

Las Olvidadas/ The Forgotten Ones



A publication of the

hispanicfederation

LATINAS and the HIV/AIDS Epidemic

Acknowledgements

The Hispanic Federation and the author would like to gratefully acknowledge the cooperation of the individuals listed below. These individuals participated in interviews which informed this report, freely sharing their invaluable expertise, experiences and insights.

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Our deepest appreciation is extended to all the members of the LUCES coalition (listed below) for their invaluable insights and relentless advocacy on behalf of the Latino community. This report would not have been possible without their support and encouragement.

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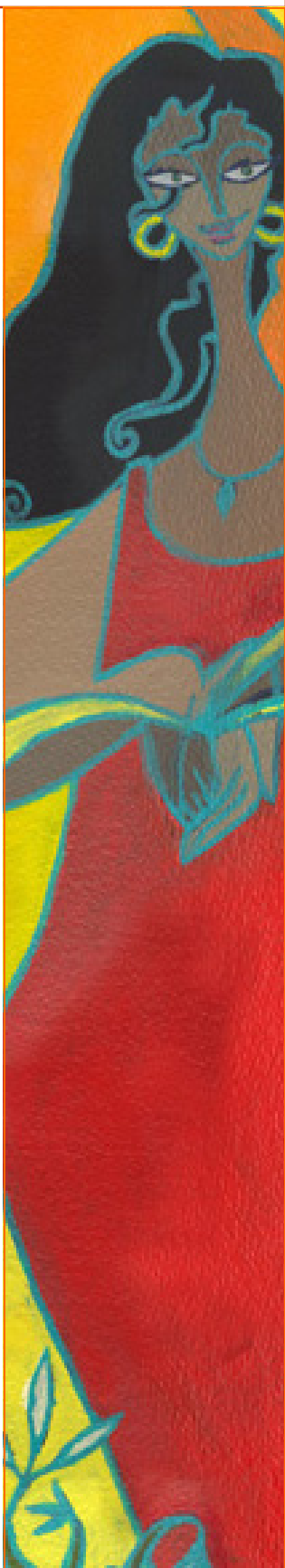
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The Price of Neglect

Executive Summary



While Latinos account for 14% of the U.S. population, they account for 20% of new AIDS cases and 18% of the cumulative AIDS cases in the United States. HIV/AIDS has had a devastating impact on Latino communities and is responsible for the death of more than 92,000 Latinos in the United States through 2003. The Centers for Disease Control estimates that more than 80,000 Latinos are currently infected with AIDS, signaling that the HIV/AIDS epidemic will continue to devastate Latino families and communities well into the future.¹

Latinas have been especially hard hit. The rate of infection among Latinas as a proportion of all Latino AIDS cases has climbed from 15% in 1990 to 23% in 2002.² This change represents a 53% increase in the number of Latinas with AIDS since 1990. Latinas now account for 21% of all AIDS deaths among women,³ with AIDS becoming one of the leading causes of death for Latinas between the ages of 25-44.⁴

Despite these facts, Latinas remain virtually ignored by health policy makers and are one of the most underserved HIV-affected populations. For instance, in New York, the epicenter of the HIV/AIDS crisis, there are only a handful of Latina-centered HIV programs to meet the needs of thousands of Latinas who are HIV positive or at risk of HIV.⁵

Not surprisingly, HIV/AIDS continues to disproportionately impact Latinas, their families and communities. Latinas are more likely to be unaware of their positive HIV status, to learn of their HIV diagnosis at later stages of disease progression, and face numerous obstacles in accessing health care services. They are also more likely to experience considerable discrimination and patient-provider communication barriers that affect the quality of care they receive.

Latinas are most certainly “*Las Olvidadas*” – *the Forgotten Ones*. The price of such neglect has been the unacceptable loss of many Latina lives that have left Latino families and communities fractured and vulnerable.

This report is a Call to Action! The report and action agenda provides an analysis of key factors fueling the HIV/AIDS epidemic among Latinas and offers policy recommendations and action strategies to address Latinas’ priority needs. The analysis and recommendations provided are framed from a social justice perspective that takes into account the intersection of race, ethnicity, class, gender and immigration status, among other factors. The report concentrates on the experiences of Latinas in New York, the state with the highest AIDS case rate and the largest concentration of Latinos living with AIDS. However, similar trends are occurring across the country and the action agenda is designed so that it can be easily adapted to the needs and circumstances of other states, as well as national advocacy efforts.

Creating an Engine for Latina Activism and Leadership

The Latina HIV/AIDS crisis will only worsen without aggressive action from key legislators, public health officials and institutions, the media and community-based organizations. Latina advocates must be front and center in articulating Latina-centered strategies and solutions and successfully advocating for their adoption. Towards this aim, the following steps must be undertaken:

1. Building Capacity: The Need for a Latina HIV/AIDS Advocacy Coalition

Efforts to address the HIV/AIDS crisis among Latinas will require that we galvanize our best thinkers, community leaders, health care providers and strategists under a single, unified and powerful advocacy umbrella consisting of a Latina HIV/AIDS Advocacy Coalition. By bringing together health experts, health providers, researchers, advocates, civic leaders, consumers and health policy makers, the Latina HIV/AIDS Advocacy Coalition can garner the necessary expertise and strategic insight necessary to articulate cutting-edge strategies and solutions to address the rising tide of HIV/AIDS among Latinas. An investment in the development of a permanent infrastructure will enable the Latina HIV/AIDS Advocacy Coalition to regularly pool the advocacy resources of its organizational partners, establish early credibility and enhance its negotiating position and leveraging power in support of its goal.

2. Development of a Latina AIDS Agenda and Advocacy Campaign

One of the coalition's initial steps must be to build broad-based consensus concerning the top priorities for strategic action that will most effectively address the prevention barriers and health access problems faced by Latinas. Towards that aim, sponsorship of a Latina AIDS Summit (the "Summit") to develop agreement on priority needs and strategies would generate a shared vision and advance coordinated action. The Summit would serve to galvanize and facilitate dialogue among diverse sectors of the Latino community in order to work cooperatively to establish an agenda for action and map out a Latina AIDS Advocacy Campaign with measurable goals and objectives to achieve strategic impact.

3. Investing in Public Education and Strategic Communications

For the most part, Latino/as and non-Latinos alike remain unaware of the serious HIV prevention barriers and health access problems affecting Latinas. As a result, Latinas public health needs are frequently and more readily overlooked by public officials. A wide-scale public education and strategic media campaign must be developed that educates the general public about the HIV prevention and health care needs of Latinas. The campaign would also serve as a strategic vehicle by which to hold elected officials accountable for adopting sound public health policies and promoting increased HIV/AIDS funding and services for Latinos.

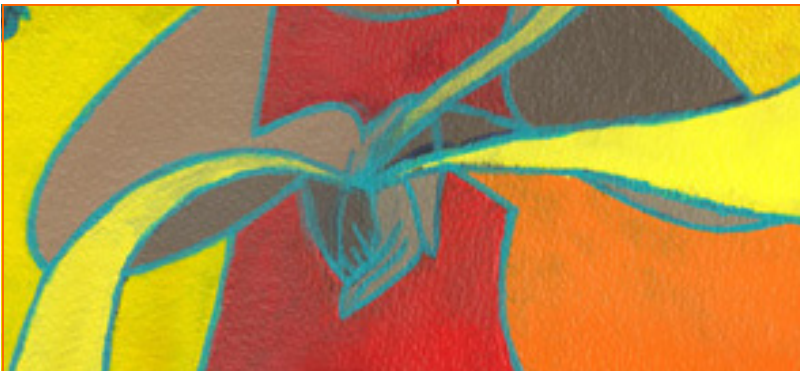
Since many laudable advocacy campaigns have been lost not on their merits but based on public perceptions, it is imperative that the Latina HIV/AIDS Advocacy Coalition develop the capacity to continually assess and influence public opinion. Conducting periodic assessments is an important step in developing a program of communication and action that promotes the publics' understanding of the issues and generates appropriate levels of support.

The number of Latinas with AIDS has increased by 53% over the past ten years.

4. Promoting Grassroots Organizing and Leadership Development

Most importantly, the Latina HIV/AIDS Advocacy Coalition must also be able to build a vocal, sophisticated and diverse constituency base with the capacity to mobilize quickly and efficiently and to continually inform policy positions through regular dialogue and active participation in a wide range of advocacy activities. This effort could entail focusing on developing Latina leadership through the development of local community advocacy networks, peer leadership programs, sponsorship of community meetings and HIV/AIDS advocacy “teach-ins”, as well as providing technical assistance to local groups engaged in AIDS policy and advocacy activities.

In summary, the Hispanic Federation and the LUCES coalition believe it is crucial that Latino communities across the nation take bold, proactive steps to demand that increased health funding and services be directed to Latinas. The strategies described above represent a first step in this effort. We hope the report will serve as one of several vehicles by which to generate discussion and strategic action to address the HIV prevention and service needs of Latinas in our communities.



An Overview

HIV/AIDS in the Latino Community

The United States has witnessed a tremendous growth in the Latino population across the nation. The most recent Census Bureau estimates indicate that there are more than 40 million Latinos residing in the U.S. In fact, over the past decade the Latino population increased by 58%, positioning Latinos as the single largest group in the U.S. after whites.⁷ Despite their growing numbers, Latinos continue to face higher rates of poverty, unemployment and major health disparities. HIV/AIDS in particular, has had a devastating impact on Latino communities. According to the Centers for Disease Control (CDC), 155,722 adults and adolescent Latinos have been diagnosed with AIDS through 2002, representing 19% of the total AIDS cases in the United States.⁸ Of these, more than 92,000 Latinos have died.

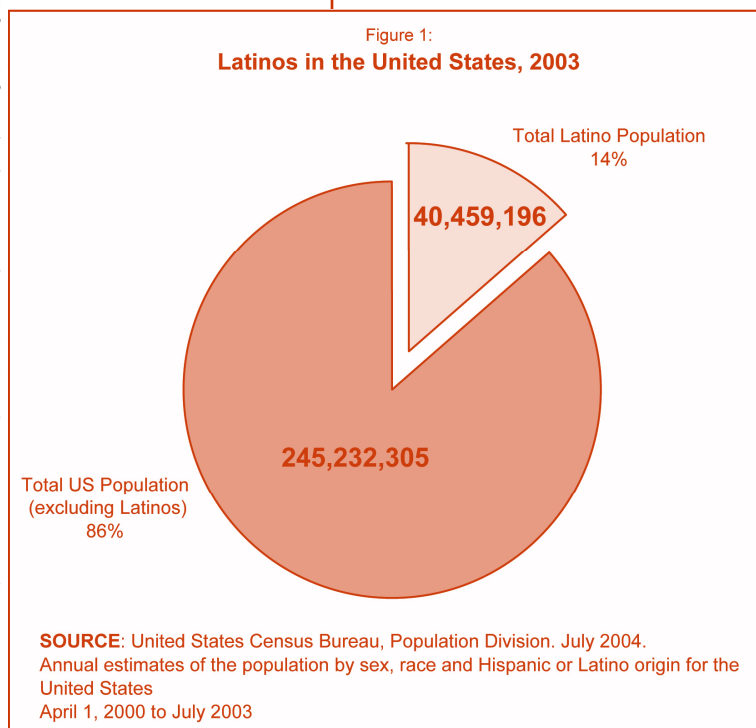
Latinos also account for 19% of the 43,158 new HIV infection cases estimated to occur in the United States each year.⁹ Not surprisingly, in a national survey of Americans conducted by the Kaiser Family Foundation in 2004, three in ten Latinos (30%) reported being personally concerned about becoming infected with HIV, compared with only 10% of whites.¹⁰ According to the Hispanic Federation's 2005 Survey, an even more striking number of Latino New Yorkers, nearly two-thirds (64%), are concerned that someone they love will become infected with HIV.

The Latino AIDS case rate per 100,000 differs sharply from whites. In 2003, the rate for Latino men was 40 per 100,000 contrasted to 12.8 per 100,000 for whites. For Latinas, the AIDS case rate was 12.4 per 100,000 compared to 2.0 or more than six times that of white women.¹¹

Latinas account for 19 million or 48% of the total U.S. Latino population and the number of Latinas is expected to grow considerably.¹² It is estimated that by the year 2050, one out of ever four women in the U.S. will be Latina.¹³ Despite their many contributions and the increasingly prominent role they play in American society, Latinas continue to face serious health care access barriers and, consequently, higher incidences of disease and poorer health outcomes.

In addition to HIV/AIDS, Latinas are faring far worse in numerous areas of health, including breast and cervical cancer, sexually transmitted diseases and teen pregnancy. For example, the rate of cervical cancer among Latinas is twice the rate of whites,¹⁴ the rate of gonorrhea is three times higher for Latinas than white women and Latinas have the second highest teen pregnancy rate of any group.¹⁵ However, the most alarming indicator of all is the rise of HIV infection among Latinas.

Latinas are six times more likely to be living with AIDS than white women.



Latinas are among the fastest growing segment of the U.S. population infected with HIV/AIDS. Nationwide, Latinas account for 19% of the cumulative AIDS cases among women. While among Latinos the majority of AIDS cases have occurred among Latino men (126,350), Latinas account for 19% of the cumulative Latino AIDS cases (29,372) through 2002.¹⁶ In urban areas of our nation the data is even more alarming. In New York City, for instance, Latinas account for a staggering 33% of the cumulative female AIDS cases.¹⁷ In fact, nearly 60% of Latinas estimated to be living with AIDS reside in ten metropolitan areas, with the largest number living in New York City, followed by Los Angeles and San Juan, Puerto Rico.¹⁸

The percentage of new AIDS cases among Latinas also continues to grow. In 1990, Latina AIDS infections represented 15% of all Latino AIDS cases. Today, the rate of infection among Latinas represents almost a quarter (23%) of all Latino AIDS cases.¹⁹ This change represents a 53% increase in the number of Latinas with AIDS since 1990.

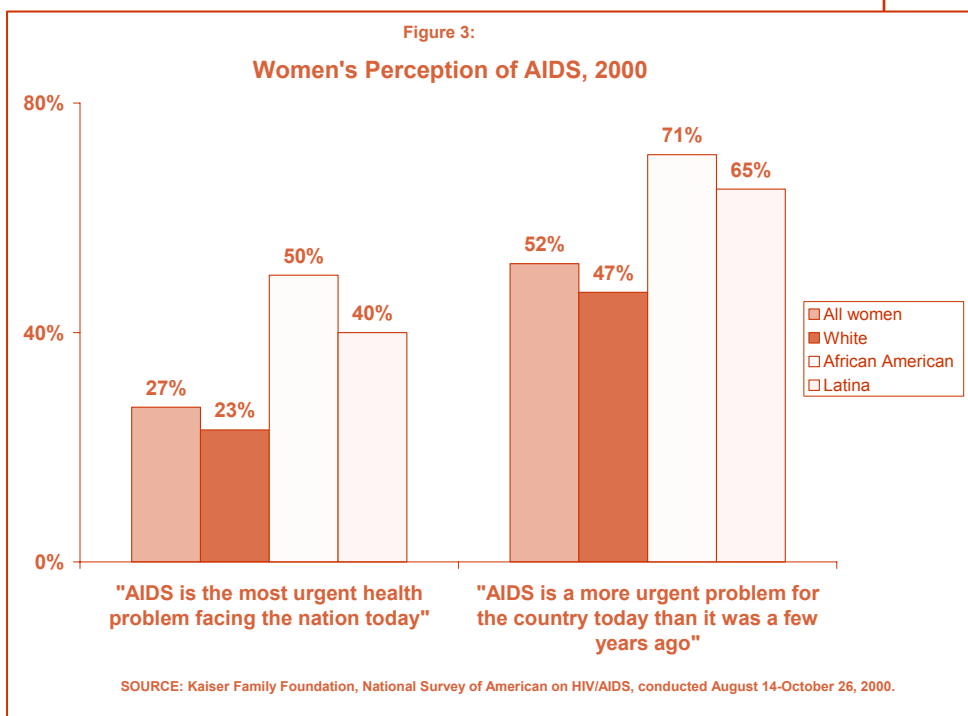
Additionally, in recent years, HIV transmission patterns have also changed in the U.S. and far more Latinas are being infected through heterosexual contact (65%) as compared to injection drug use (32%).²⁰ Several factors contributing to the increase in HIV/AIDS infection among heterosexual Latinas are highlighted in the following sections of this report.

From the very onset, the HIV prevention needs of Latinas have been largely ignored. The first cases of AIDS among women were diagnosed in 1982²¹ and by 1986, only five years into the HIV/AIDS epidemic, Latinas already accounted for one in five AIDS cases among women in the United States.

Nearly 60% of Latinas estimated to be living with AIDS reside in ten metropolitan areas, with the largest number living in New York City, followed by Los Angeles and San Juan, Puerto Rico.

Challenges to HIV Prevention and Safer Sex Negotiation

Despite the life threatening nature of HIV disease, funding for HIV prevention efforts specifically targeting Latinas remains woefully inadequate. And while more Latinas consider HIV/AIDS an urgent problem, far fewer Latinas are able to incorporate HIV prevention activities into their daily lives. Undoubtedly, there is an urgent need to develop culturally competent, Latina-centered, HIV prevention programs. A critical component of this effort must be the development of strategies to help Latinas attain the confidence and skills necessary to effectively negotiate safer sex.



Approximately half of all Latinas in the United States are of childbearing age,²² the majority of whom are or will become sexually active in the coming years.²³ In fact, Latinas represent 15% of all women of reproductive age in the United States, signaling the importance of investing in HIV prevention efforts specifically targeted to Latinas who comprise the youngest and fastest growing sector of the female population. Increasing HIV prevention efforts are especially important given that many Latinas lack basic knowledge about their bodies and key reproductive health matters such as birth control, sexually transmitted diseases, HIV and pregnancy.

Understanding ones' body and gaining a basic level of comfort in discussing sexuality matters is fundamental to sexual health and safer sex negotiation. However, a recent study suggests that too little sexuality education is occurring in Latino homes. Data from the National Family Growth Survey indicates that less than half of Puerto Rican and Mexican American women received sex education on sexually transmitted diseases (STDs), birth control or how pregnancy occurs from their parents,²⁴ placing Latinas at a disadvantage when attempting to discuss sex with their partner and negotiating the use of condoms.

While 65% of Latinas surveyed perceived AIDS to be an increasingly urgent problem for the nation, few resources have been dedicated to addressing the rise of HIV infection among Latinas.

As of 2001, only 19 states required schools to provide sexuality education. Of these states, only 9 required schools that teach abstinence to also teach about contraception including condom use.

HIV Prevention: A Foremost Imperative

The aforementioned findings are particularly disconcerting given that sex education is positively associated with condom use. For example, in a study among 372 sexually active African-American and Latino adolescents in New York, Alabama and Puerto Rico, Latino teens who talked with their mothers about condoms before their first sexual intercourse were three times more likely to use condoms. Furthermore, condom use at first intercourse has been associated with a 20 fold increase in lifetime condom use.²⁵ However, in a recent study only 30% of Puerto Rican women and 19.2% of Mexican women reported using a condom for disease protection “all of the time.”²⁶ Even among younger Latinas, the use of condoms is less than adequate; another study showed 38% of Latina college students reported having unprotected sex due to their partners’ influence.²⁷

Sex and sexuality are often treated as taboo subjects in Latino families. This is particularly true among less acculturated families who are more likely to adhere to traditional cultural values and religious doctrine promoting virginity and denouncing premarital sex and the use of birth control.

The need for culturally sensitive HIV prevention programs for Latina adolescents and adults is particularly important since sex education in schools is often limited as well. As of 2001, only 19 states required schools to provide sexuality education. Of these states, only 9 required schools that teach abstinence to also teach about contraception including condom use.²⁸ Even in states where comprehensive sex education is offered, many young, sexually active Latinos will continue to lack basic access to sex education. In New York State, for example, health education is required in every grade. However, recent studies indicate that at least 75 percent of City schools are not in compliance with the State’s health education mandates. One survey conducted of New York City public schools found that only one third of high school students in NYC had received any HIV/AIDS education since entering high school and only six percent had received all mandated lessons.

Lack of HIV knowledge is also a primary concern. For example, in a 2004 survey conducted by the Kaiser Family Foundation, misconceptions about HIV transmission were still prevalent; among Latinos surveyed, 23% believed that HIV could be transmitted by sharing a drinking glass and 31% believed HIV could be transmitted by touching a toilet seat.²⁹ Similarly, the Hispanic Federation’s 2005 survey of Latino New Yorkers also showed large gaps in HIV knowledge; 25% did not know that HIV could be transmitted through unprotected heterosexual intercourse and 57% were unaware that HIV could be transmitted through oral sex.³⁰

Many Latinas also remain unaware that women are three to eighteen times at greater risk of becoming HIV infected through heterosexual contact than their male counterparts, primarily due to higher concentrations of HIV in semen. Similarly, many Latinas do not realize that sexually transmitted infections may facilitate HIV transmission and that increasing numbers of men are “on the down low,” secretly engaging in sex with other men.³¹ Moreover, women are less likely than men to inquire about their partner’s sexual or injection drug history prior to engaging in sex.³²

Culturally sensitive, HIV education and empowerment focused programs that dispel misconceptions and help Latinas develop the skills and strategies necessary for safer sex negotiation are essential given the barriers described in the following sections.

Compounding the problem are recent policy trends linking HIV funding to abstinence-only programming. Efforts to institute local review panels that may seek to censor HIV prevention and safer sex campaigns will only serve to undermine the work of already under-funded and overburdened HIV prevention and service organizations.

In a recent study, only 30% of Puerto Rican women and 19.2% of Mexican women reported using a condom for disease protection “all of the time.”

Another study showed that more than a third of Latina college students reported having unprotected sex due to their partners’ influence.

Access to HIV Counseling and Testing

Many Latinas remain unaware that testing for HIV later in the course of HIV infection can have serious health consequences. Individuals who become aware of their HIV status at a later stage of HIV disease may not be able to fully benefit from antiretroviral therapy and prophylaxis to prevent opportunistic infections and may continue to engage in risky behaviors that may expose others to HIV as well as compromise their own immune systems.

As noted in a recent report issued by the NYC Office of the Public Advocate, “early HIV detection in women is seriously hampered by the fact that women are not perceived as being at risk and tend to be overlooked even by health care providers.”³³ Thus, health providers often miss the opportunity to

Safer Sex Dynamics

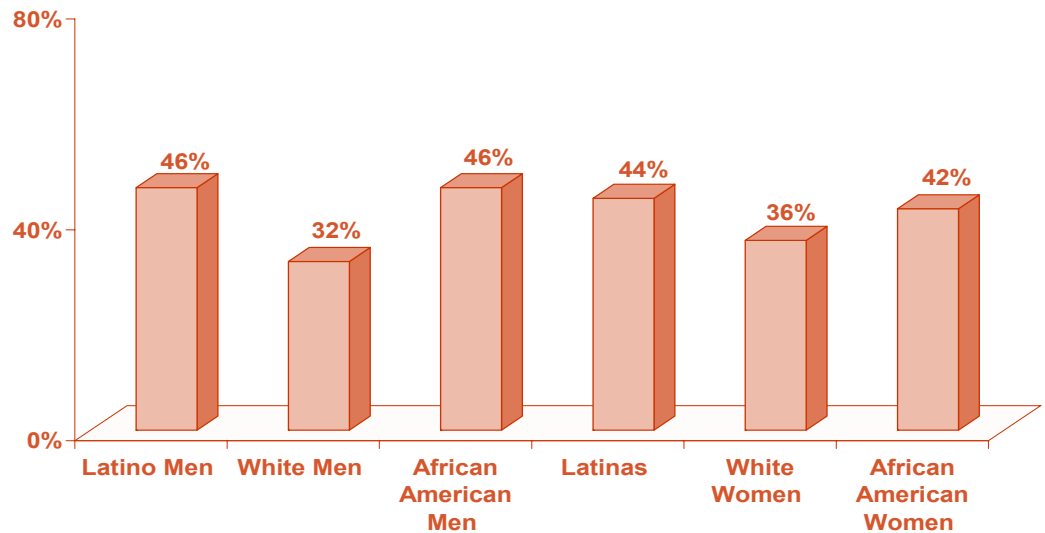
For men, condom use is a personal decision, but for women protection must be negotiated. HIV prevention programs must help Latinas address barriers to safer sex negotiation, such as:

- Low levels of comfort among Latinas regarding discussions about sex and sexuality;
- Adherence to traditional sex roles and the prevalence of gender based, power imbalances in many relationships;
- Religious doctrine opposing the use of any form of birth control;
- Concerns that asking a sexual partner to use a condom will be perceived as a breach of trust - implying doubts about the partner’s fidelity, character and integrity;
- Fear of the partner’s rejection and/or intimate partner violence; and
- Concerns that condom use will be perceived as a tacit admission of the Latinas’ sexual promiscuity or HIV positive status.

provide critically important HIV prevention information and to discuss HIV testing. In a 1999 survey conducted by the Kaiser Family Foundation, 51% of sexually-active Latinas reported that they did not receive HIV counseling at their last gynecological exam.³⁴ Perhaps even more alarming, only 33% of Latinas reported having ever talked to a health care provider about HIV or AIDS and an even lesser number of Latinas reported specifically discussing HIV testing with a health provider (22%).³⁵ Not surprisingly, Latinas are more likely to access testing at later stages of HIV disease than African-American and white women, thereby missing critical opportunities to receive early intervention services that can promote longevity and quality of life.

Figure 4:

Late Diagnosis of HIV/AIDS by Race/Ethnicity, 1990-1999



SOURCE: Centers for Disease Control and Prevention, 2001 National HIV Prevention Conference Abstract, Campsmith and Burgess, "Race/Ethnicity and Gender Differences in Late HIV-Testing-Results from a Supplemental HIV/AIDS Surveillance Report." "Late testers" were diagnosed with AIDS at initial HIV test or developed AIDS within one year from initial test.

An alarming 44% of Latinas were diagnosed with AIDS either at the time of their first HIV test or within one year of testing HIV positive.

Access to Care

It is estimated that between 42-59% of people living with HIV have not been tested or are not receiving treatment or both.³⁶ In fact, access and quality of care remain a central problem for HIV positive individuals. For example, despite the diverse and sophisticated constellation of HIV services funded through the Ryan White CARE Act, it is estimated that in New York City, 3.5% to 10% of HIV positive individuals remain unconnected to HIV health and social services.

Early diagnosis and access to care are crucial to the management of HIV disease. Yet, even after testing HIV positive, many Latinos delay seeking treatment. One survey found that Latinos were more likely than whites and African-Americans to report delaying HIV care due to one or more competing needs.

Furthermore, a recent study showed 31% of women testing HIV positive delayed seeking care for 3 months or longer due to fear, anxiety or depression,³⁷ demonstrating the need to create linkage programs that provide supportive counseling and a seamless transition into care.

The Importance of Reproductive Health Services and STD Screening

Access to reproductive health services is vitally important for women who are HIV infected and at risk for HIV, since approximately 80% of HIV positive women experience gynecological symptoms and often times these symptoms are the first indicator of HIV disease.³⁸ Women with HIV frequently have a more pronounced and accelerated disease pathology and often present with very different signs and symptoms than their male counterparts.³⁹ Yet women are more likely to be treated for recurrent gynecologic problems for an extended period before health providers ever discover the underlying HIV disease. Although the first cases of AIDS among women were diagnosed in 1982 it was not until 1993 that the AIDS definition was modified to include many of the AIDS-related diseases found in women, such as cervical cancer.⁴⁰ In fact, often times women are not diagnosed with HIV/AIDS until they require hospitalization or become pregnant.⁴¹

Moreover, women with HIV are at increased risk for developing or contracting a range of reproductive health problems including cervical dysplasia⁴² and human papillomavirus (HPV),⁴³ considered precursors to cervical cancer. Consequently, a delayed HIV diagnosis may severely impact the ability to manage life threatening health complications experienced by HIV positive women.

Many women are unaware that HIV is more easily transmitted from men to women during sexual intercourse and that the presence of certain STDs make women two to five times more vulnerable to HIV infection through sexual contact. STD prevention and early treatment is particularly important for Latinas given that the rates of STDs such as gonorrhea and syphilis are 2-3 times higher among Latinos as compared to whites, largely due to disparities in access to health care services.⁴⁴

The Consequences of Delayed Care

Latinas continue to learn of their HIV status later in the disease process, missing the opportunity to receive early access to an array of life enhancing health and social support services. Latinas not only test for HIV later and enter care at later stages of HIV disease but exhibit higher viral loads and lower CD4 counts at entry than their male counterparts.⁴⁵ The consequences can be devastating. For example, in New York City, one of every six Latinas testing HIV positive in 2002 also received a concurrent diagnosis of AIDS. Moreover, in that same year, Latinas accounted for 30% of HIV-related deaths among women.⁴⁶

Structural and Institutional Barriers

As noted by Latina researcher Dr. Hortensia Amaro, “The risk of HIV infection takes place within a larger social context that is shaped by how gender, race, ethnicity, and class are defined [and] how resources are allocated...”⁴⁷ Consequently, the task of developing strategies to address HIV in Latino communities requires a closer examination of the structural and institutional factors that operate to keep so many Latinos poor and deny many Latinos access to basic health care services.

Accessing quality health care often requires Latinas/os to maneuver a daunting obstacle course in order to secure even the most basic health care services.

Nearly two thirds of HIV positive women have annual incomes of less than \$10,000.

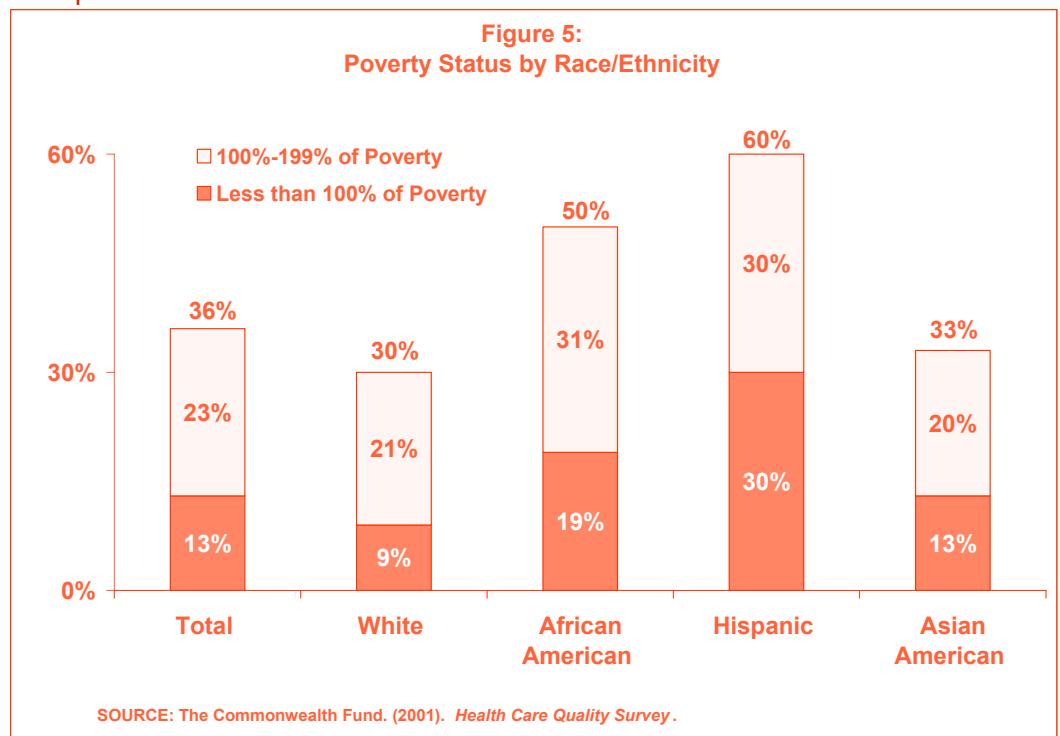
Women and AIDS Fact Sheet
Kaiser Family Foundation

Accessing quality health care often requires Latinas/os to maneuver a daunting obstacle course in order to secure even the most basic health care services. Some of the health care barriers faced by Latinas include:

- poverty and socioeconomic stress;
- lack of health insurance;
- access barriers and poorer quality of care;
- discrimination in health care delivery & public health policies; and
- lack of linguistically appropriate and culturally competent health care services.

Socio-Economic Stress

Latinas make extraordinary contributions to the social and economic well-being of our nation. Yet, despite their valuable contributions, Latinas often times face racial, ethnic and gender discrimination. Overall, Latinas/os continue to be concentrated in the lowest paying jobs, have the second highest rate of unemployment and the lowest rate of home ownership and asset accumulation.⁴⁸ It is estimated that at least 23% of Latinos live in poverty and the rate is even higher among Latino children who represent nearly 31% of children living in poverty.⁴⁹



A survey conducted by the Commonwealth Fund paints an even bleaker picture, with 60% of Latino respondents living below or near the poverty line. One of the contributing factors to the high poverty rate is that close to 25% of Latino households are headed by single Latinas who are the lowest paid wage earners of any group.⁵⁰

Studies show that for every dollar earned by white men in 2003, white women earned 80 cents, African-American women earned 69 cents and Latinas

earned 57 cents.⁵¹ There is also a wide wage gap between Latinas and Latino males. The median wages for Latinas in 2003 was \$21,320 as compared to \$24,128 for Latino males, \$25,532 for African American women and \$29,484 for white women.⁵² Another contributing factor is lack of educational opportunities and access to quality education, leading to lower educational attainment. For example, 6.7% of Latinas have less than a 9th grade education. Only 30% of Latinas are high school graduates and less than 22% have secured a bachelor's degree or higher.⁵³ The combined effects of gender, racial and ethnic discrimination are made apparent by the fact that a Latina with a college degree earns less than a white woman with a high school diploma.⁵⁴

For HIV-positive women, the situation becomes even more abysmal. Women with HIV/AIDS are disproportionately low-income. Nearly two thirds of women with HIV/AIDS have annual incomes below \$10,000 as compared to only 41% of men with HIV/AIDS.⁵⁵ For HIV infected women who are isolated and lack social supports, the results can be devastating. Many Latinas find themselves homeless, unable to afford even the most basic necessities such as food or to pay for transportation to health care appointments. Against this backdrop, many forgo seeking health care and taking medication altogether in order to attend to pressing survival issues.

Lack of Health Insurance

Without access to primary care, Latinas are less likely to receive HIV prevention counseling or to be screened for communicable diseases that would include tuberculosis, HIV and STDs. Lack of health insurance is arguably the major barrier Latinas face in accessing health care services. Latinas have the lowest median weekly earnings among all women and racial/ethnic groups, earning only \$410 per week as compared to \$567 for white women and \$715 for white men.⁵⁶ As such, many uninsured Latinas often have no other recourse but to either delay or forgo needed health services because they simply cannot afford to pay for health care. Forgoing health services is especially disconcerting considering that 29% of Latinas report being in fair to poor health as compared to 14% for white women and 24% for African-American women.⁵⁷

Latinas not only have the highest uninsured rate of women from any racial/ethnic group (37%) but the number of uninsured continues to rise and shows no signs of abating.⁵⁸ For example, in 1994, among low-income women, 46% of Latinas reported having no health insurance and by 1998, the number of uninsured, low-income Latinas had climbed to 51%.⁵⁹ Moreover, welfare and immigration reform has severely impacted the ability of low-income Latinas to access safety net programs such as Medicaid. A recent study commissioned by the Kaiser Family Foundation found that the percentage of Latinas receiving Medicaid decreased from 29% to 21% between 1994 and 1998 and that overall, *women in their childbearing years were the most likely to lose Medicaid and become uninsured.*⁶⁰

Thus, too many Latinas are missing critical opportunities to receive HIV prevention counseling, early HIV testing and care. According to Hilda Melore, Project Coordinator of Voices of Women of Color Against HIV/AIDS, many newly diagnosed Latinas, especially immigrant, Spanish-language dominant women lack information about free HIV services and medication available through the Ryan White CARE Act and the AIDS Drugs Assistance Program.⁶¹

Many uninsured Latinas often have no other recourse but to either delay or forgo needed health services because they simply cannot afford to pay for health care.

“There is a need for language accessible programs. Right now HIV positive Latinas have to depend on their kids for translation at the hospital.”

Hilda Melore, Coordinator
Voices of Women of Color
Against HIV/AIDS

The Need for Culturally Competent & Linguistically Accessible Services

Recognizing that the provision of culturally competent health services is an essential strategy towards the elimination of racial/ethnic health disparities including HIV/AIDS, the DHHS Office of Minority Health has developed *Recommended Standards for Culturally and Linguistically Appropriate Health Care Services* (CLAS) to provide health care institutions and providers with guidance for achieving cultural competence.

Cultural competence in health care delivery requires providers to have an understanding of the beliefs, values, traditions and practices of a cultural group, including culturally-based beliefs about the etiology of illness and disease and concepts of health and healing practices.⁶² The provision of culturally competent health care can improve health outcomes for individuals and communities, increase levels of patient satisfaction and improve cost efficiency.

According to the Health Resources and Services Administration (HRSA), culturally competent practices enable providers to:

- Obtain more specific and complete information to make a diagnosis;
- Facilitates the development of treatment plans that are more likely to be adhered to by the patient and supported by the family; and
- Enhances overall communication and interaction between patient and provider.⁶³

A key component of providing culturally competent services is the delivery of linguistically appropriate services. In a recent study conducted by the Commonwealth Fund, 43% of Spanish dominant Latinos reported communication difficulties with their health providers.⁶⁴ Another 16% of Latinos reported not following the doctor's advice simply because they didn't understand it. Latino patients with language discordant doctors are more likely to omit medication, miss office appointments and rely on the emergency room for care, often leading to poorer health outcomes.⁶⁵ The widespread impact cannot be underestimated. According to a recent report issued by the New School for Social Research, there are 1.8 million New Yorkers who do not speak English well and therefore may encounter problems communicating with health providers.⁶⁶ Given that a 95% medication compliance level is required for antiretroviral therapy to be effective, the consequences can be life threatening for limited English proficient (LEP) HIV positive Latinas who may not understand how to take their medications.

By contrast, language concordance between physician and patient has a positive impact on health behaviors. A study conducted at the General Medical Practice of the University of California – San Francisco, found Spanish monolingual patients whose physicians spoke Spanish had better recall of their physician's recommendations and asked more questions during their visit than their counterparts seen by non-Spanish speaking clinicians.⁶⁷

Compounding this problem is the lack of language interpreter services; it is estimated that only half of Latinos needing interpreter services actually receive such services. Undoubtedly, providers limit opportunities for patient education and treatment compliance when they fail to recognize and address the needs of their limited English proficient patients.

To ameliorate the problem faced by LEP consumers, health care institutions and social service agencies must accelerate efforts to hire and train bilingual staff. Additionally, these institutions must develop the capacity to provide interpreter services and factor in the need to provide additional assessment and patient education time during the course of health care and supportive services visits with LEP consumers. Furthermore, service providers must take into account that a substantial number of LEP consumers⁶⁸ also experience low literacy rates even in their dominant language, therefore HIV outreach and educational materials should be tailored accordingly.

Finally, health care advocates must also demand the hiring of Latino health care executives that can work to ensure institutions deepen their commitments to providing culturally sensitive and linguistically appropriate services. From coast to coast, Latinos are underrepresented in the governing and policymaking bodies of public health institutions. For instance, in New York City, where Latinos account for nearly 30% of the population, there are no Latinos in senior management positions in 12 of the City's 13 voluntary hospitals.⁶⁹

Discrimination in Health Settings

Recent survey findings indicate that nearly one in five Latinos have felt disrespected by a health provider because of their capacity to pay for services, language difficulties and/or their race/ethnicity.⁷⁰ Perhaps even more telling, 13% of Latinos believe they would receive better health care if they were of a different race or ethnicity.

Discrimination in health care delivery settings can take many forms: from outright racial/ethnic slurs by health care personnel, to subtle forms of differential treatment by providers, such as when providers spend less time taking a patient history, order fewer diagnostic tests or take less time to explain a diagnosis and treatment plan to patients.

In 2002, the Institute of Medicine, an independent research institution that advises Congress, released a report that found that racial and ethnic minorities in the United States receive lower quality health care than whites, even when their insurance and income are the same. The report concluded that the racial and ethnic disparities contribute to higher death rates among minorities from cancer, heart disease, diabetes and HIV infection.

Other indicators of discrimination include disparities in health care spending. For example, in 1996, \$1,428 was spent on the average Latino Medicaid recipient compared to \$4,074 for the average white recipient.⁷¹ In other cases, institutional discrimination is less blatant, such as when hospitals separate their privately insured postpartum patients on different floors or wards from their uninsured and Medicaid patients who are primarily people of color.⁷²

Moreover, the adoption of coercive public health policies that disproportionately impact Latinos and other people of color also serve as impediments to accessing health care. For example, in the 1950's public hospitals in New York City sterilized thousands of Latinas, primarily Puerto Rican women, without proper counseling and safeguards to insure informed consent,⁷³ fostering a deep sense of distrust within the Latino community. A recent example of a coercive public health policy disproportionately impacting women of color was the use of a public hospital operated by the Medical University of South Carolina to collect evidence used to criminally prosecute pregnant addicted mothers. The majority of women taken into custody as a result of the hospital's actions were women of color.

Quality of Care

The health care Latinas receive, even when they are able to promptly access care, may be suboptimal. Several factors impinge upon the quality of care received by Latinas as a group, including lack of continuity of care and difficulty communicating with providers:

- ▶ Approximately 31% of Latinas do not have a regular health provider as compared to 14% for whites and 17% for African-Americans;
- ▶ Latinas are more likely to rely on hospital clinics and health centers (38%) and emergency rooms (7%) for their care where staff turnover can be greater;
- ▶ Latinas are more likely to report being treated by doctors who do not usually take the time to answer all of their questions (14%), as compared to white (9%) and African-American women (8%);

Against this backdrop it is not surprising that Latinas are more likely to rate their health as being fair or poor.

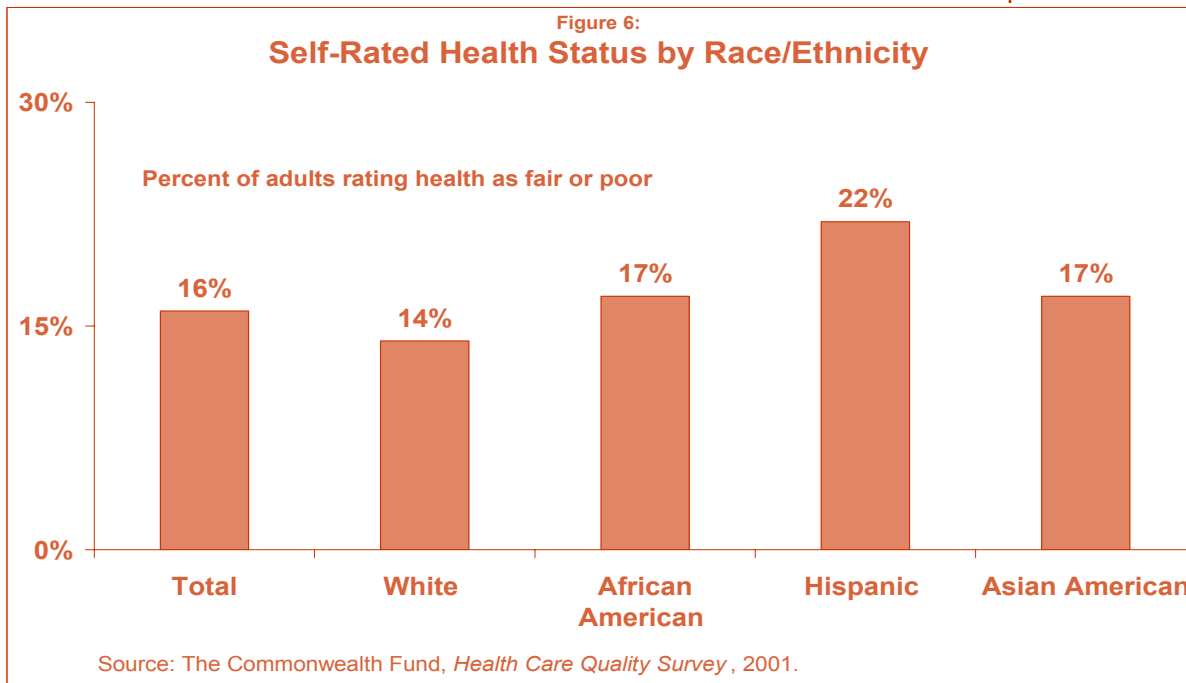
With respect to the management of HIV disease in particular, there are several indicators that have been found to suggest suboptimal care, including infrequent office visits for persons with HIV disease, the use of emergency departments when there is no need for hospitalization, increased hospitalizations, and failure to take appropriate anti-HIV medications.⁷⁴

Past studies have indicated that HIV positive women of color are less likely to have had an outpatient visit in the last six months, to receive prophylaxis for opportunistic infections, and to be on antiretroviral therapy, all of which are indicators of suboptimal care. One study of 1700 women found that whites were 1.5 times more likely than women of color to receive antiretroviral drugs. Moreover, studies indicate African-American women and Latinas are least likely to receive therapy meeting federal guidelines.⁷⁶

Finally, while advances have been made in the treatment of HIV disease, Latinos have simply not benefited at the same rate as other groups, as illustrated by the following:

- ▶ AIDS cases among Latinos declined by 56% as compared to 73% for whites between 1993 and 2001.⁷⁷

- ▶ Estimated deaths among Latinos declined by only 56% as compared to 80% for whites between 1993 and 2001.⁷⁸
- ▶ Estimated AIDS prevalence among Latinos increased by 130% as compared to 68% for whites between 1993 and 2001.⁷⁹



The Need for Social Support and Mental Health Services

Seventy six percent (76%) of women with HIV/AIDS are living with children under the age of 18 as compared to only 34% of men. For many low income Latinas, personal health is often a lesser priority than attending to immediate survival needs such as paying the rent, securing food, taking care of their families and carrying out their parental responsibilities. Consequently, the added childrearing and concomitant economic responsibilities Latinas face can be a factor leading to delays in HIV testing and treatment, as well as poor treatment compliance.⁸⁰ Moreover, many HIV prevention, treatment and supportive services are not designed in a manner that takes into account the central role of family in the lives of Latinas. For example, according to Elisa Rivera, Manager of the Women and Families Initiative at the United Way of New York, very few programs offer childcare services to facilitate women's participation in HIV education and treatment.⁸¹ While case management services are now more widely available than before, Latinas often lack access to bilingual case managers. Bilingual case managers are few and far between and are rarely compensated for the higher caseloads they must assume.

Respite services are also needed to help Latinas reduce the stress associated with parenting demands and to allow for self care, especially for the growing number of single mothers. Respite care is also needed for other caretakers, as we are now witnessing HIV across multiple family members and several generations (e.g. mother and infant, mother and adolescent) requiring other family members, such as grandmothers, to assume responsibility for the

“What we need is an integrated and comprehensive system of care – not just medical services but counseling and follow-up support.”

Marilyn Aguirre-Molina, Ph.D.
Professor of Public Health,
Mailman School of Public Health
Columbia University

“To this day there are almost no programs for heterosexual HIV-positive women infected by their partners.”

Lillian
HIV Latina Peer Educator

children when the mother becomes ill or has passed away. Bilingual family and children’s counseling services to help families cope with the impact of HIV in their lives are also desperately needed.

Furthermore, studies indicate that a substantial number of HIV positive women have histories of sexual and/or physical abuse⁸² and require counseling and support to heal from the trauma. These experiences often times leave women feeling depressed, vulnerable and with a diminished sense of self-efficacy. For example, research findings show that battered women perceive themselves to have less control over safer sex, demonstrate lower efficacy in sexual negotiation, lower self-esteem and lower participation rates in HIV programs.⁸³ Supportive counseling services are needed to address past trauma and help women achieve better self-esteem and self-efficacy.

The need for culturally, competent linguistically appropriate mental health services is particularly important as it is estimated that 60% of HIV positive women experience symptoms of depression that can interfere with treatment adherence.⁸⁴

Treatment Adherence

Even when HIV positive individuals are connected to health care services, Latinas may miss appointments, fall out of care and/or fail to understand and/or adhere to complex HIV medication regimens. Failure to adhere to HIV medication regimens and to attend regular medical appointments results in the inability of the health provider to evaluate viral load, monitor the side effects and efficacy of HIV medications and screen for opportunistic infections. Poor treatment adherence places Latinas at risk for poorer health outcomes, unnecessary hospitalizations and premature death.

Treatment adherence refers to the health consumers’ ability “to develop and follow a plan of behavioral and attitudinal change that serves to empower the individual to improve his/her health and self-manage a given illness.”⁸⁵ *Medication adherence* in HIV care refers to “the ability of persons living with HIV/AIDS to be involved in choosing, starting, managing and maintaining a given therapeutic combination medication regimen to control viral (HIV) replication and immune function.”⁸⁶ It is estimated that a 95% medication adherence rate is required to maintain HIV viral suppression and to prevent the emergence of drug resistance⁸⁷ that can render HIV medications ineffectual in fighting HIV disease progression. Yet there are numerous barriers that can interfere with treatment and medication adherence: psychological distress, psychoactive drug use, cognitive dysfunction, lack of social support, financial obstacles, unstable housing, lack of education and medication side effects.⁸⁸

As mentioned earlier, a 95% medication compliance level is required for antiretroviral therapy to be effective yet only three quarters of women receiving antiretroviral therapy report taking medications as or almost as required,⁸⁹ often due to competing survival needs and family responsibilities.

Access to medication is also unequal. Past studies have shown that women are less likely to receive highly active antiretroviral therapy (HAART)⁹⁰ than

men. Moreover, women with a history of mental health disorders, substance abuse or both have been frequently denied HAART.⁹¹ Depression, which is common in HIV positive women, can also interfere with treatment adherence.⁹²

Family-friendly treatment adherence counseling programs are needed to help HIV positive women fully understand the importance of treatment and medication adherence and to develop the skills and strategies to effectively manage the many competing demands placed upon them.

In addition, culturally sensitive, community-based programs with flexible hours of operation and on-site child care services, case management and treatment adherence counseling are crucially important to this effort. Incorporating peer educators with similar life experiences to help Latinas effectively overcome barriers to treatment adherence have proven to be especially effective.

Underserved Populations

Latina/o Adolescents

At least half of all new HIV infections are estimated to occur among those under the age of 25⁹³ and Latina/o adolescents are especially at high risk. Latinas already account for 19% of cumulative AIDS cases among young women in the U.S.⁹⁴ and 34% of the cases in New York City.⁹⁵ This number is likely to significantly increase given the relative youthfulness of the Latino population and lower rates of condom use among Latino teens.

In 2001, 44% of Latinas in grades 9-12 reported having had sexual intercourse.⁹⁶ One out of every ten sexually active Latina high school students reported having four or more lifetime sexual partners. Perhaps even more alarming, over half of Latina high school students said they did not use condoms at last sexual intercourse (52%), heightening their risk of HIV infection.⁹⁷

A substantial number of Latina teens are also experiencing early puberty and engaging in sex at an earlier age with older boyfriends. Often younger girls lack the negotiation skills, self confidence and assertiveness necessary to delay first sexual intercourse or to demand the use of condoms. Having an older boyfriend has been associated with an increased risk of pregnancy and sexually transmitted infections including HIV.⁹⁸ Undoubtedly, Latina adolescents need support in developing communication and negotiation skills and in establishing shared responsibility for sexual decision making.

Over half of Latina high school students said they did not use condoms at last sexual intercourse (52%), heightening their risk of HIV infection.

Latina Drug Users

The epidemics of drug use and HIV are intertwined. Earlier in the HIV epidemic, injection drug use (IDU) accounted for a larger share of AIDS cases among women. In 1997, for example, IDU accounted for 45% of AIDS cases among women in the U.S. Although the percentage of AIDS cases attributed to injection drug use has decreased to 38%, drug use continues to play a central role in the lives of Latinas infected and at risk of HIV infection. IDU and sex with male IDUs accounts for 58% of the total AIDS cases among Latinas in United States through 2002.⁹⁹

For many women, the downward spiral commences with social drug use as a method for coping with high levels of stress and prior traumas. However, as women become enmeshed in the drug lifestyle and become further isolated from their families and communities, they respond by increasing their drug use and become more dependent on sexual exchanges as a means of earning income or securing drugs. The use of crack-cocaine and injection drug use are associated with inconsistent condom use among both HIV infected and uninfected women, increasing the risk of HIV infection or re-infection with another HIV strain.

Generally, women drug users are more likely to report that they use multiple drugs taken concurrently, live with a partner dependent on drugs, and have more family and job pressures than their male counterparts.¹⁰⁰ Moreover, women drug users are more likely than men drug users to be socially isolated, depressed and dependent on their partners.¹⁰¹

Often, women who use illegal drugs have histories of abuse and are frequently physically and sexually abused during the time of their drug use.¹⁰³ For many Latina drug users, the end result is a vicious cycle of early trauma, drug use, isolation, marginalization, increased drug use, illegal activity and the ongoing risk of HIV exposure, violence, incarceration and homelessness. Latina injection drug users with children are especially reluctant to seek out help due to fears that their children will be taken away from them.

Moreover, researchers indicate that few drug treatment programs pay sufficient attention to addressing HIV transmission through heterosexual contact. These researchers point out that studies suggest that Latinas are at greater risk through sexual exposure from their drug using partner than due to their own drug use.¹⁰³

Although substance use is prevalent among women with HIV/AIDS, most drug treatment programs were designed to serve men.¹⁰⁴ For example, although 60% of women with HIV/AIDS have children under age 18, few residential drug programs allow children to join their mothers, forcing many women to forgo treatment altogether because they are unable to secure alternative care for their children.¹⁰⁵ Additionally, many Latinas are afraid to access drug treatment services due to fears of being deemed an unfit mother and having their children taken away from them by the child welfare system.

Harm reduction programs specifically targeting women are also scarce. For example, a survey conducted by the Office of the Public Advocate showed

that of the twenty-eight (28) harm reduction programs in New York City, only five (5) programs served women and no mention was made of any programs specifically designed for Latinas.¹⁰⁶

Latina Sex Workers

Sex workers face a constellation of barriers that work to undermine HIV prevention efforts, including violent and unsafe working conditions, fear of criminal prosecution, drug dependency, lack of access to regular health care and unstable housing among others. Within this group, the most vulnerable to HIV infection are street workers. This population encompasses many individuals who are poor or homeless, alcohol and/or drug dependent, individuals with mental illness and a growing sector of young people that include runaways.¹⁰⁷ Survival needs such as food and housing coupled with drug addiction often work to override concerns about HIV infection.

In a study of female prostitutes in six U.S. states, injection drug use was identified as the main risk factor for HIV infection.¹⁰⁸ When compared to sex workers who do not inject drugs, female injection drug users who trade sex for money or drugs are more likely to share dirty needles that can carry HIV.¹⁰⁹

As noted by one author, “Condom use requires a social assertion of power, control and self esteem that most women find difficult to maintain on the street.”¹¹⁰ The illegal nature of prostitution often places sex workers at odds with police and public health officials who are perceived by sex workers to threaten their livelihood. Against this backdrop, it is not surprising that sex workers often feel they have few societal protections or personal power to insist on the use of condoms with their clients.

Additionally, economic concerns are often paramount to sex workers who often agree to unprotected sex if a client offers substantially more money. Consequently, for this population in particular, there is a great need to offer meaningful alternatives to sex trading or prostitution, which can only be accomplished by providing a comprehensive array of employment training and job assistance, drug treatment, legal assistance and stable housing, among other needed services.

Latina Immigrants

Immigrant Latinos account for 39% of the total Latino population in the United States¹¹¹ and therefore are an important sector to consider when designing Latina/o HIV prevention and treatment programs. Overall, individuals born outside of the United States comprise a substantial number of AIDS cases. For example, data indicates that foreign born individuals accounted for a total of 25,128 or 17% of the cumulative AIDS cases reported in New York State through December 2001. New York City accounts for the vast majority of these cases, representing 9 out of every 10 AIDS cases (cumulative) among foreign born individuals in New York State.

In the case of women, Latina immigrants sometimes find themselves at risk of HIV infection after reuniting with their husbands in the United States, who in the interim may have become HIV infected through commercial sex workers or other means. A recent report indicated, for example, that commercial sex workers actively solicit male migrant workers at labor camps, bars and check cashing places, especially on payday.¹¹²

“Condom use requires a social assertion of power, control and self esteem that most women find difficult to maintain on the street.”

D. Worth
Sexual Decision-Making and AIDS
Studies in Family Planning

In a study conducted in California and Texas, only 38% of Latino undocumented immigrants had visited a physician at least once in the past year as compared to 66% for all Latinos and 75% for the total U.S. population.

Additionally, in light of stricter immigration laws, the Patriot Act and growing anti-immigrant sentiment in the nation, the fear of deportation looms heavily on the shoulders of immigrant Latinas and may impinge upon health-seeking behaviors. The fear of deportation or jeopardizing ones' legal status is so strong that many immigrant Latinas forgo HIV testing and treatment and suffer social isolation in order to keep their HIV infection a secret.

Undocumented immigrants are especially vulnerable because they are the least likely to be insured and tend to have fewer ambulatory visits than legal immigrants and U.S. citizens. In a study conducted in California and Texas, only 38% of Latino undocumented immigrants¹¹³ had visited a physician at least once in the past year as compared to 66% for all Latinos and 75% for the total U.S. population.¹¹⁴ Without access to basic health care, few immigrant Latinas are able to access HIV prevention counseling, testing and treatment.

The majority of undocumented immigrants in the U.S. come from Latin America. Mexicans account for 57% of all undocumented immigrants. Following Mexico, the source countries with the highest numbers of unauthorized immigrants to the U.S. were El Salvador, Guatemala, Columbia, Honduras, China and Ecuador.¹¹⁵

Given that more than 2 million undocumented immigrants entered the U.S. from 2000 to 2003,¹¹⁶ the number of undocumented Latinas in need of HIV prevention and treatment services is likely to continue to rise in the near future. An investment in HIV prevention and early treatment services targeting Latina/o immigrants must be made today in order to prevent a wave of new HIV infections within the immigrant community.

Latina Elderly

Ten percent of new AIDS cases in the U.S. occur in people over 50. Among Latinos, the number of AIDS cases is even greater among women aged 50 and older in certain geographic areas. In New York City, for example, older Latinas accounted for 20% of new Latina AIDS cases in 2002.

Generally, 71% of men and 51% of women in their sixties report being sexually active, yet few older Americans perceive themselves to be at risk for HIV infection. In fact, it is estimated that 59% of adults age 50 and older have not adopted safer sex practices to prevent HIV infection. Moreover, early intervention for HIV disease is critically important given that the life expectancy after a diagnosis with AIDS is generally much shorter for older adults. This is primarily due to the combined effects of HIV-related immunodeficiency, age-related immunodeficiency and the effect of co-morbidities, such as diabetes that is disproportionately high among Latinos. For older Latinas who perceive themselves as family matriarchs and community elders, an HIV diagnosis may generate shame and the fear of being stigmatized. Furthermore, few programs are specifically designed to serve the needs of older women, let alone older Latinas.

Against this backdrop, older Latinas are more likely to withhold disclosure of their HIV status, forgo or delay treatment, live in isolation and suffer symptoms of depression. Greater efforts must be made to increase HIV prevention, early HIV testing and linkages to care that provide intensive support services to reduce the sense of stigmatization, isolation and depression often encountered by this vulnerable population.

Incarcerated and Formerly Incarcerated Latinas

Perhaps one of the most alarming trends to date is the increasing numbers of incarcerated Latinos. In fact, Latinos are the fastest growing group of prisoners in the nation. In 1985 Latinos accounted for 10.9% of all state and federal prison inmates and by 2001 that number had climbed to 15.6%.¹²⁰ Latinas are disproportionately represented among female prisoners and Latinas are three times more likely to go to prison in their lifetime as compared to white women (1.5% vs. 0.5%).¹²¹

Currently, Latinas comprise 15% of women state prisoners and 32% of female federal prisoners.¹²² Moreover, they are four times more likely to be incarcerated for the same offense than their white counterparts.¹²³ Not surprisingly, between 1992-1997, New York City witnessed a 54% increase in the number of arrests of Latinas as compared to a 4% increase among white women. By 1997, Latinas accounted for 31% of all arrests among females in New York City.

It is estimated that one third of women in prison attribute their incarceration to the need to purchase drugs and approximately 50% were under the influence of drugs or alcohol at the time of the offense.¹²⁴ In New York State, for example, Latinas accounted for approximately 29% of females entering prison in 1998 and 44% of women sentenced to prison for drug offenses.¹²⁵ A high degree of family disruption occurs when women are imprisoned given that the majority of women prisoners are mothers. In New York State, approximately 75% of female prisoners report being the parent of one or more children.

The percentage of HIV-positive incarcerated women is very high. In New York State, more than 18% of incarcerated women are HIV positive.¹²⁶ In New York City, 26% of the women in the jail system are HIV-infected.¹²⁷ While in prison, women often report inadequate and sometimes incompetent health care, as well as, lack of access to needed medications and nutritional foods that can strengthen the immune system.¹²⁸ Additionally, widespread use of injection drugs and physical and sexual assault by prison guards and other inmates has also been reported, making prisons one of the most unhealthy and dangerous environments for HIV-positive women.¹²⁹

Upon release many HIV-positive Latinas find themselves without any source of income, estranged from family, homeless or unstably housed and without a social support network to guide them through the re-entry process. Against this backdrop, many resort to selling drugs, prostitution or other illegal activities to meet basic survival needs, activities that may very well lead them back to prison.

Comprehensive, transitional programs that help formerly incarcerated Latinas successfully re-enter society are urgently needed. These programs must include assistance with housing and employment, and linkages to drug treatment, health services and legal assistance. Mental health and supportive services to address issues of depression, trauma associated with physical and sexual abuse, drug dependency and family re-unification are also needed.

“There are a lot of older Latinas in New York serving time for drug related offenses as a result of the Rockefeller drug laws. However, there are not enough transitional programs for when they get out. They need transitional housing, job assistance, health care and legal services to regain custody of their children.”

Joyce Rivera
Executive Director
St. Ann's Corner of Harm Reduction

Funding and Capacity Building for HIV/AIDS Community Based Organizations

A review of CDC *Targeted Funding to Latino Communities* indicates that funding directly to community based organizations commenced as late as 1993 at the level of only \$6,510,000 nationwide with a funding increase of only \$230,000 in a six year period, from 1993 to 1999.

Table 2: Summary of CDC Targeted Funding to Latino Communities (in millions)

	1988	1993	1998	1999
State and Local Health Departments (Community Planning)	3.45	5.06	35.18	37.54
Capacity-building and Technical Assistance	3.73	3.71	4.46	6.71
Community-based Organizations		6.51	6.74	6.74
Other Minority Initiatives	0.02	1.14	1.35	1.83
Mother to Child Transmission				2.0
Gay Men of Color				2.0
Correctional Facilities				1.75
TOTAL	7.20	16.42	47.73	58.57

SOURCE: Centers for Disease Control and Prevention, *Combating HIV and AIDS: Protecting The Health of Latino Communities*, July 2000.

Moreover, during this period, the only clearly identified funding initiative specifically targeting Latinas has focused on preventing mother-to-child HIV transmission, rather than HIV prevention for Latinas. This initiative commenced for the first time in 1999 after Latino infants accounted for 25% of all mother to child HIV transmission cases. However, even this initiative was significantly under-funded - only 2 million dollars was allocated for early HIV testing and preventive therapy to reduce mother to child HIV transmission nationwide. The report issued by CDC entitled *Combating HIV and AIDS: Protecting the Health of Latino Communities*, in which the above mentioned information is contained, states:

“As important as the public health response, though, is the mobilization of diverse Latino communities, organizations, and institutions throughout the country. More Latinos organizations must become involved in the response to AIDS, and sectors of the Latino population that have remained on the sidelines must join this fight.”

However, in order to make greater involvement possible, there must be a much greater investment made in supporting Latina/o community based organizations, who attend to the multiple and urgent problems faced by Latinos each day throughout this country.

An essential strategy in the fight to prevent the further spread of HIV/AIDS within the Latino community must include increasing resources and strengthening the organizational capacity of Latino organizations at the frontline of the fight against HIV/AIDS. For too long, Latino organizations have been forced to accept inadequate funding levels that in turn make it difficult to hire and retain staff, develop programs, strengthen infrastructure and conduct program evaluation – essential ingredients for organizational efficacy and long term sustainability.

Moreover, there is little recognition of the complexities of providing services to Latinas that may experience low literacy levels, high rates of co-morbidities, substantial health disparities, lack of health insurance and limited English language proficiency requiring Latino organizations to adopt a more labor intensive approach and sustained engagement over longer periods of time.

Developing and Supporting Latina/o Leadership to Combat HIV/AIDS

Efforts to promote HIV prevention, testing and treatment must include the development of a cadre of HIV positive Latinas and Latinos capable of providing leadership and directing advocacy campaigns aimed at increasing funding and improving services to underserved groups, such as Latinas. However, HIV positive Latinos and Latinas have enjoyed limited representation on policy making boards that influence HIV funding and service delivery.

For example, an analysis of the membership of HIV Community Planning Group (CPG) membership nationwide indicates that not only are Latinos underrepresented but there has actually been a decline in Latino participation. In 1998, Latinos accounted for 12% of CPG membership and in 1999 that number declined to 10%.¹³⁰

This is especially disconcerting given that Latinos represent 20% of new HIV cases in the U.S. and that Latinas are particularly underserved. Latina peer education, advocacy and leadership development programs are a critical first step towards ensuring that Latinas have a voice in determining HIV/AIDS policies that directly impact their lives and the well-being of their families and communities.

An essential strategy in the fight to prevent the further spread of HIV/AIDS within the Latino community must include increasing resources and strengthening the organizational capacity of Latino organizations at the frontline of the fight against HIV/AIDS.

Conclusion and Recommendations

“The increasing rates of AIDS among women of color reflects our failure to view women’s risks separately from men’s risks and to analyze the unique forces that affect women’s lives.”

Dr. Sanders-Phillips
Director, Research Program
on the Epidemiology and
Prevention of Drug Abuse
Howard University

HIV/AIDS continues to have a devastating impact on Latinas, their families and communities. Latinas are more likely to be unaware of their positive HIV status, to learn of their HIV diagnosis at later stages of disease progression, face numerous obstacles in accessing health care services and experience considerable discrimination and patient-provider communication barriers that affect the quality of care they receive.

Some of the paramount challenges Latinas are facing include, but are not limited to, the following:

- ▶ Lack of accurate, culturally and linguistically appropriate HIV information, prevention messages, and outreach targeted to Latinas at risk;
- ▶ Underutilization of health care services due to concerns about AIDS stigma, competing survival needs, lack of health insurance, fears of deportation, distrust or unfamiliarity with western medical approaches;
- ▶ Lack of knowledge about the availability of HIV prevention, healthcare and supportive services;
- ▶ Institutional barriers that serve to diminish access to care such as lack of culturally competent staff, lack of translators, inflexible hours of operation (e.g. no evening or weekend hours), long waiting periods to secure an appointment or to see a health provider, lack of childcare services; and
- ▶ Pervasive concerns about HIV disclosure on the part of immigrant Latinas who fear jeopardizing their immigrant status, and/or application for adjustment of status.

As noted by one researcher, “the increasing rates of AIDS among women of color reflect our failure to view women’s risks separately from men’s risks and to analyze the unique forces that affect women’s lives.” This is particularly true in the case of Latinas and to remedy this problem, we must invest in the development of Latina-centered strategies to combat HIV/AIDS.

Designing Latina Centered Strategies to Combat HIV/AIDS

Latinas have indeed become *Las Olvidadas* – *the Forgotten Ones* and the price paid by them, their families and communities in terms of human loss and diminished quality of life is unacceptable and can no longer be tolerated. Investments must be made towards the development of Latina-centered strategies to combat HIV/AIDS that directly address the cultural, gender, familial, and socio-economic circumstances faced by Latinas and the numerous systemic barriers they encounter in accessing health care. Towards this aim the following recommendations are offered:

Strengthen Organizational Capacity and Latina/o Leadership

- ▶ Demand a 300% increase in CDC funding directly available to Latino CBO's.
- ▶ Provide capacity-building support so that CBO's can develop Latina-centered initiatives and expand their overall capacity to serve Latinas, in a manner that is sustainable over the long term.
- ▶ Develop special initiatives and incentives to increase the representation of Latinas on HIV/AIDS policy-making bodies at the local, state and national level.
- ▶ Fund initiatives to increase the number of Latina peer educators, peer advocates and case managers.
- ▶ Convene national, state and local *Latinas and HIV/AIDS Taskforces* to develop strategies and offer policy and funding recommendations for combating HIV/AIDS among Latinas.
- ▶ Increase overall funding for HIV prevention and education media and grassroots education campaigns as many Latino/as continue to be under-informed or misinformed about HIV matters.
- ▶ Develop a National Resource Center on Latina and HIV/AIDS that can serve as a repository of information on best practices, research, treatment and policy trends pertinent to Latinas with HIV/AIDS.

Enhance HIV Prevention, Testing and Counseling Strategies

A substantial number of Latinas delay seeking HIV testing and were more likely to test as a result of becoming ill or learning of a partner's seropositive status. These findings suggest the need to increase outreach, HIV prevention and education activities, as well as improve access to HIV testing and counseling. Towards this aim, the following recommendations are offered:

- ▶ Increase funding to community based organizations, especially those organizations with expertise in serving Latinas for the purpose of conducting targeted outreach and developing HIV prevention messages and strategies directed towards high-risk Latina groups.
- ▶ Increase funding to develop culturally and linguistically appropriate, Latina-centered *Know Your Status* campaigns that encourage early voluntary HIV testing and promote greater understanding of the benefits of early HIV testing in preventing and/or delaying the onset of HIV-related disease.
- ▶ Promote HIV prevention and testing through the use of Spanish language radio, television programs and newspapers.
- ▶ Invest in the hiring and training of bilingual staff and Latina peer educators that can conduct outreach, HIV prevention and HIV rapid testing in Latino communities.

Promote Sexuality Education and Safer Sex Counseling

- ▶ Invest in the development of innovative sexuality education programs offered in multiple settings such as: after-school programs, youth employment programs, GED programs, maternal and child health programs serving young mothers, and STD clinics in order to promote healthy dialogue and improve Latinas' sense of empowerment and efficacy with respect to safer sex negotiation.
- ▶ Initiate Latino HIV Prevention Parenting Programs to help Latino parents effectively communicate with their children on sexuality issues and HIV prevention.
- ▶ Increase funding for safer sex partner initiatives, including couple's counseling and support groups focused on education and behavioral strategies to prevent HIV transmission in HIV sero-discordant couples and secondary HIV infection between HIV positive partners.

Develop Programs to Serve Latina Subpopulations

- ▶ Fund a diversity of program models that address the distinct needs and realities of subpopulations encompassed under the rubric of Latinas including: adolescents, older Latinas, sex workers, injection drug users, incarcerated and formerly incarcerated Latinas, newly arrived immigrants versus U.S. born Latinas, undocumented Latinas, etc.
- ▶ Increase harm reduction programs for Latinas, including the number of residential drug treatment programs that allow mothers to bring their children with them to treatment.
- ▶ Needle exchange programs have been proven to be a cost-effective method for reducing HIV without increasing infection drug use and provide an entry point for drug treatment. Expand the number of needle exchange programs, especially programs with weekend and evening hours that cater to women.

Increase Access to Care and Supportive Services

- ▶ Increase training provided to health care and social service providers and administrators so as to deepen understanding of the unique needs of Latinas.
- ▶ Increase funding for early intervention services that help link and keep HIV infected Latinas in care.
- ▶ Develop bilingual public education campaigns to inform Latinas, including undocumented Latinas, about ADAP coverage and other free or low cost HIV/AIDS services.

- ▶ Fund initiatives to increase the number of Spanish language translators in HIV care settings.
- ▶ Provide intensive supportive services, including housing assistance, employment and vocational training, English as a second language classes, transportation, and nutritional assistance to meet the survival needs of Latinas.
- ▶ Fund culturally competent, mental health services for Latinas to address higher rates of depression, as well as, physical and sexual abuse experienced by HIV positive women.
- ▶ Conduct *Know Your Rights* workshops or teach-ins to bring lawyers out into the community and help Latinas better understand their legal options and rights and connect them to legal services concerning issues of domestic violence, immigration, living wills and health proxies, permanency planning, etc.
- ▶ Develop HIV service programs in suburban and rural areas where the Latina population is growing (e.g. Westchester and Long Island, New York).

Treatment Adherence

Ongoing adherence support and counseling is essential for HIV positive individuals to achieve the full benefits of antiretroviral therapy (ARV). These benefits include: the preservation and/or restoration of immune function, improvement of overall health, the prolongation of life and the suppression of viral replication.

- ▶ Increase funding for the development of community based, culturally competent adherence counseling programs specifically targeted to Latinas.
- ▶ Train health providers to effectively communicate with and counsel consumers on treatment adherence issues and management of side effects.
- ▶ Increase Spanish language, low literacy, culturally competent educational materials on HIV disease, the importance of treatment adherence and the management of side effects.
- ▶ Provide best practice training on innovative treatment adherence support programs, especially those which include peer advocacy and support components.

Research and Planning

A literature search of HIV prevention intervention research targeted towards Latinos revealed that out of 271 studies only 15 were found to be methodologically sound and controlled interventions. Of these, only five studies focused on heterosexual Latinas. The limited HIV behavioral research and epidemiological information on Latinas makes it difficult for service providers to design effective programs to properly serve this population. As a means of addressing this problem, the following recommendations are offered:

- ▶ Provide training and technical assistance to community-based organizations on conducting needs assessments, program planning and program evaluation specific to serving Latina groups and disseminate findings and best practices recommendations.
- ▶ Publish and widely disseminate epidemiological data and behavioral research updates on Latinas with HIV/AIDS.
- ▶ Fund collaborations between community-based organizations and research institutions that address HIV/AIDS research topics of importance to Latinas with the aim of combining knowledge and action for social change to improve community health.

Improve Access to Clinical Trials and Microbicides

There is also a need to increase the number of women participating in clinical trials given that the absolute number of women in trials remains small, and thus the power to detect sex differences in efficacy and adverse effects continues to be limited. The need for female controlled methods to reduce the risk of HIV infection are also urgently needed. Towards this aim the following recommendations are offered:

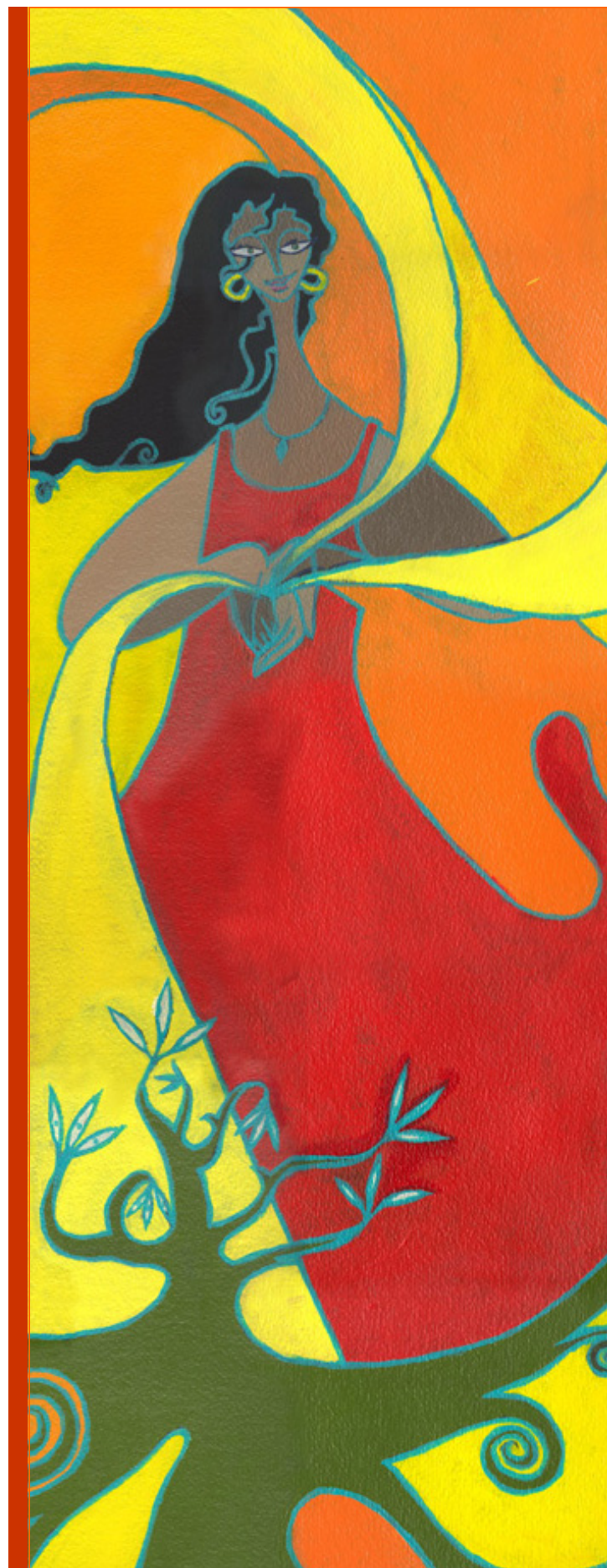
- ▶ Fund initiatives to educate Latinas on the availability of HIV clinical trials.
- ▶ Promote efforts to advance research in the area of female controlled methods for HIV risk reduction, including the use of microbicides.

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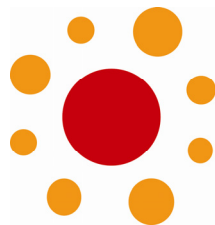
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The **Hispanic Federation** is a service-oriented membership organization that works with 90 Latino health and human services agencies to promote the social, political and economic well-being of the Latino community. No other non-profit in the northeast brings together organizations representing every major segment of the region's diverse and growing Latino community.

The Federation provides a wide-range of services and programs geared towards strengthening Hispanic families, and supporting institutions that aid in their growth and prosperity.

In 1995, the Hispanic Federation forged the creation of **Latinos Unidos Contra El SIDA** (LUCES). Comprised of Latino community-based organizations with long histories of service to diverse groups of Latinos throughout the tri-state area, LUCES exists to develop public policy, serve as an advocate for a Latino HIV/AIDS agenda, and provide culturally competent AIDS education to the Latino community.



A publication of the
hispanicfederation

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