

30 FOR 30 CAMPAIGN

BRIEFING PAPER

Immigrant Women & HIV

Advocacy • Equity • Action

Introduction

The United States (U.S.) has a complicated, controversial history with immigration. Despite the complexity that historically marks the country's relationship with immigrants, and its current challenges in crafting and implementing equitable immigration policies, the U.S. consistently receives more immigrants than any other country in the world. In 2013, 13% of the U.S. population was foreign born.³ For many people the process of moving to the U.S. provides opportunities that were lacking in their country of origin. It is also fraught with challenges — including language barriers, economic insecurity, and educational disparity — that uniquely impact immigrants. Language barriers, as well as family size, underemployment, and other factors, contribute to immigrant families' increased likelihood of living in poverty, regardless of educational attainment.^{4,5} Such challenges often exacerbate the health disparities immigrant women experience, and are evident when addressing the health care needs of immigrant women living with HIV, and at risk of HIV. This policy brief seeks to explore some of the issues particular to the health of immigrant women living with HIV or vulnerable to acquiring HIV, and identify research priorities and policy recommendations to better address their needs and improve prevention and treatment efforts for these communities.

HIV is Prevalent among Latina, African, and API Immigrants

While the U.S. is home to many unique immigrant populations, this brief will broadly address HIV among African, Latina, and Asian and Pacific Islander (API) immigrant communities. Each has distinct needs, but all experience either disproportionate rates of HIV diagnosis, increasing rates of diagnosis and/or disparities in care for those living with HIV, in stark contrast to the U.S.-born white population. An estimated 42.4 million people immigrated to the United States in 2014, the most recent year for which data

The 30 for 30 Campaign is dedicated to ensuring that the unique needs of women living with and affected by HIV, including transgender women, are addressed in the national HIV response. We are especially committed to illuminating and eliminating the gaps in prevention and care services for Black and Latina women who currently make up over 80% of the epidemic among women but only 12% and 14% of the U.S. female population respectively.¹

The Campaign is concerned with the current state of HIV prevention and care for women as studies continue to show that women, especially women of color, have consistently poorer health outcomes despite there being no significant clinical difference in treating men or women living with HIV.²

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is available. Of those, 51.6% emigrated from Latin American countries (including Central America, South America, and the Caribbean), 30% emigrated from Asian countries, and just 4.6% came from African countries.⁶

African immigrants face the highest rates of HIV diagnosis, despite their relatively small population size. Moreover, they are a growing population. Between 2000 and 2010 the African immigrant population in the United States almost doubled from 881,300 to 1.6 million.⁷ One survey of cities with the highest population of African-born U.S. immigrants found the rate of HIV diagnosis six times higher than the overall rate among the general population of the United States, 12 times higher than among U.S.-born white people and two-thirds higher than among U.S.-born Black people.⁸ African-born women are more acutely impacted, with 70% of HIV diagnoses among black women occurring among foreign-born women, and 48% of those occurring among women from Sub-Saharan Africa.⁹ Immigrants from Mexico and other Latin American countries constitute the largest population of immigrants in the U.S.¹⁰ HIV occurs more frequently among immigrant Latinos than their U.S.-born counterparts. While only 37% of the U.S. Latino population are immigrants, they account for over half of new HIV cases among Latino residents.¹¹ Latina women, U.S. and foreign born, also experience rates of HIV four times higher than white women.¹² The number of HIV diagnoses among Asians in the United States has increased by nearly 70%¹³ in recent years.¹⁴ Unfortunately, data on Asians and Pacific Islanders is incredibly limited, highlighting the need for disaggregated data discussed in further detail below. Most statistics lump immigrants and U.S.-born API people together, but more accurate information on subpopulations is necessary to create targeted interventions.

Immigrant Women Face Many Barriers to Care

Immigrant Women are Denied Access to Health Insurance Coverage

The Affordable Care Act (ACA), introduced in 2010, has resulted in increased health insurance coverage for many communities. However, many immigrant families are not included in new programs, and remain unable to access the healthcare they need. The ACA imposes limitations on specific groups, when it comes to coverage under the Marketplace, CHIP, and Medicaid. For instance, a small portion of lawfully

present immigrants have Marketplace coverage, yet individuals granted relief from deportation under the Deferred Action for Childhood Arrivals (DACA) program were specifically excluded.¹⁵ It is likely that U.S. residents who benefit from Deferred Action for Parental Accountability (DAPA) will soon be similarly barred.¹⁶ The ACA expressly prohibits undocumented immigrants from participating in Health Insurance Marketplaces, and undocumented immigrants continue to be barred from public health coverage programs like Medicaid and the Children's Health Insurance Program (CHIP).

In 2014, the first full year of the ACA's implementation, immigrant women who were not U.S. citizens were more than three times as likely to be uninsured as women born in the United States (42% vs. 13%).¹⁷ More than twice as many noncitizen women living at or below the federal poverty level are likely to be uninsured compared to their citizen counterparts (57% of noncitizen women were uninsured vs. 22% of U.S.-born women).¹⁸ Immigrant Latinx people, for example, often work in industries that do not offer health coverage and are unable to afford private health insurance. In 2011, 66 percent of non-citizen Latinas did not have access to employer-sponsored coverage, and 45 percent did not have any health insurance coverage at all.¹⁹ LGBTQ Latinx people are also more likely than their non-LGBTQ peers to be without employer-sponsored coverage, resulting from higher rates of unemployment.²⁰ These barriers to coverage for Latina women and LGBTQ people mean that those at highest risk of HIV are more likely to go without access to preventive services and treatment.

A person living with HIV who does not have insurance coverage may access Ryan White Programs for HIV care and treatment.²¹ The Ryan White Program provides health insurance specifically for people living with HIV, regardless of immigration status, to cover health care services directly related to HIV for any individuals who test positive for HIV.²² However, even with Ryan White care, an immigrant who does not have access to comprehensive health insurance will not have their other non-HIV-related health care needs easily addressed. This results in lower health status for people living with HIV who are immigrants, and is especially pronounced for those who are undocumented. Additionally, prior to diagnosis there are distressingly few resources for preventive care including HIV testing or pre-exposure prophylaxis (PrEP), leaving the uninsured without tools to prevent HIV.²³

Lack of Documentation or Immigration Status Causes Uncertainty in Seeking Care

Documentation can prove a difficult barrier to both testing and care for immigrants at risk of or living with HIV. Lack of documentation may serve as an actual logistic barrier, but even its mere perception as a barrier stops immigrants from seeking services. In a survey conducted in Los Angeles County, undocumented people were far less likely to seek HIV testing than their documented counterparts.²⁴ For some immigrants, lack of documentation may cause them to fear utilizing free anonymous testing services or obtain HIV care even through the Ryan White Program. Immigrant women are unlikely to seek treatment or care from other “safety-net” healthcare providers at community health centers or emergency rooms, in fear of deportation and detention policies.²⁵ For women with derivative legal status, whose ability to access services and remain in the U.S. is dependent on their spouse, seeking healthcare for themselves may be exceptionally difficult. And many undocumented immigrants simply do not believe that some healthcare services are provided regardless of immigration status, rooted in negative experiences with immigration enforcement, difficulty navigating the health care system²⁶ and distrust of systems and practices.²⁷

As illustrated by the experience of transgender Latina women, “obtaining legal documentation to live in the United States can protect against HIV risk among undocumented transgender Latinas by affirming their identity, making it easier to avoid controlling sexual partners, and providing access to greater employment opportunities and public services.”²⁸ Without valid documentation — especially documentation that expresses true name and gender markers for all women — it can be harder to find housing, employment, and other stability that facilitates seeking regular and recommended healthcare. Without these resources, immigrant women (both transgender²⁹ and cisgender³⁰) may resort to sex work, also referred to as exchange or survival sex, to meet these basic needs, placing them at even greater risk of contracting HIV.

Lack of Cultural Competency from Providers and Language Barriers Cause Negative Health Outcomes

Hesitancy to seek out HIV testing and care may also occur among immigrant women who are documented but nevertheless culturally do not understand or believe in the anonymity of services.

For instance, in a 2015 study comparing HIV testing attitudes, perceptions, and behaviors between African-American and East African immigrant women in Washington DC, East African immigrant women expressed concerns about HIV diagnosis not actually being confidential.³¹ Additionally, in Asian and Pacific Islander communities HIV-related stigma is so powerful that people avoid getting tested, since an HIV-positive test can disgrace the individual as well as the family and community.³¹ In order to address these concerns and ensure that immigrant women receive appropriate and reassuring information about HIV testing and care, it is critical that services and education be provided in culturally competent ways, using native languages and addressing varied cultural assumptions and stigma.

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Meaningful access to healthcare must be provided regardless of language barriers, and recent anti-discrimination provisions of the ACA make clear that this is a Federal priority, consistent with basic civil rights tenets.³³ Implementation, however, will likely be slow to follow, and gaps remain. Most healthcare providers are now required under the ACA to post non-discrimination and translation notices, for example, but only in their state’s fifteen most common languages.³⁴ Asian and Pacific Islanders represent 40 different ethnicities speaking more than 100 languages and dialects. A large percentage of the Asian and Pacific Islanders population in the U.S. are first generation immigrants and many are monolingual or limited English proficient.³⁵ With such variety in languages, providers may not have interpretation services or fail to use an interpreter. Reliance on family members to translate intimate details can be awkward and uncomfortable, and is often legally prohibited, leading women to avoid seeing health care providers. In California, a state with a large Latina immigrant

population, there are only 50 physicians for every 100,000 people that speak Spanish.³⁶ In the entire U.S., Latinos constitute 14% of the nation's population but only 5% of all physicians practicing medicine.³⁷ Lack of comprehensive language services generally results in poor health outcomes for immigrants: according to one healthcare quality report, "nearly 9% of the U.S. population is at risk for an adverse event because of language barriers."³⁸ Language barriers also increase distrust of health systems and feelings of isolation and fear among women living with HIV.³⁹ HIV is a chronic disease that requires constant monitoring and communication between patient and physician, placing women living with HIV who cannot communicate with providers at even higher risk of complications.

HIV Stigma is Complex and Persistent

Stigma presents a large and complex challenge to HIV care and prevention among different populations. Advances in medical treatment have changed the prognosis for HIV and significantly shifted public perception of what it means to have HIV over the past few decades, but stigma around HIV persists as a barrier to care for people living with HIV, and to HIV prevention efforts. HIV stigma, like stigma surrounding other chronic physical and mental health conditions, is greater among some immigrant populations due to different and deeply rooted cultural beliefs.⁴⁰ Additionally, immigrant women often face compounded stigma around female sexuality and gender roles, which can further stigmatize HIV.

Stigma, which includes ideas that a person living with HIV is inherently "bad," and real or perceived rejection by or social ostracism from communities,⁴¹ has been identified as having a direct negative impact on HIV testing among immigrant women. For example, in 2015 East African immigrant women in Washington DC were more likely than U.S.-born women to believe that seeking HIV testing implied that a woman was already living with HIV.⁴² In their home countries these women had seen HIV diagnoses drive discrimination, resulting in housing and employment loss.⁴³ The same women expressed fear that stigma associated with testing and HIV would prompt negative reactions from a partner, and that the act of seeking testing alone could mean distrust, disrespect, or infidelity within a relationship.⁴⁴ Fear of such outcomes may prevent women from seeking testing in the first place, and can lead women who do receive an HIV diagnosis into isolation.⁴⁵ This isolation in turn can have severe negative impacts on both physical and mental health. Stigma around even discussing HIV is pervasive in

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API communities. A woman may fear rejection by her family and community if she discusses her sexuality openly or is discovered getting tested for HIV. The stigma not only prevents people from learning about HIV, but also increases the likelihood that women will engage in unsafe behaviors.⁴⁶ Stereotypes and assumptions on the part of providers, family and community also contribute to lack of discussion and result in missed prevention, screening and treatment opportunities.⁴⁷ U.S.-born women, by contrast, are more likely to view HIV testing as a routine aspect of their sexual health care.⁴⁸

General stigma toward women's sexuality also impacts HIV acquisition. Recent studies have suggested, for example, that Latina immigrant women have lower sexual negotiation power than their non-immigrant counterparts.⁴⁹ In 2012, a survey of Central American immigrant women in Houston found that though most were in monogamous relationships, nearly one third believed that their partner had concurrent sexual partners in the past year.⁵⁰ Regardless of their partners' infidelity, 88% of the women reported having sex without a condom.⁵¹ Women often fear that requesting condom use implicates distrust in the relationship and is not appropriate in a woman's role, which then results in lower condom use and the attendant greater risk of HIV acquisition. Studies among African immigrant women reach similar conclusions, noting that "[g]ender dynamics and the different standards for men and women put African-born women more at risk for contracting HIV."⁵²

Addressing the Epidemic Requires Perspective Shift and Research to Fill Gaps in Knowledge

Encourage new research and disaggregated data on immigrant populations.

Immigrant populations are culturally diverse and geographically widespread, making it incredibly difficult to draw broad inferences about any population. While many studies examine different discrete communities, there remains a striking lack of general knowledge about immigrant women, especially those who are undocumented. There is

even less concrete data about how HIV impacts these women. Research on HIV by racial or ethnic group often lumps together people with many disparate origins and risk factors.⁵³ Most HIV prevention strategies currently base prevention efforts on broader definitions of race and ethnicity, without taking into account the cultural and language disparities between, for example, foreign-born Black people of different backgrounds.⁵⁴ The necessity of disaggregation by origin country becomes even more apparent in Black immigrant populations as the slowly-increasing number of discrete studies show distinct differences in risk behavior, exposure, and transmission between foreign-born and U.S.-born Black people.⁵⁵ Other communities, such as API immigrant populations, remain largely ignored. Targeting research and prevention efforts to subpopulations of immigrant communities is crucial to understanding and addressing their needs.

Provide services in multiple languages and with attention to cultural differences and entrenched stigma.

Providing basic information — in appropriate settings and languages — about HIV transmission modes, effective prevention, confidential testing, and no-cost treatment options is crucial to empowering immigrant women living with or at risk of HIV. Fostering open dialogue with women in immigrant communities can also help lessen stigma surrounding HIV, and encourage better understanding of the ways that immigration status and identity impact women's willingness to utilize HIV testing and health services. Identifying, understanding, and addressing cultural beliefs of specific immigrant groups impacted by HIV in the U.S. is instrumental in improving both the quality of care and life for women living with HIV, and contributes to more effective HIV prevention efforts for these populations.

While researchers acknowledge the impracticality of engaging staff from all conceivable areas of the world, prevention efforts might include regional liaisons from different parts of Africa,⁵⁶ as well as other world regions, to ease communication and foster cultural competency in prevention, treatment, and care efforts. It is important that such efforts balance public health aims while maintaining respect for immigrant populations' various cultures. Academic literature on the role of stigma in HIV acquisition and care is growing, but like other research on HIV and immigrants, there is limited information available. Understanding the level of stigma associated with

HIV testing and the fears associated with such stigma will be important for developing approaches to make HIV testing more routinized for immigrant women, emphasizing anonymity of testing and promoting protections against discrimination.

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Recognize multiple identities and intersectional oppressions that immigrant women face.

Discussion of immigrant women and HIV must also necessarily consider the intersectional axes of oppression that women of color face in the United States,⁵⁷ and the additional institutions that penalize women for survival behaviors like sex work. It is well established that women who engage in sex work, transwomen, and immigrant women are criminalized at disproportionate rates, and women who become involved in the criminal legal system face additional barriers to HIV testing and care. For women who claim multiple of these identities, the layered obstacles often seem insurmountable.⁵⁸ There are innumerable additional identities and institutions impacting immigrant women that merit attention and should be acknowledged and further explored when addressing HIV among immigrant populations. Crafting sensitive and comprehensive policies is critical to reducing the HIV epidemic among immigrant women, and improving quality of health for those living with HIV.

Policy Recommendations

Federal and state policies which bar immigrants from participating in public and affordable health coverage programs on the sole basis of their immigration status contribute to very high uninsurance rates among immigrant women and families. Congress must advance immigrant equity in health by lifting

all citizenship and immigration status requirements on public and affordable health coverage programs including CHIP, Medicaid, and the ACA.

2017 will usher in a new presidential administration, and with this shift in leadership comes a new opportunity to further improve effective prevention efforts and health outcomes for immigrant women living with HIV. Advocates must join together across the fields of HIV, women's health, and immigration to establish and implement a clear roadmap for policy change. To address the barriers and gaps in knowledge that this brief has highlighted, the authors make the following recommendations:

- Increase data collection on immigrant populations, and disaggregate data by gender, race, age, and national origin.
- Support stigma-reduction efforts and research, and promote public health interventions that incorporate these findings in a culturally sensitive way.
- Provide language services including conveying basic information and confidential translation options to increase understanding of services and decrease distrust of health systems.
- Improve resources for women regardless of immigration status, including increased access for women with undocumented or derivative

legal statuses. Rescind barriers to healthcare for those with DACA, and those who will be eligible for DAPA.

- Remove harmful policy and legal barriers to affordable health care coverage, including access to Medicaid, through new and existing legislation.
 - **The Exchange Inclusion for a Healthy America Act of 2015 (H.R. 3659)** would expand health access under the Affordable Care Act to undocumented women and families by allowing undocumented immigrants, including DACA and DAPA recipients, to purchase coverage through the Marketplace.
 - **The Health Equity & Access under the Law (HEAL) for Immigrant Women and Families Act of 2015 (H.R. 1974)** lifts legal barriers to healthcare for immigrants authorized to live and work in the United States, including those granted DACA and those that would be granted relief under President Obama's proposed DAPA program.

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