receptive anal sex in the last six months, and having a high number of sex partners in the last six months.¹⁴⁸ Another study of 110 Latino gay/bisexual men found that almost half (47%) reported at least one instance of intoxication (from drugs or alcohol) during sex in the last thirty days, with more than one-third (39%) reporting at least one instance of unprotected anal sex in the last six months.¹⁴⁹

FIGURE 3





C. Latino Groups and Subgroups Most Vulnerable to HIV/AIDS

As HIV continues to exploit the fault lines of social inequality with respect to sexual orientation, race and ethnicity, gender and gender identity, and SES, vulnerability to HIV becomes manifest in Latinos in general and for Latino subgroups in particular, as described in this section. The term vulnerable group is preferred over risk group, given the latter term's perhaps unintentional associations with blaming groups for their high rates of HIV as opposed to the former term's intended associations with framing risk within contexts of socially unjust disadvantages that fuel patterns of health disparities in America.

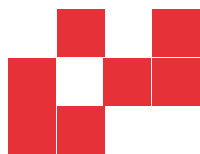
Latinos are the largest foreign-born population in the U.S., accounting for 53% of all foreign-born inhabitants.¹⁵⁰ Among Latinos, Mexico is the leading country of birth with a ratio of six to one to the next highest country. Studies have reported that Latinos, compared with non-Latino Whites, have a higher percentage of previously undiagnosed HIV-positive status, experience delays in receiving HIV test results, and have AIDS-defining conditions at the time of diagnosis.¹⁵¹ As can be seen in Figure 3 above, the steady rise among U.S.-born Latinos underscores the need for research regarding the acculturative process and its relationship to HIV risk. Furthermore, the fact that decreases have not been observed among those born in Mexico and Central and South America may warrant additional research as to why incidence is not declining. Available research indicates that HIV/AIDS affects Latinos in all regions of the country, and that Latino subgroups are disproportionately affected. For example, MSM remain the most vulnerable to contracting HIV, followed by transgender Latinos; however, heterosexual transmission continues to increase, specifically affecting Latina women and youth because of gendered and age-related vulnerabilities. Below is a review of HIV risk in these specific Latino subgroups, with an emphasis on the multiple contexts that render them vulnerable to HIV risk.

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

In 2011, Latino MSM represented 79% of the reported HIV-positive Latino men.¹⁵² If the categories of Latino MSM and Latino MSM who also report IDU are combined, they account for more than 80% of the HIV diagnoses reported in Latino men for 2011 alone.¹⁵³ Data collected from the fifty states, Washington, DC, and six U.S.-dependent areas demonstrate that Latino males have a rate of HIV diagnoses that is three times that of White males.¹⁵⁴ Among Latino MSM, 43% occurred in those under age 30.¹⁵⁵ Latino MSM represent the population most severely affected by HIV and the only group in which new HIV diagnoses have been increasing steadily since the early 1990s.¹⁵⁶ 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.¹⁵⁷

Transmission rates of HIV indicate that the most vulnerable groups are among MSM and heterosexual women.¹⁵⁸ In 2011, Latino MSM and heterosexual females possessed the highest rates of HIV diagnoses (65% and 49%, respectively).¹⁵⁹ Latinos have also been reported to have the highest rates of unprotected male-to-male sexual contact.¹⁶⁰ 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.¹⁶¹ Compared with 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.¹⁶²

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



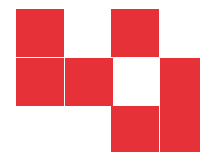
information about the contextual HIV-related risk behaviors and prevalence of HIV among the Latino MSM population in an especially risky geography: the San Diego–Tijuana border region.¹⁶³ In a recent study, nearly one-fifth of participants from Tijuana (20.3%) and one-fourth from San Diego (27.8%) indicated 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. Lack of health care, transience of the border population, economic hardship, and homophobia, among other factors, intertwine to exacerbate the HIV epidemic on the border, affecting both women and men and placing them at high risk for HIV. A greater proportion of MSM from Tijuana reported lifetime and recent sexual relations with female partners (MSMW) compared with 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.¹⁶⁴

It is vital that strategies targeting Latino MSM engage overlapping gay and Latino communities and address factors such as the lack of open identification with homosexuality and the high rate of relationships with women. The compounding effects of xenophobia, homophobia, economic discrimination, and biased religious and cultural norms may render Latino males less likely to incorporate HIV prevention into their daily lives. A participant in a recent National Alliance of State and Territorial AIDS Directors publication entitled *A Través de Nuestros Ojos* [Through Our Eyes] illuminated the dilemma of being gay and Latino 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.¹⁶⁵

Similarly, a study concerning existing HIV-prevention services for the Latino MSM community in the Denver metro area¹⁶⁶ 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 regions of origin, education status, and health literacy. Participants reported feeling marginalized and perceived high 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) 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.

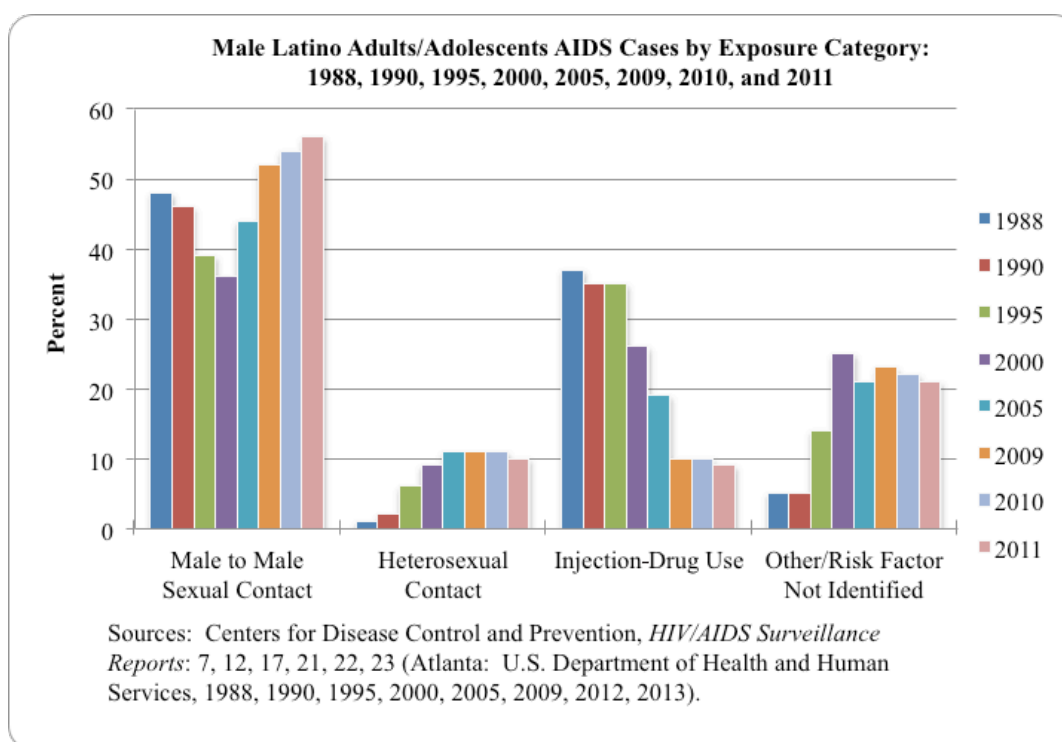
Research among Latino MSM demonstrates the negative associations with HIV testing; although 39% acknowledged having been exposed to HIV risk through sexual encounters, 11% reported not wanting to know their HIV status.¹⁶⁷ Latino men's exposure to homonegativity, combined with their engagement in behaviors that are highly stigmatized, may render the act of testing an admission of having engaged in stigmatized sexual behavior.¹⁶⁸



2. Heterosexual Latino Males

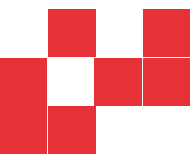
As seen in Figure 4,¹⁶⁹ Latino AIDS cases due to heterosexual contact increased from 1% to 11% between 1988 and 2009 and then decreased to 10% in 2011. Although it is the least-reported exposure category, HIV acquisition via heterosexual contact is a reality for Latino males. Due to the stigma associated with IDU and MSM categories and the resulting discomfort with being classified as such, there is an assumption that many of the reported cases 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 risk factors or sometimes 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;¹⁷⁰ the increase from 5% to 21% in the “other/risk factor not reported or identified” category may be indicative of an increase in heterosexual transmission between 1988 and 2011. Hence, the contexts associated with HIV risk in Latino male heterosexuals warrant further investigation.

FIGURE 4



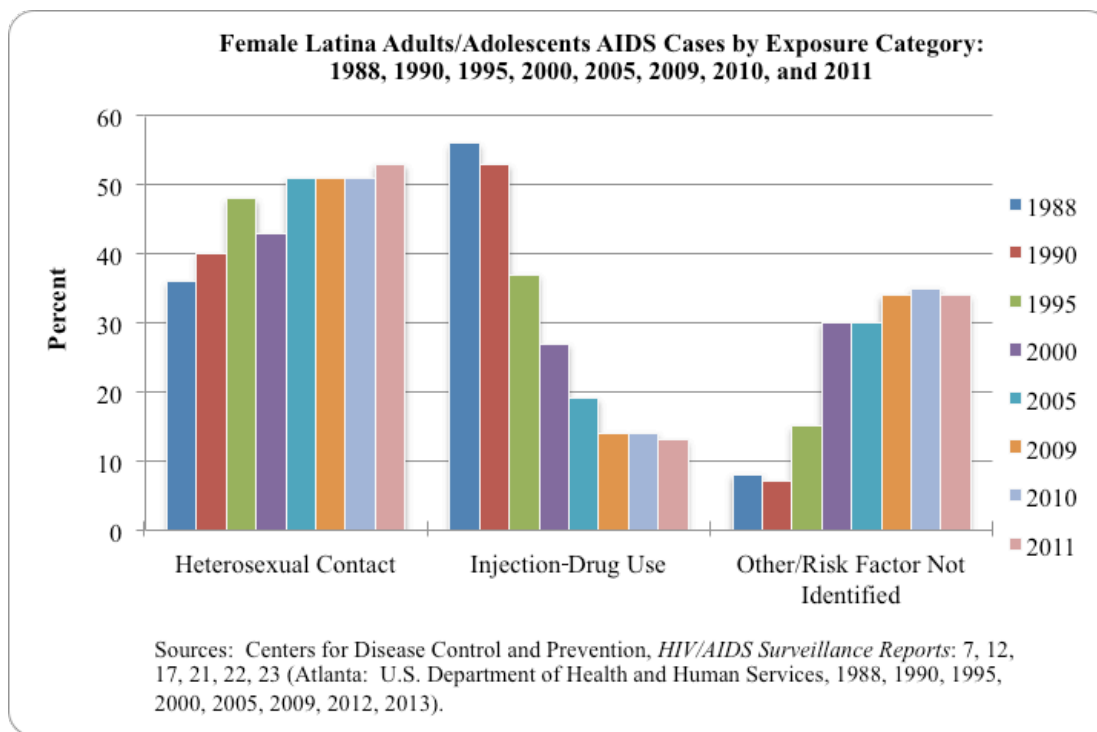
3. Heterosexual Latinas

In 2011, more than half of Latina women diagnosed with AIDS acquired the disease through heterosexual contact. Between 1998 and 2011, heterosexually acquired AIDS among Hispanic women increased from 34% to 53% (Figure 5).¹⁷¹ When compared with White women in 2011, Latinas had five times the rate of AIDS and accounted for 18% of new AIDS diagnoses among women.¹⁷²

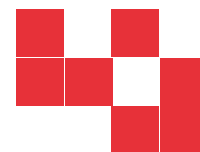


Consequently, HIV has become a major cause of illness and death among women, especially among women from racial and ethnic minority populations.¹⁷³

FIGURE 5



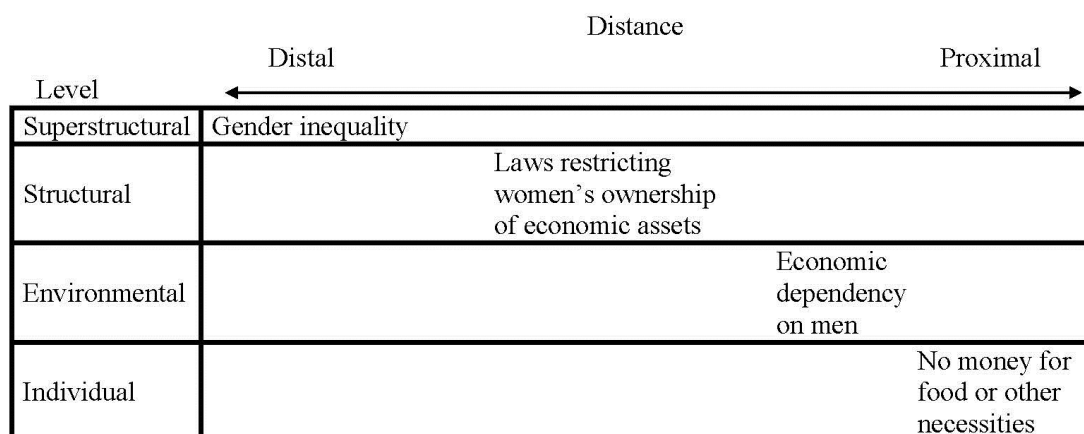
Gendered risk. Latinas experience risk factors that contribute to HIV diagnoses similar to their male counterparts; however, they also vary in perceived risk and susceptibility, cultural norms (gender/male interactions), and lack of access to care due to socioeconomic and legal statuses.¹⁷⁴ These variations relate to a unique aspect of Latina risk: Marriage has been cited as the largest risk factor for HIV among Mexican women.¹⁷⁵ 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 being HIV-positive.¹⁷⁶ 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. 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.¹⁷⁷ 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.¹⁷⁸ 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.¹⁷⁹ 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 the vulnerability of Latinas acquiring HIV. Evidence indicates that many HIV-positive MSM also have sex with women¹⁸⁰ and have low disclosure rates with female partners regarding their sexual behaviors with other men.¹⁸¹ The stigma associated with being gay increases the pressure felt by Latino MSM to live heterosexual public lives while keeping their same-sex behavior hidden.¹⁸²

FIGURE 6

Structural-Environmental Model of HIV Risk in Women Relevant to Latinas



Source: Geeta Rao Gupta et al., "Structural Approaches to HIV Prevention," *The Lancet* 372, no. 9640 (2008): 765.

To illustrate the inadequacy of focusing excessively on individual behaviors without addressing structural-environmental risk factors, Gupta et al. offered a structural-environmental framework (illustrated in Figure 6)¹⁸³ for HIV-prevention research that describes HIV causality on a continuum from distal structural-environmental factors to proximal individual-level factors. This structural-environmental framework is consistent with a multilevel Latino lens in that it reveals the extent to which individual risk factors, such as having no resources for food or other basic necessities combined with dependence upon men, could lead to increased HIV/AIDS risk for women given the persistence of gender inequality in society.

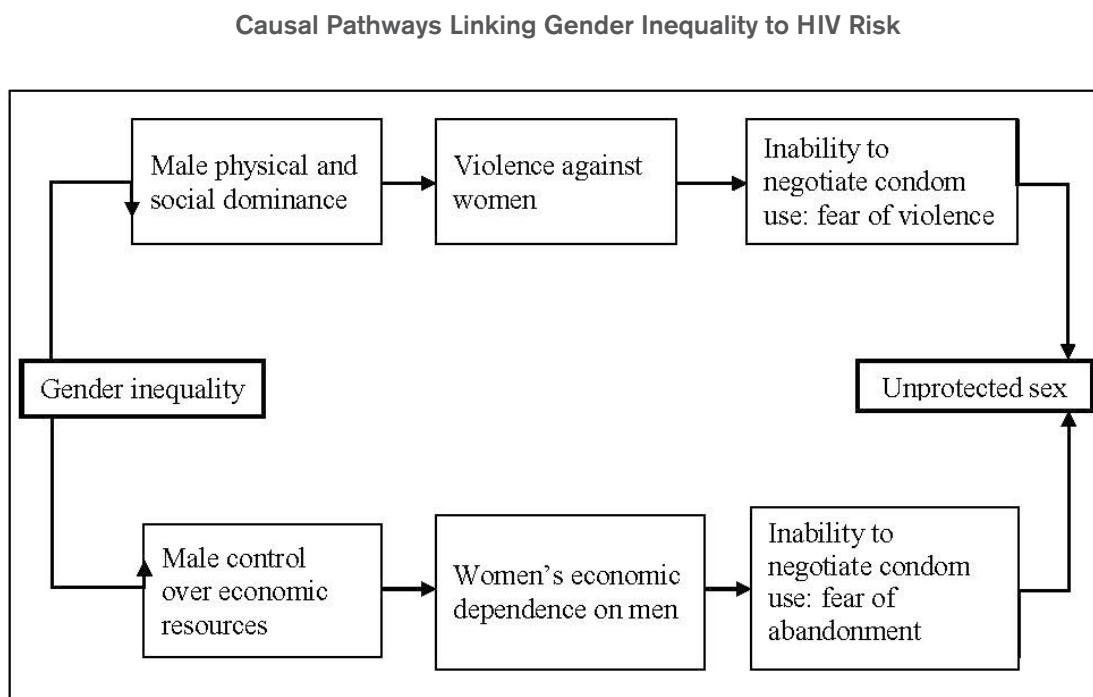
There is an urgent need to theorize and describe the various structural-environmental pathways, from distal structural-environmental causal factors to proximal individual risk factors, for the different Latino groups for whom we develop HIV-prevention interventions. Once structural-environmental pathways are sufficiently identified and described, such causal pathways offer multiple potential points of prevention intervention from individual risk factors to risk factors embedded within the environments (e.g., policies promoting social and economic gender equality) in which people live, as well as within structural factors that reproduce such risky environments that frame risk behaviors.

A qualitative study assessing Hispanic women's experiences with substance abuse, intimate-partner violence, and HIV risk conducted with 81 females found that participants endured abusive sexual relationships due to their perceived difficulties in leaving their partners because of economic dependence, poor self-esteem, fear, undocumented legal status, and lack of support services. Further, participants wanted to keep their families together and expressed the hope that partners would change.¹⁸⁴



Participants referred to this as *la crianza que nos han dado* [the upbringing/legacy that they have given us], pointing back to traditional cultural and familial norms in the Hispanic community. Social-structural factors such as economic barriers, perceived lack of police support, difficulty in accessing social services, and legal status were also cited as fundamental structural-environmental barriers for participants in this study.

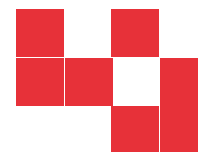
FIGURE 7



Source: Geeta Rao Gupta et al., “Structural Approaches to HIV Prevention,” *The Lancet* 372, no. 9640 (2008): 768.

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.¹⁸⁵ 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 contracting HIV,¹⁸⁶ with prevalence rates among MTF transgender-identified persons ranging from 11% to 78%, with an average of about 35%.¹⁸⁷ Racial and ethnic differences in HIV seroprevalence among MTF transgenders have been reported in studies conducted in San Francisco and Los Angeles, where Blacks showed the highest HIV seroprevalence (44%–63%), followed by Latinas (26%–29%), Whites (16%–22%), and Asian/Pacific Islanders (4%–27%).¹⁸⁸ An analysis of CDC-funded programs among transgender persons found that Blacks (4.4%) and Latinos (2.5%) were the most likely to be HIV-positive.¹⁸⁹ A 2005–2009 study in New York City found 206 new cases of HIV among transgenders, 95% of whom were MTF. In addition, researchers found that 90% of those newly diagnosed were Black and Latino. Among newly diagnosed transgender persons, 50% had documented histories of substance use, commercial



sex work, homelessness, incarceration, and/or sexual abuse compared with 31% of such histories in their HIV-positive, non-transgender counterparts.¹⁹⁰

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 and 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 because epidemiologically they are included within the statistics of MSM.¹⁹¹ Studies of MTF transgender individuals have relied on small convenience samples that lack the power to determine independent predictors of HIV.¹⁹² Few national studies have quantitatively assessed HIV risk among FTM transgenders to date.¹⁹³ Furthermore, MTF and FTM transgenders have yet to become official risk categories and remained unmentioned within the CDC HIV Surveillance Report, the most recognized compilation of HIV/AIDS-related data in the U.S. Transgenders' lack of visibility within data-reporting mechanisms has rendered both their risk and plight largely invisible. Moreover, the HIV/AIDS-related contexts associated with being transgender and a race or ethnicity other than White remain largely unexplored.

The Center of Excellence for Transgender HIV Prevention at the University of California, San Francisco has advocated for a series of standardized questions to better capture transgender across surveys. These include sex or gender categories that comprise the following selections: male, female, transmale/transman, transfemale/transwoman, genderqueer, additional category (please specify), and decline to state. Furthermore, the center advocates for inquiring about an individual's gender assigned at birth, particularly due to the relatively common issue of ambiguous gender being determined at birth by health care providers. These categories would include: male, female, and decline to state.¹⁹⁴ The CDC is considering employing this method in several projects to achieve greater accuracy in acquiring sex and gender information from participants.¹⁹⁵

In a systematic review of existing studies, Herbst et al.¹⁹⁶ found a high prevalence of HIV and risk behaviors among MTF transgenders (27%–48%) but low prevalence rates and risk taking among FTM transgenders. The lack of acknowledgment of or focus on transgender populations has serious health implications, as several studies have identified a high prevalence of HIV and risky sexual behaviors among this population, particularly within Latino communities. Because this population is often ostracized due to xenophobia among Latino immigrants, religious beliefs, and traditional cultural views regarding gender, designing effective HIV-prevention interventions is 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 have not been investigated. The social, cultural, and structural-environmental factors leading to multiple marginalities for transgender Latinos display multiple vulnerabilities that are best addressed by engaging overlapping transgendered and Latino communities.

A recent study evaluated risk factors for HIV/ STIs among 517 MTF transgenders age 19–59 from the New York metropolitan area.¹⁹⁷ 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 pronounced need for basic health and social services, and experienced alienation from social networks.¹⁹⁸ The study concludes that it is important to work toward 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.¹⁹⁹ The high incidence of risky sexual-health behaviors, HIV, and rape, and recent violence against and murders of transgenders—particularly Latina MTF in the U.S. and Puerto Rico—underscores not only the compounded impact of racism, misogyny, and xenophobia within the U.S.,²⁰⁰ but also the

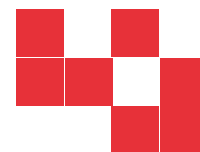
urgent need for public health interventions and a broader civil rights campaign to advocate on behalf of transgender health, overall and within the Latino community in particular.

Transgender sex work and HIV risk. Female sex workers and MTF transgender populations experience multiple vulnerabilities resulting in elevated levels of HIV: stigmatized social status, economic instability, racism, chemical use and dependency, high rates of sexual and physical abuse, and mental health issues.²⁰¹ In Los Angeles County, 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 a Los Angeles County-based study, MTF transgenders reported sex work as their main source of income due to employment discrimination and lack of family support, including, for many, being kicked out of the family home during adolescence.²⁰² This alludes to the importance of understanding the significant role that discrimination, on multiple levels, plays in transgenders' limited ability to engage in lawful employment, and how together these factors compel MTF transgenders to engage in survival sex work, which in turn exacerbates related violence and high risk for HIV and STIs.

While the challenges to transgendered people in general and Latinos in particular are immense, longtime advocate, clinician, and researcher JoAnne Keatley has described building multilevel service capacity for transgenders in San Francisco where none had previously existed.²⁰³ Such capacity began with an office space in which transgender-specific health issues were addressed, followed by the first-ever residential treatment program for alcohol and substance-abuse problems for transgenders, as well as transgender-focused mental health services. One popular Latina-focused activity was *Costura y Charla* [Sewing and Chatting], in which transgender Latinas met to learn sewing and pattern making while engaging in health discussions with local speakers. Keatley's work blossomed into statewide and then nationwide centers of excellence for HIV prevention for transgendered persons. These centers have focused on leadership training of transgendered people and training service providers in best practices for this unique population, accompanied by training publications. Advocacy in both research and policy has also been an important focus of these centers, consistent with a multilevel focus on HIV-related problems and solutions for transgendered people, enhanced by Keatley's keen Latino lens.

5. Migrant Workers

Just as the largest proportion of immigrants in the U.S. are of Mexican origin, the migrant laborers that provide essential labor to various sectors of industry and service vital to the U.S. are also predominantly Mexican and secondarily Central American. Not surprisingly, Latino migrant working men (including the day-laborer subpopulation) are vulnerable to HIV due to many aspects of the migrant experience in the U.S.,²⁰⁴ including poverty, discrimination, racism, and lack of documentation and access to health care.²⁰⁵ Migrant workers tend to be young men with very low incomes and educational attainment, leading to low literacy and high rates of English nonproficiency.²⁰⁶ They are away from home for prolonged periods of time, which often results in disruptions of marriages and social relations, feelings of isolation and loneliness, and consequent stress and depression.²⁰⁷ These factors have been shown to increase the consumption of alcohol,²⁰⁸ illicit drug use, and sex with commercial sex workers,²⁰⁹ putting them at high risk for STIs and HIV. The improbability of obtaining a work visa or citizenship forces Latino migrant workers to enter the U.S. without documentation, which also makes returning home unlikely given how dangerous and expensive it is to cross (e.g., hiring coyotes to cross over). An example of a possible structural intervention with the potential to reduce HIV risk in migrant workers is immigration reform (e.g., by regulating documented labor as part of free trade with Mexico and Central America and thereby improving the living and working conditions of Latino migrant workers in the U.S.).



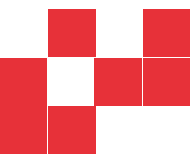
Further, Latino MSM who migrate to the U.S. are reported to be at significantly high risk for contracting HIV due to similar factors such as poverty, social isolation, limited knowledge of STIs, and opportunities arising in a freer sexual environment.²¹⁰ One study reported that recent Latino migrant 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.²¹¹ In a binational study of male and female Mexican migrants to California in 2004–2005, the authors found HIV risk behaviors related to more sexual partners and substance abuse and lower risk related to increased condom use during vaginal sex, as well as greater HIV testing.²¹² A qualitative study by Sowell, Holtz, and Velasquez found that men migrating to the U.S. are at 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.²¹³

D. Current Gaps in Latino Surveillance Data

Heterosexual Latinas and MTFs are particularly susceptible to under-representation in CDC surveillance data due to misclassification in reporting heterosexual HIV transmission. The CDC's current methodology for HIV/AIDS surveillance data collection underestimates the mode of transmission for heterosexual women in general.²¹⁴ Thus, surveillance data are in effect masking the true rates of heterosexual HIV transmission for Latinas. This under-representation results from the fact that, for Latinas who report heterosexual HIV transmission, subsequent classification of their HIV-positive status 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 5 for a list of potential classifications).²¹⁵

An HIV-positive woman's transmission category is classified as “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 and it is not documented in the chart. If the woman does not want to disclose (perhaps due to stigma, embarrassment, and/or denial), then she is defined as “no risk identified.” The fact that, for Hispanic females, “other/risk factor not reported or identified” has risen nearly fivefold, from 7% to 34%, between 1988 and 2011 (Figure 5), suggests 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 fuel increases in reported HIV cases among Latinas and women in general. The reliance on statistical methods used to adjust for “missing risk-factor information” may be severely limiting our understanding of HIV transmission patterns. 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,²¹⁶ in turn decreasing the perceived need to be tested for HIV.

²¹⁵The 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.



HIV/AIDS among Latinos may also be underreported because the name-based reporting requirement may discourage Hispanics from taking the HIV test for fear of compromised confidentiality and concerns over employment and other potential discriminatory issues,²¹⁷ particularly at a time when anti-immigrant—hence anti-Latino—laws and initiatives abound. Although data from all fifty states are now included, expansion of categories to include “presumed heterosexual” and accurate categories for transgender individuals are needed if we are to acquire a more complete and accurate picture of HIV/AIDS in the U.S. and its impact on underserved populations.

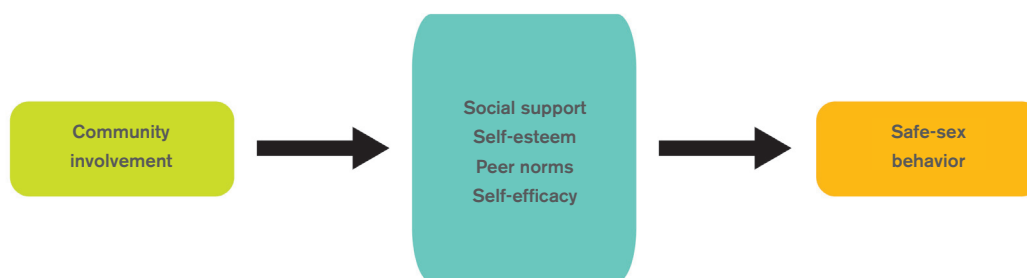
III. HIV/AIDS PREVENTION AND TREATMENT THROUGH A LATINO LENS OF COMMUNITY-ENGAGED RESEARCH

Excellent examples of HIV-prevention research utilizing the Latino lens of community engagement have begun to accrue to illustrate this urgently needed approach to more powerful and pervasive HIV prevention and AIDS treatment with Latino populations. This section begins with compelling illustrations of HIV-prevention research with Latinos that work by engaging community and family systems and multiple cultural assets. The section is followed by a selective review and critique of the literature, leading to recommendations regarding needed programs and approaches to ensure that Latino perspectives and contexts are woven into the ways in which we, as a nation, address HIV/AIDS and other health disparities.

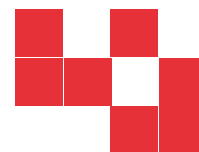
Over the past twelve years, Dr. Jesus Ramirez-Valles and colleagues have developed²¹⁸ and tested²¹⁹ a model of community engagement for increasing safe-sex behavior in Latino groups most vulnerable to HIV risk: gay/bisexual men and MTF transgendered women. This instructive research demonstrates that community involvement in HIV/AIDS-related causes, especially in LGBTQ populations, resonates well when compared with more general community activities (e.g., helping the homeless, political-party activities). Furthermore, involvement in community-engagement activities is associated with decreased risky sexual behavior.

FIGURE 8

Conceptual Model of the Mechanisms of Community Involvement and Safe Sex among Gay and Bisexual Men and Transgender Persons



Source: Jesus Ramirez-Valles, Lisa Kuhns, and Haiyan Li, “Enhancing Peer Norms, Self-efficacy, Self Esteem, and Social Support for Safe Sex in Naturalistic Environments: The Role of Community Involvement in Latino Gay, Bisexual, and Transgender Communities,” in *HIV Prevention with Latinos: Theory, Research, and Practice*, ed. Kurt Organista (New York, NY: Oxford University Press, 2012), 27.



More specifically, and as illustrated in Figure 8, involvement with LGBTQ and HIV/AIDS organizations was significantly related to greater social support, peer norms toward safe sex, and self-efficacy toward safe sex. Predictor analysis showed that both safe-sex peer norms and self-efficacy to practice safer sex were related to lower levels of unprotected anal sex, and peer norms also predicted lower levels of sex under the influence of alcohol and substances. Hence the power of community engagement to curb risky sexual practices appears to happen by way of connecting typically marginalized people to larger human rights causes that are personal, rendering the political adage “the personal is political” ever more salient. It is within these transformative experiences that LGBTQ Latinos interact with similar peers to deploy prevention campaigns that make unsafe sex dissonant and confront each individual on a personal level about risk behaviors emanating from lack of support and healthy peer groups, resources that heterosexual Latinos take for granted. As Ramirez-Valles notes:

Interventions based solely on psychosocial or cultural factors, while showing some success usually are individually based, overlooking the social processes (e.g., the group), in which the self is embedded, and their effects may not be long lasting because these interventions are not built on existing resources and with the active participation of individuals themselves. Conversely, active participation in the solutions of self and community’s problems, such as the case of HIV/AIDS and discrimination against LGBT people, fosters ownership and critical understanding.²²⁰

Another excellent illustration of the power of community engagement in decreasing HIV risk in Latino gay men in New York City is the *SOMOS* [We Are] program described by Vega et al.²²¹ The name *SOMOS* came from preliminary community research that yielded a name crafted to signify belonging, an assertion of identity, and a much-needed blending of Latino and gay identities. A community advisory board (CAB) of local community-based-organization staff and gay community leaders and members was formed to oversee the goals and cultural content of this project. As Vega et al. note:

CAB members were eager to have an intervention that highlighted each member’s life story and nationality while impacting and integrating into a larger network. Thus, the social identity was at the bedrock of the intervention as CAB members helped create an intervention in the participant’s self-concept that emanated from and was enhanced from perceived membership in social groups.²²²

Venue-based sampling by peers already embedded in the venue networks was conducted continuously between 2002 and 2006, during which ten cohort/intervention cycles were completed, consisting of a total of 113 sexually active gay Latino men. Impressively, 100% of participants engaged in all intervention activities, pre-assessments, and three-month post-assessments throughout the four-year period. The effectiveness of *SOMOS* emerged from a combination of group sessions, social-marketing activities, and community presentations. Five facilitated group sessions focused on shared experiences in Latino and gay families and communities, identity and challenges to coming out, impacts of societal homophobia, culture and race-related body image and masculinity across local and larger norms, and challenges to safe-sex practices. Following the insightful group sessions, the social-marketing component involved each of the ten cohorts crafting newspaper articles for both gay and heterosexual Latino communities that addressed issues that emerged in group sessions and asked the reader, *¿Y tú qué piensas?* [And what do you think?]. Further, more than twenty-five community presentations (e.g., at service organizations, universities, and gay and Latino venues) were conducted by participants with staff and CAB assistance. For example, in *Mi Otro Yo* [My Other Self] participants presented on being both gay and Latino, and other presentations addressed gay marriage and immigration reform.



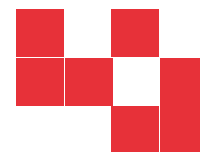
Outcome measures ranged from individual self-esteem to social self-esteem, including degree of connectedness to larger gay and Latino communities and related identities. Other outcomes included sources of social support, internalization of homophobia, and several risky sexual behaviors. Pre- and post-comparisons of this carefully conceived study of gay and Latino community connectedness were consistently significant across almost a dozen of the above outcomes. Most strikingly, predictor analysis revealed that social connectedness was a strong predictor of lower sexual risk taking. Like the work of Ramirez-Valles, *SOMOS* illustrates how the use of a Latino lens of community engagement elevates HIV-prevention research to include relevant community and cultural contexts. Furthermore, this form of community engagement also allows for optimal use of the cultural capital that exists within diverse groups.

While the aforementioned studies illustrate the strategic engagement of community systems by and for LGBTQ populations, engagement of Latino family systems in HIV prevention and sexual health more generally is illustrated by a pair of studies by Dr. Britt Rios-Ellis and colleagues: *Rompe el Silencio* [Break the Silence]²²³ and *Hablando Claro* [Clear Talk].²²⁴ As these carefully crafted study titles imply, strategic discussions about HIV/AIDS and sexual health more generally are urgently needed in Latino families and can be facilitated by utilizing the Latino lens in such studies as described below.

Rompe el Silencio was an initiative funded by the U.S. Office on Women's Health to reduce sexual risk by improving communication and HIV testing within intergenerational groups of women. This intervention involved a number of creative activities designed to improve sexual risk communication within intergenerational family-based dyads of women (predominately mothers and daughters). In this study, Rios-Ellis and her colleagues facilitated discussion between fifty Latina mother and adolescent (age 12–18) daughter dyads about sex, pregnancy, STDs, HIV/AIDS, etc., with the goal of increasing such infrequent conversation while increasing sexual risk knowledge. This communication is particularly crucial for families in which the older woman's perceptions and experiences regarding sexuality were shaped in her home country, whereas her daughter's or niece's ideas were developed in the U.S.

In the activity *La Conquista* [The Conquest], Latina mothers role played the boyfriends of their adolescent daughters, attempting to convince the girls to engage in unsafe sex. This exercise was highly insightful for both generations as the younger women perceived their older female family members as knowing very little about sex in the context of contemporary male sexual behavior. In the cases in which younger family peers reluctantly consented to have sex without a condom, mothers and aunts recognized that they needed to increase the opportunity for sexual risk dialogue in their homes. When mothers weren't able to convince their daughters, the youth took great pride in role modeling clear communication to both generations of women, and it reinforced assertive sexual risk-reduction negotiation. Results revealed a consistent pattern of significant findings across desired outcomes: the ability to culturally sanction sexual risk communication in the Latino home, therefore increasing HIV/AIDS knowledge and the frequency and breadth of conversations about sex, and comfort discussing such issues across generations. This study was accomplished through the utilization of the Latino lens of family-systems engagement designed to build upon the specific cultural value assets of *respeto* (for parents on the part of youth) and *familismo*, or the imperative of protecting family members and especially youth.

More specifically, mixed research methods were used, beginning with formative focus groups of sixty-six Latina mothers and daughters of diverse age groups and language abilities and preferences (Spanish and English) to inform the development, implementation, and evaluation of this cross-generational intervention. Participants were asked to address questions such as: "What are the differences between Latino male and female roles and how do these affect HIV/AIDS risk?" "What were the messages you received about sexuality from your family?" and "What are the difficulties or barriers that parents have when they want to talk with their children about sex?" Analysis of qualitative group data, and specific recommendations elicited from participants, resulted in *Rompe el Silencio*'s



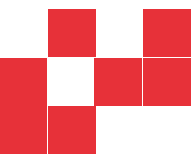
four-module format that included sexual values, family communication, HIV/STIs, and prevention. *Rompe el Silencio* proved to be an auspicious prelude to *Hablando Claro*.

Hablando Claro was constructed around the family-engaged focus of *Rompe el Silencio* in that this intervention also facilitated intergenerational, parent– (n = 122) adolescent (n = 171) dialogue about sex with the goal of increasing such urgently needed dialogue at home in order to increase a wide variety of intentions, including delaying sexual initiation, using condoms if sexually active, proactive HIV-prevention behaviors within mother–daughter dyads, HIV testing, and sexual risk communication and negotiation skills. Parents were primarily Spanish-speaking and of immigrant background. The *Hablando Claro* intervention also included six monthly support groups and two four-hour interactive educational sessions to fortify the intervention and create natural and ongoing support networks within the target communities. Discussion topics also superseded those of *Rompe el Silencio* by including homosexuality, homophobia, and domestic violence, and supplemented the intervention with HIV risk reduction Spanish-language community theater. Statistically significant increases were found from pre-intervention to three-month post-intervention in HIV/AIDS knowledge, frequency and comfort discussing sexual risk-related issues with family members and sexual partners, intention to discuss HIV/AIDS risk with partners, intention to use condoms and comfort in using and discussing condoms, and increased breadth of sexual risk topics discussed. The pattern of statistically significant pre- to post- and follow-up findings included increases in HIV/AIDS-related knowledge for both groups, increases in sexual risk-reduction communication frequency and comfort on the part of both mothers and daughters, mothers' increase in sexual risk communication and condom use with their partners (many daughters did not report sexual partners), and an increase in HIV testing and intention to test for both groups. It should be noted that many of the older female participants were married and/or had been in lengthy sexual relationships, and were still able to initiate the discussion and use of condoms in their relationships.

Supplemental analysis of the correlates of *familismo* found this central Latino value and practice to be associated with different desirable outcomes for the two groups. For adults, *familismo* was significantly correlated with the ability to convince their partners to postpone sex and use condoms correctly, and the conviction that it is possible to enjoy sex responsibly. For youth, *familismo* was significantly associated with greater certainty about being able to talk about safe sex with family members and friends.

The above illustrations of the integration of a Latino lens into HIV-prevention research respond to the frequently asserted needs of stakeholders across the country. For example, in a 2010 survey of its membership—consisting of individuals of various professional levels and in private and nonprofit sectors working on HIV/AIDS-related issues—the National Latino AIDS Action Network (NLAAN) found that nearly two-thirds of those surveyed believed that national efforts had not addressed the need for Latino-specific homegrown interventions. When asked to name what they believed should be the top three from a list of nine national efforts from the 2011 HIV/AIDS national policy recommendations, NLAAN members advocated the following priorities: 1) increase funding for Latino-specific outreach, education, and prevention (54.5%); 2) increase Latino-specific prevention interventions (50.6%); and 3) improve inclusion of Latino community members in planning, implementation, and evaluation (42.9%).

Few Latino-specific organizations and community members are asked to contribute to research strategies and programmatic recommendations. Rather, Latino organizations are too 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 often 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 and family members, and population-specific components for diverse, vulnerable Latino groups. This section describes how HIV/AIDS prevention and treatment efforts can be improved through integration of a Latino lens by engaging community and family systems, including the strategic integration of salient Latino values and community assets, and including lay community helpers and paraprofessionals committed to the health of their communities.

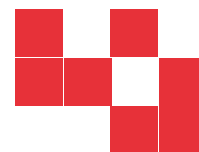
A. Integrating Cultural Values into Community-Engaged HIV/AIDS Prevention and Treatment Strategies

The fact that two of five (38%) Latinos living in the U.S. are foreign born²²⁵ underscores the importance of studying the cultural influences that may affect the health behaviors of Latinos and related outcomes.²²⁶ Cultural influences such as traditionally accepted gender roles and the importance of family have been shown to affect the health behaviors of Latinos across a number of studies.²²⁷ Research has demonstrated that *familismo* is a centrally important cultural value and practice among Latinos.²²⁸ 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 and AIDS treatment. Other salient 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 relationships²²⁹ and is considered to be an intrinsic Latino cultural characteristic that is present in many aspects of daily life.²³⁰ 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, usually a family member or friend].²³¹ Thus, *confianza* may be an untapped cultural asset for future HIV-prevention and treatment efforts within the Latino community.

As illustrated above, an important Latino cultural factor such as *respeto* should be utilized to develop culturally specific prevention and treatment efforts. 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.²³² Interactions occur within a hierarchical structure that is 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.

Another successful example of prevention intervention that integrates core Latino values is ¡*Cuídate!* [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. ¡*Cuídate!* incorporates *familismo*, *machismo*, and *marianismo* in their varying forms. For example, the positive aspects of *machismo* (e.g., protector of the family, often referred to as *caballerismo*, the Spanish term for gentleman²³³) can be incorporated into HIV-prevention efforts instead of the typical negative portrayals of the negatively perceived *machismo*. *Machismo* could potentially 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 HIV.²³⁴ Additionally, through the integration of role playing, videos, music, interactive games, and hands-on practice, ¡*Cuídate!* builds HIV knowledge and understanding of vulnerability to HIV, identifies attitudes and beliefs about HIV and safe sex, increases self-efficacy and skills for correct condom use, and facilitates learning developmentally appropriate negotiation of abstinence and safer sex practices.

Two noteworthy studies with Latinas achieved desired outcomes by integrating the gendered cultural context of HIV risk in the lives of adult and adolescent Latinas. The first study adapted a previously successful and widely disseminated HIV risk-reduction intervention originally developed



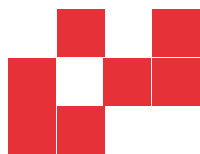
for Black women (the SiSTA intervention) for use with adult Latinas in Miami. Adaptation involved incorporating relevant cultural activities and exercises, including information on salient social, relational, and gender constructs that affect sexual behavior among Latinas, such as the previously mentioned values of *machismo*, *marianismo*, and *familismo*. How immigrant status can affect sexual behaviors was also included. Results from a rigorous, randomized controlled trial evaluating the intervention indicated that over the six-month follow-up period, participants in the intervention were more than 4.5 times as likely as comparison participants to use condoms consistently during the previous ninety days and 53% less likely to report never having used condoms. Additionally, intervention participants reported fewer traditional views of gender roles, higher HIV-knowledge scores, fewer perceived barriers to using condoms, and greater perception of power in their sexual relationships. Given that the participants were predominantly immigrant Latinas in long-term sexual relationships, the observed changes in condom behaviors and attitudes are notable.²³⁵

The Latina adolescent-focused intervention study SHEROs (a female-gendered version of the word *hero*) was designed for Mexican American adolescents by targeting developmentally relevant cultural and social factors that contribute to sexual risk behaviors: pressures/desires to be a mother, sexual relationships with older men, gang affiliation, and inequitable gender roles in sexual relationships. SHEROs interventions consisted of nine small-group sessions. Participants demonstrated positive changes in beliefs supporting sexual health and were more likely to have carried condoms and to have abstained from sex at the post-test compared with youth in the comparison group.²³⁶

More gender-focused, Latino approaches to HIV prevention are needed and should include relationship-based issues such as assertive sexual communication—for example, culturally sensitive assertiveness training that introduces requests for condom use with qualifiers such as *con todo respeto* [with all due respect], acknowledging the frequent 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. In fact, several sexual and reproductive health interventions have used a couples approach rather than targeting women by themselves, given the importance of relationship and power dynamics in shaping sexual risk behaviors.²³⁷ HIV/AIDS-prevention programs should include the prerequisite of training HIV educators in Latino culture and countering potential resistance or anger from males.²³⁸ If possible, these HIV educators should come from the Latino communities engaged in the prevention efforts.

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

Closely related to the integration of Latino values into HIV/AIDS prevention and treatment research and services is the integration of broader Latino community assets, including groups and activities infused by Latino values. Despite economic challenges, Latino communities are traditionally more tightly knit and community-focused than their Western counterparts.²³⁹ The limited number of Latino community-engaged HIV-prevention efforts and the predominance of individual-focused behavior-change efforts mean that we have yet to harness the potential of Latino communities with their long histories of collectivism and grassroots activism. In fact, interventions attempting to ameliorate both health- and education-related disparities within diverse Latino communities tend to focus on deficits found within Latino SES profiles. However, such approaches too often ignore positive Latino cultural traits and practices at family and community levels. Fortunately, several studies have begun to demonstrate the power of community engagement, despite formidable economic, social, and cultural challenges. For example, 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.²⁴⁰ One especially important Latino community asset is *promotores de salud*, described below.



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

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

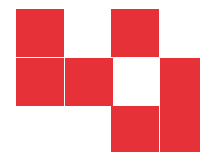
...lay members of communities who work either for pay or as volunteers in association with the local health care system in both urban and rural environments and usually share ethnicity, language, socioeconomic status and life experiences with the community members they serve. They have been identified 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.²⁴¹

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.²⁴² With regard to HIV prevention and treatment, *promotores* can facilitate skills acquisition through role playing to help male and female clients apply new 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.²⁴³ As the role of *promotores de salud* continues to evolve, they will undoubtedly play an increasingly important part in the health care and disease prevention of individuals who have little experience with the U.S. health care system.

2. The Patient Protection and Affordable Care Act of 2010 (ACA)

Although the ACA is projected to ameliorate some of the disparities in Latinos' access to health insurance, the current act as it stands excludes undocumented people who continue to number in the millions.²⁴⁴ 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.²⁴⁵ In terms of prevention-related outcomes, and as discussed above, a recent community-based participatory-research intervention found that *promotores*-driven *charlas* [educational conversations] increased HIV knowledge as well as the level of HIV-prevention and sexual risk-related conversations within Latino households ninety days post-intervention.²⁴⁶ 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.²⁴⁷ 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.²⁴⁸ 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.²⁴⁹

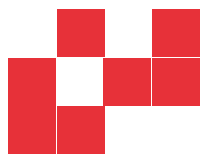
Community health-worker programs can also be adapted to meet the needs of various populations and frameworks. A study using the Popular Opinion Leader Intervention, called Young Latino *Promotores*, was adapted to meet the needs of two diverse migrant communities. Despite high participant mobility, results showed that participants’ HIV knowledge increased and that they were more likely to use condoms when engaging in anal sex.²⁵⁰ 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 in HIV prevention.²⁵¹

We end this section by describing an impressive series of studies conducted by a community-based participatory-research partnership in North Carolina that actively engaged multiple Latino values and community assets to decrease HIV risk and increase testing among recently arrived immigrant Latinos to new growth communities with little Latino-focused services. This remarkable series showcases inclusion of a Latino lens to develop effective HIV-prevention interventions aimed at diverse Latino immigrants, including men, women, and MSM.

The first study focused on heterosexual males by developing an intervention called *Hombres Manteniendo Bienestar y Relaciones Saludables (HoMBReS)* [Men Maintaining Well-Being and Healthy Relationships], which involved a collaboration with local Latino men’s soccer leagues. The research team trained a group of soccer players to be lay health advisors. These men worked with their teammates over a period of eighteen months to provide information and resources and also played a role as opinion leaders, changing expectations and norms about sexual health and what it means to be a Latino male. In evaluating the effects of the intervention, the researchers found that men on the intervention soccer teams were more likely than men on control soccer teams²⁵² to increase their condom use and HIV testing. Additionally, their knowledge of HIV transmission and prevention, and their self-efficacy to use condoms, also increased.

A subsequent study by the above research team targeted Latino MSM by developing an intervention called *Hombres Ofreciendo Liderazgo y Apoyo (HOLA)* [Men Offering Leadership and Help], which harnessed the informal social networks of Latino MSM living in rural communities. Latino MSM were trained as health advisors who worked with their friends to increase condom use and HIV testing. Program activities were included that helped men to deconstruct harmful social and cultural norms that contribute to risky behaviors, to learn strategies to cope with social pressures and reframe them, and to support each other in engaging in healthy behaviors.²⁵³

The third study developed an intervention in partnership with Latina women called *Mujeres Juntas Estableciendo Relaciones Saludables (MuJERes)* [Women Together Establishing Healthy Relationships], which also built on the strong social networks of Latinas. Latina women were trained to serve as health advisors or *comadres* [godmothers] within their social networks. They held formal and informal educational sessions with their friends, opening discussions on issues such as communication barriers with sexual partners, and providing opportunities to learn and practice condom-use skills. Taken together, this auspicious series of studies by Dr. Scott Rhodes and colleagues convincingly demonstrates that use of a Latino lens in HIV-prevention research is not rhetoric but also a compelling reality in need of expansion to more powerfully decrease vulnerability to HIV/AIDS in Latino communities.



C. Developing a Latino Lens in HIV-Prevention Research

The above review of Latino community-engaged HIV-prevention and treatment research strongly supports the need to continue developing a Latino lens in our efforts to address health disparities such as HIV/AIDS. The selective review of Latino-focused research demonstrates that conceiving and conducting studies through a Latino lens combines research skills with community-grounded perspectives, experiences, and creativity in ways that deepen our understanding of crucial nuances regarding Latino recruitment and retention into clinical trials, HIV-prevention and testing efforts, and sustained behavioral change as developed within the contexts of Latino lives. The presence of a Latino lens can enhance the research enterprise's effectiveness in framing a path of inquiry that accurately addresses Latino contexts.

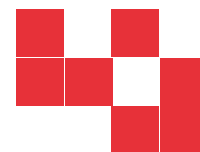
1. Need for Latino-Specific Research Training and Mentoring Programs

While some programs have been designed to train Latino researchers and thus increase the Latino skills base and focus, such programs need to be replicated within diverse areas of health foci, including HIV/AIDS. For example, programs such as the *EX/TO* [SUCCESS] a predoctoral program at the University of Texas, San Antonio for cancer research, and the National Hispanic Science Network at the University of California, San Diego for behavioral health can serve as examples for training Latino and Latino-focused researchers and scientists to meet the needs of the largest and fastest-growing ethnic population in the U.S. However, existing research-training programs are rarely centered in Hispanic-serving institutions (i.e., with a Latino student population of 25% or higher), which tend to be teaching institutions that house the greatest number of underserved Latino students, and hence prospective researchers. The NIH Working Group on Diversity in the Biomedical Research Workforce prominently states the need to strengthen the infrastructure of under-resourced institutions, such as minority-serving institutions, with a documented track record of supporting the development of under-resourced students in the sciences.²⁵⁴ The need for Latino researchers is reflected by the fact that only 2.9% of Latinos reported having a doctoral degree in 2008,²⁵⁵ and the number of Latino doctoral degrees demonstrated only a slight increase from 2.6% to 3.3% from 1996 to 2006.²⁵⁶

Additional attention must also be given to the “science of culture” within HIV-prevention, testing, and treatment efforts. Although a number of research studies attempt to acquire information regarding the behaviors of high-risk groups, few support inquiry into the structural-environmental, social, and cultural contextual factors that shape communities, relationships, and individual behaviors within them, thereby rendering our efforts to reach diverse populations less effective than they could be. When such narrow approaches fail, populations are often conveniently defined as “hard to reach.” As opposed to presuming that one behavioral or biomedical approach “fits all,” even when partially effective, it is imperative that research-funding institutions and initiatives be channeled into the science of culture and how it can lead us to better integrating Latino foci into the process. In addition to these overarching goals needed to better frame HIV/AIDS research in ways that are Latino-community engaged, a number of basic Latino-enhanced methodological strategies are recommended below.

2. Need for Family-Based Strategies for HIV Prevention and Testing

As described above, HIV-prevention strategies able to tap the power of *familismo* have demonstrated effectiveness in altering risk factors particular to Latinos.²⁵⁷ Intervention efforts that address acculturation into U.S. norms by facilitating cross-generation communication within the family



have proven to be successful among Latino families.²⁵⁸ Indeed, Latino youth who communicated with their parents about sex decreased their sexual activity and pregnancy rates and engaged in more responsible sexual behaviors.²⁵⁹ Research indicates that Latino adolescents and their parents desire open discussions of sexual issues, but that communication is often difficult.²⁶⁰ A recent family-based, HIV-prevention intervention effort among one hundred 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.²⁶¹

Recent research has shown that family-based strategies for HIV prevention must consider Latino cultural issues such as acculturation and mixed Spanish- and English-language communication. Further research is needed to investigate how the strong family unity that accurately depicts the majority of Latino families can serve to foster open communication inclusive of Latino and American cultural values and languages in order to best prevent the spread of HIV 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.²⁶²

3. Need to Measure Cultural Constructs Relevant to HIV Prevention

Groups are more receptive to health-behavior interventions when 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.²⁶³ A review of Latino behavioral HIV-prevention intervention studies published since the late 1980s found that the most successful intervention studies addressed cultural factors and were developed to specifically target the population of interest.²⁶⁴ These findings show the need for research that identifies and measures relevant Latino cultural factors that can then be better integrated into intervention research.

Research is needed to empirically develop measures of cultural constructs, such as the many values reviewed above, in order to assist prevention scientists in understanding the ways in which specific Latino cultural factors influence the emergence of HIV risk and preventive behaviors. Further, the ability to measure values in valid and reliable ways allows for quantification of the impact of the specific mediators of HIV-related behavioral change, thus increasing understanding of their role in HIV prevention. For example, in their multidimensional measure of *machismo*, Arciniega et al. demonstrated positive and adaptive aspects of *machismo* (e.g., supporting and protecting one's family) that can be assessed and enhanced in order to prevent HIV risk and vice versa for negative and maladaptive aspects (bravado, male superiority and control over women, homophobia, etc.).²⁶⁵

Because many Latinos receive the majority of their care at community clinics and health centers, measurement instruments must be designed to reduce the response burden and increase ease of administration in busy clinic settings. This would provide researchers and practitioners with a greater understanding of how Latino cultural factors may be scientifically employed to minimize the occurrence of HIV and other infectious diseases among the Latino population.



4. Biomedical Approaches to HIV Prevention and Treatment in Need of a Latino Lens

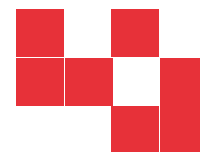
Several recent biomedical approaches to HIV prevention and treatment have demonstrated great promise in preventing HIV among discordant couples and other vulnerable populations.²⁶⁶ Promising biomedical approaches include: HAART, treatment as prevention, pre-exposure prophylaxis (PrEP), post-exposure prophylaxis (PEP), male circumcision, microbicides, and HIV vaccine-research efforts.²⁶⁷

Because of dramatic advances in basic research to understand HIV, as well as advances in treatment research, some scientists are now hopeful that we can begin to develop research strategies toward further curbing the pandemic. The case of Timothy Ray Brown, the “Berlin Patient,” provides insight into the role of stem cells as an approach to maintain long-term control of HIV.²⁶⁸ However, the absence of active and replicating HIV relied heavily on the CCR5 delta32 mutation, a natural mechanism that confers HIV resistance but that is mostly found among northern Europeans.²⁶⁹ Another promise for long-term control of HIV/AIDS occurred in the case of a baby in Mississippi who was treated aggressively at birth after her HIV-positive mother did not receive standard prenatal care. At eighteen months old she had no detectable or replicable virus. Additionally, the NIH is supporting the study of a group of HIV-positive adolescents who were treated from birth in Massachusetts and are showing no signs of viral replicability.²⁷⁰

Although biomedical research contributions have great potential to stem the pandemic, the majority of Latino communities and other underserved populations have yet to be integrated into this dialogue, and we have not yet laid the platform on which such aspirations can be achieved. However, if biomedical approaches are to effectively stem the epidemic within Latino and other communities, these strategies, like any prevention interventions, must consider the various contexts of risk experienced by diverse Latino populations, including the environments in which they live and risky situations that they frequently encounter embedded within structural (e.g., low SES, immigration status) and cultural (e.g., stigma and discrimination) factors. Furthermore, these approaches urgently require formative research in partnership with the Latino community in order to assess community knowledge of, reactions to, acceptability of, and readiness to integrate biomedical interventions into their lives. Finally, if biomedical interventions are to reach their full efficacy in underserved communities and mediate the long-term control of HIV, dialogue with communities must first occur to test and adapt situations that optimize community feasibility of their use. To skip integrating a Latino lens may result in decreased efficacy and the failure to integrate biomedical interventions for those most affected within underserved communities.

Antiretroviral therapy (ART). Optimal adherence to ART (taking medication as prescribed $\geq 95\%$ of the time) supports health and survival outcomes and leads to viral suppression in HIV-positive individuals.²⁷¹ Reduced morbidity and mortality are evident among adults who initiate ART with CD4 counts between 300–500 cells/mm³, with more profound salutary outcomes in earlier initiation at CD4 counts greater than 500 cells/mm³. While early entry into ART has public health implications by reducing community viral load, inequities are evident in the fact that those who initiate ART earlier tend to be White and non-poor with access to private health care providers.²⁷² As previously mentioned, very early entry into ART actually resulted in a “functional cure” in an HIV-positive infant.²⁷³ Early initiation at thirty hours of age may have prevented a latent HIV reservoir from being established, resulting in this child having no detectable or replicable virus.

Treatment as prevention. ART use by an HIV-positive individual as a means of suppressing personal viral load and reducing the risk of transmission has been used since the 1990s in preventing mother-to-child (perinatal) transmission. A landmark study showed that by giving zidovudine to HIV-positive pregnant mothers and their newborns, the risk of perinatal transmission was reduced from 25% to 8%.²⁷⁴ Informed by these findings and by routinely testing pregnant women and treating



HIV-positive mothers according to treatment guidelines, perinatal transmissions have been reduced by 90%.²⁷⁵

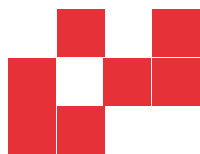
ART treatment as a prevention strategy was theoretically translatable to other populations; however, sufficient evidence was lacking until recently. Hailed by *Science* magazine as the 2011 breakthrough of the year and dubbed in that article “treatment as prevention,”²⁷⁶ the HIV Prevention Trials Network (HPTN) reported that early use of antiretroviral drugs reduced the risk of heterosexual transmission among serodiscordant couples by 96% (HPTN 052).²⁷⁷ Given the near universal results, the trial was halted early by an independent monitoring board who advised that antiretroviral medication be offered to all HIV-positive participants immediately as well as requesting that results be made public as soon as possible. As well as helping to prevent the spread of HIV, participants assigned early use of ART experienced fewer serious health problems associated with HIV.²⁷⁸

While ART-related findings and discoveries are cause for excitement, the now famous Gardner Cascade²⁷⁹ is a sober reminder that 20% of HIV-positive individuals in the U.S. remain unaware of their status, and of HIV-positive persons who are aware of their seropositivity, 25% do not link to care within six to twelve months of their diagnosis; 50% are not engaged in regular care; 25% of those eligible for ART are not on the protocol; and only 20% are adherent to treatment and have undetectable viral loads. Although the estimates by Cohen et al.²⁸⁰ are slightly more optimistic, showing that 28% of HIV-positive individuals are adherent to treatment with undetectable viral loads, fewer than one-third of the estimated 1.2 million are receiving optimal care, thus underscoring the variety of obstacles related to access to and retention in care. The HIV Care Engagement Cascade moves along the continuum: 1) HIV infected, 2) HIV diagnosis, 3) Linked to HIV care, 4) Retained in care, 5) Needing ART, 6) Adhering to ART, and 7) Adhering to treatment/having an undetectable viral load. With such sobering medication treatment data as a backdrop, one can only imagine the barriers to medication that Latinos face today.

Adherence to ART has well-documented salutary personal and community results (e.g., decreased individual and community viral load²⁸¹), but limited HIV knowledge, medication side effects, and structural factors (e.g., health care access) are profound barriers to optimal adherence.²⁸² Among limited extant research on Latinos in care, supportive patient-provider relationships were associated with treatment adherence,²⁸³ whereas being recently diagnosed (≤ 6 years), female, in poor health, and having multiple recent sexual partners were associated with suboptimal adherence.²⁸⁴ In order to improve ART adherence, collaborations among community members, health care providers, and policymakers are required to provide a system of quality health care to Latinos that ensures continuity and addresses Latino-specific factors of adherence. Latinos merit a more comprehensive understanding of the obstacles to each step in the HIV Care Engagement Cascade through research developed with a Latino lens. Indeed, *La Cascada* [The Cascade] is ripe for discussion in Latino communities today.

Furthermore, investigation of potential interactions between Latino ethnicity and pharmacologic effects of both ART and HAART are warranted. A recent study indicated that Latinos receiving HAART had significantly greater increases in glucose levels and insulin resistance and fat redistribution when compared with Blacks and Whites.²⁸⁵ Although this was a small study, Latinos' high risk of diabetes compared with Whites and higher rate of death and complications from diabetes versus the general population warrant further investigation into the effects of ART on Latinos' specific health risks.²⁸⁶ Community engagement is essential for optimal integration of HAART into the ways that Latinos manage HIV/AIDS and other relevant health conditions.

PrEP and PEP. HIV PrEP and PEP are biomedical prevention strategies that use antiretrovirals to prevent HIV among HIV-negative persons. The *Iniciativa* PrEx [Pre-exposure Prophylaxis Initiative, iPrEx] assessed the effectiveness and safety of daily oral tenofovir/emtricitabine (FTC-TDF), a fixed-dose combination of two nucleotide reverse transcriptase inhibitors in one pill, for the prevention of

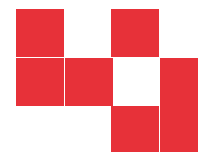


HIV acquisition in high-risk HIV-negative MSM and MTF transgenders who have sex with men. A double-blind, randomized controlled trial was conducted comparing oral FTC-TDF ($n = 1,251$) with a placebo ($n = 1,248$) in sexually active, HIV-negative adult MSM in Latin America (82%), the U.S. (9%), Thailand (5%), and South Africa (4%). HIV serostatus, safety, sexual behavior, treatment adherence, and condom use were assessed at monthly follow-up visits for three years. Results showed that oral FTC-TDF taken before exposure provided a minimum 44% reduction in new HIV diagnoses among MSM and MTF transgenders engaged in high-risk exposure.²⁸⁷ Greater efficacy was observed among individuals with greater PrEP adherence. About 40% of the sample at baseline reported using a condom during receptive anal intercourse in the past three months. Condom use increased over time and did not differ significantly between those taking and not taking oral PrEP.

The effectiveness of this work has been reinforced in studies that focused on the use of PrEP to reduce the risk of HIV acquisition through heterosexual transmission or IDU. The Partners PrEP Study trial of 4,758 HIV-discordant heterosexual couples from Kenya and Uganda found that daily, oral tenofovir combinations reduced HIV transmission by 62% and 73%, respectively.²⁸⁸ The Botswana TDF2 in 1,200 heterosexual men and women from the general population demonstrated 63% reductions in HIV transmission with no significant differences in condom use between the experimental (81.9%) and control (79.7%) conditions.²⁸⁹ More recently, the Bangkok Tenofovir Study showed that daily use of oral tenofovir reduced the risk of HIV acquisition among a sample of injection-drug users.²⁹⁰ A double-blind, randomized controlled trial was conducted comparing oral tenofovir ($n = 1,204$) with a placebo ($n = 1,209$) in recent injection-drug users recruited from drug treatment clinics in Bangkok, Thailand. Oral tenofovir reduced the risk of HIV by 48.9%. Although preliminary findings under carefully controlled research conditions demonstrate a robust protective effect of oral PrEP, these studies need to be replicated among other populations, such as Latinos living in the United States, to determine efficacy as well as community readiness and adaptation to new prevention methods.

Findings from previous studies 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, while the Vaginal and Oral Interventions to Control the Epidemic (VOICE) Study found no impact on reducing HIV acquisition with either oral PrEP or a vaginal tenofovir microbicide gel.²⁹¹ PrEP studies thus far not only highlight encouraging biomedical prevention strategies but also elucidate the need to tailor strategies with diverse populations and locations. In light of findings to date, the Food and Drug Administration approved the use of the combination medication tenofovir disoproxil fumarate plus emtricitabine in July 2012 for adults at sexual risk for HIV,²⁹² and the CDC has issued interim guidance for both MSM (2011) and heterosexual adult (2012) populations.²⁹³ However, the above findings also signal the need to engage Latino communities in formative research to assess feasibility that could potentially optimize readiness and adherence motivation.

The Department of Health and Human Services Working Group on nonoccupational PEP (i.e., post-exposure to HIV prophylactic use of medication) recommends the use of PEP for persons seeking care within seventy-two hours after nonoccupational exposure to blood, genital secretions, or other bodily fluids of a person known to be HIV-positive. Moreover, 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 a high-HIV epicenter such as Los Angeles County.²⁹⁴ 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.²⁹⁵ Therefore, 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. Challenges faced will also include medical personnel and institutional readiness to provide culturally and linguistically relevant instruction and transition to follow-up care for Latinos.

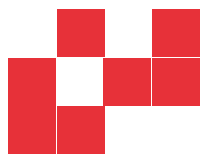


Male circumcision. Male circumcision is a long-term prevention strategy that has been shown to decrease the transmission of HIV. Two randomized clinical trials conducted on Black men have shown the protective effect of male circumcision in HIV acquisition. The two trials showed a robust 60% decrease in HIV transmission in men who were circumcised, compared with uncircumcised men.²⁹⁶ The transmission of HIV from uncircumcised men to women was studied in a randomized clinical trial in Uganda and, unfortunately, found no protective effect for women whose partner was circumcised.²⁹⁷ 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 rates among all ethnic groups, ranging from 10% to 40%.²⁹⁸ 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 one hundred 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.²⁹⁹ 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.³⁰⁰ The benefits of male circumcision are decreased risk of HIV, penile carcinoma, urinary tract infections, and ulcerative STDs.³⁰¹ However, circumcision as a biomedical HIV-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. 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. Crucial for the effectiveness of microbicides is selection of the gel base, as it can damage epithelial cells and thus facilitate the HIV infection.³⁰² A 2004 trial conducted by the Centre for the AIDS Program of Research in South Africa assessed the effectiveness and safety of a 1% vaginal gel formulation of tenofovir for the prevention of HIV acquisition in women.³⁰³ 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 KwaZulu-Natal, South Africa. HIV serostatus, safety, sexual behavior, and gel and condom use were assessed at monthly follow-up visits for thirty months. 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. There were no increases in renal, hepatic, pregnancy-related, or genital-adverse events. The increased risk of diarrhea in women using tenofovir gel may possibly have been due to a local tenofovir effect; further investigation is needed to establish the mechanism for this observed adverse effect. However the VOICE Study found no impact of a tenofovir gel in HIV acquisition among a similar sample of young vulnerable women, largely due to adherence issues.³⁰⁴



Given these discrepant findings and FEM-PrEP's demonstration of no efficacy with oral PrEP, further research is needed to determine whether or not 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 long-term adherence, modesty, lack of knowledge regarding sexual and reproductive anatomy, and cultural and religious stigma related to acknowledgment of sexual risk and contraception, considerable community-based participatory research and interventions are warranted if 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. Furthermore, just as testing the effectiveness of PrEP and PEP has largely been limited to MSM populations, microbicide clinical trials have only been conducted on heterosexual women.³⁰⁵

HIV vaccine research and clinical trials. Latinos are underrepresented in HIV/AIDS medical research in the U.S.³⁰⁶ 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-positive status, physical side effects, stigma, and false-induced HIV-positive test results and their social repercussions.³⁰⁷ 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 HIV-positive status, combat HIV/AIDS stigma, and raise awareness of the relevance of HIV/AIDS in Latino communities.³⁰⁸ Issues regarding participation in clinical trials centered on mistrust as well as lack of information, which could exacerbate doubt and suspicion. In a study of 944 Latinos, although less than half understood what a clinical trial was, almost two-thirds (65%) reported being willing to participate.³⁰⁹ Promising avenues regarding information were found to be the Internet, health care providers, and health fairs. If biomedical advances are to reach diverse Latino communities, and health and human services professionals are to reach the fastest-growing population in the U.S., increased knowledge regarding Latino subpopulation-specific acceptability, accessibility, and availability must be provided throughout various communities.³¹⁰

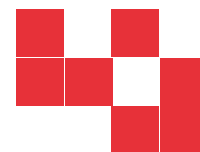
IV. RECOMMENDATIONS

...although it would be preposterous to conclude that HIV is homophobic, racist, sexist, or transphobic, we can conclude that HIV/AIDS infection patterns mirror patterns of inequality in the United States on the basis of sexual orientation, race and ethnicity, gender, and gender identity. That is, members of these particular groupings of people are structurally vulnerable to a vast array of socioeconomic, psychosocial, and health disparities, of which HIV/AIDS is one of many serious risks.

—Kurt C. Organista³¹¹

The overarching recommendation of this white paper is to address HIV/AIDS prevention and treatment through a Latino lens of community-engaged research theory, research, and practice. Such an approach better enables us to:

- Theorize HIV/AIDS as a multilevel, complex health disparity in which social inequality renders certain populations vulnerable to HIV along the lines of sexual orientation, race and ethnicity, gender and gender identity, and SES. More specifically, structural-environmental factors produce



and reproduce socioeconomic (i.e., living and working) conditions that comprise a variety of risk contexts of HIV/AIDS for vulnerable populations. Such a structural-environmental perspective enables us to theorize HIV/AIDS causal pathways between distal structural-environmental-level factors (e.g., macro-social values, laws, policies, institutions, standard ways of operating) and proximal individual-level risk factors, including risky situations in which distal and proximal factors play out in the relationships, neighborhoods, and communities of vulnerable populations.

- Learn from a diverse and rapidly growing minority population in the United States and, through the process, discover innovative ways of conducting culturally grounded, community-based participatory research.
- Develop social, cultural, and community solutions to social, cultural, and community problems in addition to pursuing biomedical and behavioral solutions to the biomedical and behavioral dimensions of a much larger and complex health disparity.
- Integrate Latino cultural values and family systems into research approaches to develop, implement, and evaluate HIV-prevention interventions, thereby tapping the potential power of cultural and other community assets, including leaders and stakeholders (e.g., *promotores de salud*) who can contribute experience, insights, and creativity to community-based prevention efforts.

Integration of a Latino lens directs us toward formative and feasibility-oriented studies in partnership with Latino communities to assess awareness of and/or reactions to so-called evidence-based interventions and, most importantly, to learn what motivates trust, action, and ownership needed to optimally roll out promising research breakthroughs that have yet to penetrate Latino communities. Thus, integration of a Latino lens helps to avoid suboptimal, top-down implementation of promising new prevention interventions too often discovered with non-Latino populations and within the confines of research methods in need of local testing in naturalistic settings.

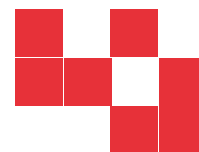
The Latino population is resilient and replete with thriving networks to facilitate survival and success, despite the many barriers that members of Hispanic communities have faced historically and continue to face on a daily basis. This is evident in the phenomenon known as the “Hispanic Paradox,” referring 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 Asians and Pacific Islanders.³¹² 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) social and cultural, 2) structural, and 3) biomedical.

A. Socially and Culturally Oriented Recommendations

Promote Community-Engaged HIV/AIDS Prevention and Treatment that Incorporates Latino Cultural Values and Other Community Assets. Academic research as well as NCLR-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 tap into the strength of Latino social networks and families and include the following themes and messages:



- **Integrate salient cultural values** to construct prevention-research efforts that resonate with diverse Latino communities and facilitate the incorporation of multiple roles into HIV risk context (e.g., gay and Latino, transgender MTF Latina, Latina daughter of immigrant parents). Local values can speak to communities and attract Latinos to prevention, testing, medical care, and clinical trials. Furthermore, this approach can speak to Latino families' participation through *familismo*, a cultural asset that is universally valued across Latino subpopulations. Efforts such as these can further 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** by culturally sanctioning sexual risk communication within Hispanic families through research and programmatic efforts. It is essential to remain cognizant of traditional gender roles and relationships, while emphasizing family protection to facilitate the eradication of taboos associated with protective sexual communication and behaviors.
- **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 their families. These approaches will provide the potential for framing *machismo* and *marianismo* in positive, proactive ways that are helpful to prevention efforts.
- **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 LGBTQ community members.
- **Promote awareness among and facilitate the empowerment of Latino youth** regarding 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. Such promotion must include customized efforts to facilitate sexual empowerment and risk reduction among LGBTQ and questioning youth.
- **Develop and evaluate culturally and linguistically relevant media campaigns targeting the Latino family and community, including messages to involve Latinos in research and clinical trials.** Media campaigns engaging and educating Hispanics about HIV testing and treatment, decreasing homophobia and transphobia, and normalizing acknowledgment 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 collaborating with Latino community-based organizations to design research efforts that target Latino vulnerable groups, communities, and families, utilizing relevant cultural values to improve message recognition and resonance. By focusing on the Latino family, the long-felt stigma associated with the virus can begin to be eliminated, as stereotypical ideas around HIV are challenged, allowing those living

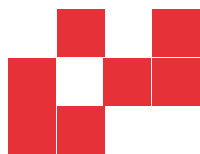


with HIV to be perceived as community peers. In addition, such models and strategies will do a great deal to engender a supportive family environment for Hispanics living with and at high risk for HIV, which contributes greatly to the social support needed to adhere to HIV/AIDS-prevention and treatment regimens. Materials should be in basic Spanish at a literacy level 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.

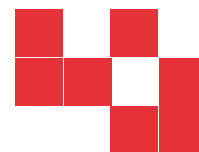
- **Promote Latino-engaged HIV/AIDS-prevention and treatment research** that involves community-based organizations and AIDS service organizations that are well established, recognized, trusted, and utilized by underserved Latino community members. They are often entrenched in the struggles of providing HIV/AIDS-related care that spans the difficulties managed by underserved and underinsured HIV-positive Latinos 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 garner the attention and focus of academic and medical researchers, 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 community-based-organization staff to participate in the peer-review process would facilitate a broader Latino lens from which to view contemporary HIV/AIDS research and prevention efforts.
- **Promote community-engaged research that incorporates *promotores* into HIV/AIDS and research 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 the involvement of *promotores* in community-based participatory-research efforts through meticulous evaluation and significant results. *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. Moreover, for many HIV-positive Latinos, serving as a *promotor/a* allows for a culturally syntonic sense of purpose, community engagement and contribution, and even employment when resources are available.

B. Structurally Oriented Recommendations

How we as a nation develop, define, and measure HIV/AIDS-related risk and research efforts and data are structural factors that determine resource allocations and impact the development of a Latino lens in HIV/AIDS-related research. Current HIV/AIDS research efforts and data related to Latinos could be improved by the following recommendations:



- **Promote the development of Latino-specific research training and mentoring programs.** The dearth of Latinos trained in behavioral and biomedical research results in the absence of the Latino lens during the conceptualization and design of research program and interventions. Given the prevalence of Latino students in teaching-intensive, Hispanic-serving institutions, training efforts should be dispersed among research and teaching-intensive universities so as to optimize involvement of young Latinos. Furthermore, building the “science of culture” is essential to ensuring that Latino-specific cultural values, resilience, and community and cultural assets can be better understood, accurately measured, and optimized within interventions.
- **Improve data on the 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 27.0 years compared with 36.9 years for the total U.S. population in 2012³¹³—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. Now that all fifty states are included in the surveillance report, efforts should be made to collect data that fully describe risk for all vulnerable groups. Incomplete gathering of data has grave repercussions on the allocation of resources and the accuracy of research efforts needed to improve 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: 1) 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; 2) *“Transgender MTF” and “FTM” 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 HIV among MTF transgenders and the extreme risk of rape and violence to this population, which exacerbates HIV risk. Accurate data reporting requires the immediate discontinuation of the practice of categorizing transgender as MSM.
- **Fund community-engaged HIV/AIDS-prevention research that addresses the structural-environmental context of risk that renders Latinos vulnerable to HIV.** Although the behavioral risk-factor model can offer promise when structural-environmental factors are within individual control, the majority of those at risk for, and living with, HIV reside within environments that are resource challenged. The over-emphasis on behavior change, often without addressing contextual factors associated with societal barriers and the at-risk individual’s environment, have had little significant impact on HIV/AIDS. 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.
- **Extend community-engaged HIV/AIDS-prevention efforts to include collaborations with Mexico, along the U.S.–Mexico border, and with Central and South American and Caribbean neighboring countries.** The number of AIDS cases among Latinos as the largest minority population in the U.S. warrants immediate attention. Epidemiologic data indicate that HIV 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. Furthermore, collaborative efforts and economies of scale could be created with Latin American and Caribbean countries’ HIV-prevention and research efforts so as to build international relations and create partnerships to prevent global health disparities.



C. Biomedical Recommendations

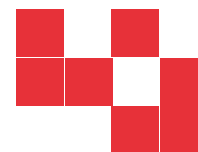
Promote formative research efforts to enhance Latino community engagement in recent biomedical HIV-prevention and AIDS-treatment approaches. Although a number of medical interventions are being developed to prevent HIV, little has been done to determine the potential responsiveness of diverse groups of Latinos, particularly the Spanish-speaking. Latino-specific community readiness for biomedical prevention interventions such as treatment as prevention, PrEP, PEP, microbicides, and HIV-vaccine trials remains unknown. Furthermore, little has been done to identify factors that might enhance or 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 and facilitators to medically based prevention as well as HIV treatment. Specific needs include:

- **Conducting focus groups and key informant interviews to enhance understanding of barriers and facilitators to treatment as prevention, PrEP, PEP, and vaccine trials** among diverse groups of Latinos with an emphasis on Latino MSM, MSMW, transgender MTF, and Latinas. Without knowledge of existing beliefs, attitudes, cultural capital, and resilience factors that could facilitate access to these prevention mechanisms, Latinos will continue to be underserved and underrepresented among those receiving needed prevention and treatment. Although it does not cover undocumented Latinos, the ACA provides the nation with a unique opportunity to engage an additional nine million Latinos in the health care system. As HIV services become integrated with general health care, new structures and strategies can be implemented to overcome stigma and universalize HIV testing, and thus reduce HIV and Latino health disparities overall.
- **Enhancing 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 the gaps in Latino community knowledge, as well as the 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. Moreover, research efforts should test the ability of cultural values, such as *familismo*, to increase acceptance and use of microbicides as part of a larger community and family health strategy.
- **Learning 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. *Familismo* and cultural capital could also increase acceptability and adherence to ART within Latino families and work to decrease the stigma associated with HIV seropositive status.

V. CONCLUSION

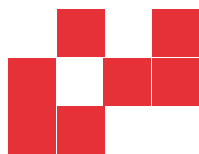
The synergy of the passage of the ACA coupled with new discoveries in HIV/AIDS prevention and management have ushered in an era with great potential to ameliorate HIV and other health disparities within the U.S. Latino population. Within less than four decades, one in three persons living in the U.S. will be of Hispanic descent. The realization that our nation's health rests on the largest, fastest-growing, and youngest minority population is becoming a national reality. While health disparities abound within underserved Latino communities, contemporary research continues to illuminate the resilience proffered by family unity, cultural values, and other factors characteristic of Hispanics, particularly recent immigrants. Undoubtedly, reducing rates of HIV and improving access to testing and treatment for Latinos is an urgent national priority. The requisite of human acceptability and adherence to these interventions is paramount to their success and, as socioeconomic and structural barriers within Latino communities worsen, strategies for community involvement and the integration of cultural capital should be paramount in the minds of the HIV-prevention community. Without the endorsement and involvement of diverse Latino communities, and research models that address structural-environmental factors impacting HIV vulnerability, the unique opportunities brought forth by the ACA will do little to control HIV/AIDS.

The development of HIV-prevention and outreach and AIDS-management strategies through a Latino lens of community-engaged participatory-research methods will ensure that HIV/AIDS prevention activities, interventions, and treatments resonate with Latino communities and subpopulations nationwide. Such social and cultural congruence is imperative to increasing program efficacy and the 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 cultural identity when seeking prevention information, testing, or treatment. Integration of a community-based Latino lens in HIV/AIDS research will undoubtedly broaden our effectiveness, garner greater community-based impact and efficacy in HIV prevention and AIDS management, and make *Nuestra Visión* a fully integrated reality.



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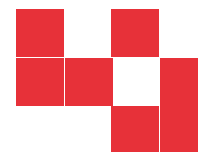
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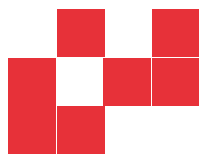
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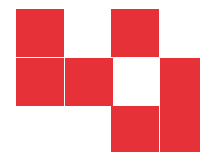
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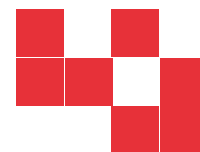
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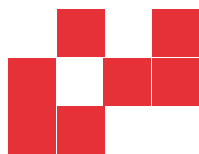
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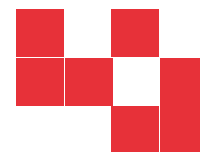
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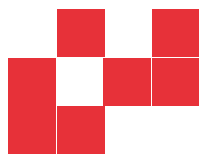
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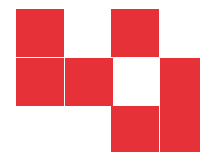
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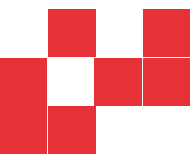
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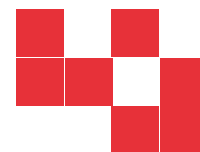
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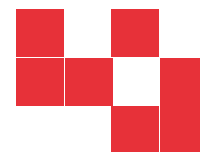
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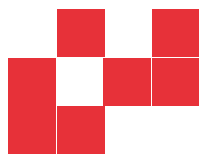
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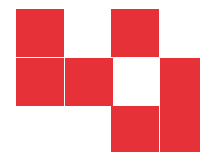
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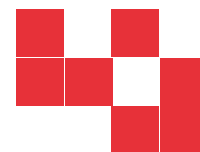
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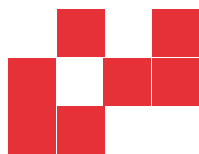
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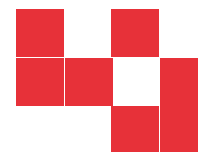
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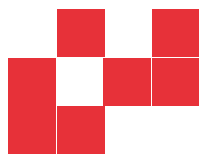
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³¹³ U.S. Census Bureau, "Hispanic Americans By the Numbers," accessed May 25, 2013, <http://www.infoplease.com/spot/hhmcensus1.html>.



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