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## Black Is Decidedly Not Just Black: A Case Study on HIV among African-born Populations Living in Massachusetts

Chioma Nnaji  
*Multicultural AIDS Coalition*

Nzinga Metzger  
*Florida Agricultural and Mechanical University*

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# Black Is Decidedly Not Just Black: A Case Study on HIV among African-born Populations Living in Massachusetts

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**Chioma Nnaji and Nzinga Metzger**

**Abstract**

*Black or African American* is a racial category that includes the descendants of enslaved Africans as well as members of foreign-born black communities who migrated to the United States from places abroad, such as Africa, the Caribbean, and Latin America. Grouping native-born and foreign-born blacks into a single homogeneous racial category may make it easier to track disease and health outcomes; however, it masks the different cultural experiences, histories, languages, social and moral values, and expectations that influence health beliefs, attitudes, practices, and behaviors. It also ignores such factors as migration, which forces foreign-born populations to examine both their traditional cultures and the culture(s) of their new environment, and also exposes populations to other health risks. The black or African American category also does not accurately reflect how health conditions are disproportionately affecting subgroups, specifically black immigrants. Rather than race, using ethnicity as an indicator situates health within a cultural framework and acknowl-

edges a person's shared sense of membership, ancestral heritage, and cultural affiliation with a specific group. Acknowledging and utilizing cultural strengths in health programming and services can facilitate individual behavior change and improve community health.

## **Introduction**

In 1997, the Office of Management and Budget (OMB) adopted standards for the classification of federal data on race (White House Office of Management and Budget 1997). At a minimum, OMB mandates that data are collected for the following five racial categories: white, black or African American, American Indian and Alaska Native, Asian, and Native Hawaiian and other Pacific Islander.

OMB defines *black or African American* as

A person having origins in any of the black racial groups of Africa. The black racial category includes people who marked the “black, African Am., or Negro” checkbox. It also includes respondents who reported entries such as African American; Sub-Saharan African entries, such as Kenyan and Nigerian; and Afro-Caribbean entries, such as Haitian and Jamaican. (U.S. Census Bureau 2011)

As previously mentioned, population data for African Americans encompass multiple ethnic groups. The racial category “black/African American” or “black or African American” is used interchangeably in federal, state, and local health surveillance systems, including HIV surveillance. African Americans living in the United States experience a disproportionate burden of the HIV/AIDS epidemic at all stages of the disease across age, gender, and sexual orientation. In 2010, blacks/African Americans represented 14 percent of the population, but accounted for 44 percent of all new HIV infections among adults and adolescents. There are higher rates of infection among young black gay and bisexual men compared to other groups. Late diagnosis and care are common challenges that have placed AIDS among the top five causes of death for black women and men ages 25 to 44 (Centers for Disease Control and Prevention 2013).

OMB's system of defining, labeling, and assigning categories for

race and ethnicity has been documented as limiting, at the very least. Categories have been changing with each census since 1790. The current racial categories, however, do not recognize growing racial and ethnic diversity, including the influx of immigrants. The black/African American category poses a number of challenges for foreign-born blacks. Embedded in the current Census form is a tacit negation of the ethnic diversity of foreign-born blacks, specifically African, Caribbean, Latin American, and other people of African descent born outside the United States. Although racially “black” by the census definition, foreign-born blacks often do not share the same cultural experience, histories, languages, social and moral values, and expectations as contemporary U.S.-born blacks. Because here in the United States the (externally defined) race of foreign-born blacks speaks louder to ethnicity, or is more readily understood in society than their (internally defined) ethnicity, they disappear in the system.

This article will briefly outline the historical context of “black” identity as defined in this country and that identity’s complex relationship to new populations migrating from Africa. The authors summarize cultural and social nuances related to HIV/AIDS among African-born individuals. The authors will also argue that health data need to be disaggregated according to ethnicity, as opposed to race. In Massachusetts, public health officials, policy makers, and community advocates serving individuals at risk for, or living with, HIV/AIDS examined HIV surveillance data by ethnicity. This review yielded a comprehensive response to addressing HIV among the African-born population in Massachusetts. This article will conclude with a community-led initiative to acknowledge cultural difference among people of African descent and to take into account social and cultural values in developing HIV prevention and health promotion services for African-born populations.

### **The Process of Becoming “Black”**

The effects of *maafa* on “black” identity cannot be underestimated. Anthropologist Marimba Ani (1988) coined this usage of *maafa*, Swahili for disaster, terrible occurrence, or great tragedy, to describe the history and legacy of the exploitations of Africans on the continent and in the Diaspora. The trans-Atlantic slave trade affected every social institution with which it came into contact, including religious, political, and

economic systems. The social institution of family was disrupted in immeasurable and detrimental ways. Notions of personhood, which are intrinsically tied to family in many cultures in Africa, were also negatively affected. The psychological and emotional trauma of having people torn away from their lineage and sold into slavery struck at the very nucleus of one's individual, familial, and clan identity. Africans were torn from their homes and marched toward the coast to the numerous "Doors of No Return" on the West Coast of Africa, bound for the Americas. Since that time, people of African descent have remained in an ongoing process of renegotiating their identity. When the ancestors of people currently referred to as blacks in the census were living in Africa, they were not black in the way that African Americans in the United States are black, namely, as a unified racial category or group. Rather, these Africans were members of ethnic groups with distinct languages, cultures, histories, and experiences. Between being captured, stolen, or bought from different places in the interior to being warehoused in "slave castles" up and down the western coast of Africa and dispersed throughout the New World, Africans continually had to struggle to redefine themselves.

Transforming from a free person to an enslaved one presented challenges in regards to maintaining old identities and forming new ones. One of these challenges was the institution of European slavocracy, which stood to benefit the most from the largely deracinated people. Particularly in North America, there was an intentional and systematic effort to separate people from their cultures, languages, and customs in order to create a context within which enslaved people had as little independence or power as possible. Lynch (2009) details key techniques to mentally recondition enslaved women, break the union between people of the same ethnicity, and eliminate native languages. Without large numbers of people of the same ethnicity living together and forming the group cohesion fostered by a shared language, history, culture, and land, it was more difficult for enslaved people to organize effective efforts for liberation.

Removal from their homelands caused an immediate crisis of identity for many Africans. Intrinsic to the life ways of many was a definition of self built on an integrated relationship between kinship, land, and lineage. Since the slave trade disrupted the traditional lineages of captive peoples, Africans who were forced to come to the

Americas had to confront the most quintessential elements of their beliefs about their humanity, reapply them, and create social structures that reflected and affirmed those beliefs. One major example was the African family. The definition and shape of the African family had to be drastically altered to be relevant in the context of New World enslavement. In the Old World, one's station in society, one's birth-right, lineage, or the land of one's birth defined the individual. In the New World, however, these once rock-solid foundations of identity shifted threateningly beneath the feet of the newly enslaved. Africans were forced to redefine family under debilitating and dehumanizing circumstances. In many instances in the Americas, distantly related or completely unrelated groups and individuals were compelled to become "families" of interdependent people, primarily distinguishable from the society that held them captive by their skin color and their bonded status. Taking this into account, Mintz and Price (1976) illuminate the likely early beginnings of African American cultures:

Before any aggregate of plantation slaves could begin to create viable institutions, they would have to deal with the trauma of capture, enslavement and transport. Hence, the beginnings of what would later develop into African American cultures must date from the earliest interactions of the newly enslaved men and women on the African continent itself. They were shackled together...squeezed together between the decks of stinking ships, separated often from their kinsmen...left bewildered about their present and their future...and homogenized by a dehumanizing system that viewed them as faceless and largely interchangeable. Yet we know that even in such utterly abject circumstances, these people were not simply passive victims...we are thinking less of the many individual acts of heroism and resistance which occurred...than of simple but significant cooperative efforts...which may be viewed as the true beginnings of African American culture. (pp. 42-43)

As Mintz and Price explain, the generation of New World African ethnic

groups began even before captured Africans landed on American soil. Africans who may have been captured from distances far apart were now squeezed tightly together in dank slave ships. Perhaps it was these dire circumstances that forced them to immediately reevaluate the meaning of family and begin to psychologically resist the erasure of their personhoods that were predicated on family. Many African ethnic groups do indeed share similar definitions of family. Perhaps the centrality of the concept of family and the necessity for connection to fellow human beings that the crisis of captivity created took precedence over the actual presence of blood family members. This situation precipitated new definitions of family that helped people cope more effectively with their condition as enslaved individuals.

Newly arrived Africans were not rootless, even though the cultural ideals and orientations they carried with them had been ripped from the ideological soil that had previously sustained, defined, and nourished them. In the absence of the protection that land and lineage had previously provided, many enslaved people surely withered and died—some emotionally and spiritually, others physically. Some, however, found new ways to ground themselves, firmly planting themselves in New World soil. These new ways of grounding oneself, characterized by courage, resilience, spirituality, and the capacity to adapt, eventually emerged as the cultural traditions of the black peoples of the Americas. The traditions established by these Africans, and the adaptability and interconnectivity those traditions exhibited in the New World context, relayed core values, ideas about causality, methods of problem solving, and perspectives on the nature of life and of the divine. Many African people shared these values and ideas, codified them, and passed them down into what is contemporarily referred to as African American culture. Within African American culture, one of those cultural holdovers can be seen in the extended nature of the African American family, which often includes grandparents, aunts, uncles, cousins, and others beyond the nuclear family. This custom also breaches the boundaries of blood, embracing non-blood kin and enfolded them into a lineage or family.

In the crucible that was the institution of slavery, enslaved Africans changed individually and communally over time. They ceased being Peul, Serer, Ovimbundu, Igbo, Yoruba, Wolof, or Mandinka and became what today is known as *black*. This reassignment of identity was

a process within which people of the various ethnicities of Africa, by necessity, largely ceased to define their group identity based on previously held concepts of family, history, lineage, culture, language, and land and had to begin defining themselves in opposition to another newly forming identity, “whiteness.” The social construction of whiteness was tied to social privilege—having personal access to institutional power, resources, and influence based on one’s whiteness. Newly arriving European immigrants were similarly as diverse as Africans but consolidated their power over society under the flag of whiteness. Just as they exercised that power as a function of whiteness, enslaved Africans were labeled *black* and had to live with the commensurate disempowerment and lack of sovereignty that the racial designation conferred.

The process of becoming black that African captives went through during the slavery era is one that contemporary immigrants also undergo and is deeply rooted in the earliest days of U.S. history. Although contemporary immigrants do not experience slavery in its most widely understood form, the process of becoming black is just as transforming for them. Understanding the process and juxtaposing their reality to it can be shocking and difficult, particularly for foreign-born people of African descent who often relocate from countries in Africa and the Caribbean where they are the majority. In addition to having to navigate their status as immigrants, African-born individuals have the burden of being forced into a disadvantaged racial category that does not aptly refer to their experiences or describe them. Dominant narratives of blackness, whiteness, and slavery may not necessarily be a part of their historical experience, but as immigrants, these narratives become a part of their existence in the United States. Regardless of their previous life experiences, new African-born immigrants are compressed into the black or African American racial group and must learn to endure the contemporary stigma and complication of a black identity that the history of slavery and current racism has created.

### **Race, Culture, and Health**

The black or African American racial category ill fits African-born populations because it incorrectly conflates race with ethnicity. One’s membership in a particular race varies from one country to another,



while ethnicity is a description based on one's cultural affiliation. Hence, ethnicity is a function of one's culture, one's language, and one's individual and/or group history and lineage. Within an African context, ethnicity could be defined by country of origin and/or tribe. For the purpose of this article, the authors define race as the assignment of people in groups, largely depending on such physical features as hair color and texture, and skin color, and social factors like economic status. The groupings vary from place to place, and continent to continent. That is how a person as light skinned as a former Miss America, Vanessa Williams, can be considered black. If she traveled to Brazil or the Dominican Republic, however, she would not be considered black.

Both race and ethnicity are socially constructed realities invented by individuals in various societies to categorize people. The fundamental difference between race and ethnicity is that ethnicity is a relatively objective reality dependent on a person's shared sense of membership, ancestral heritage, and cultural affiliation with a specific group. Thus, when referring to foreign-born people of African descent as "African American," it becomes apparent how and why the cultural differences between blacks born in this country and those born in Africa (and elsewhere abroad) are often misunderstood, ignored, or silenced. This problem is evident through the use of the term *black* or *African American* to describe all people of African descent regardless of their ethnicity, implying that "all black people are the same."

*Culture* refers to "integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups" (Cross et al. 1989). It is often referred to as the totality of ways being passed on from generation to generation and reinforced in families and institutional structures. Cultural change may occur over time in response to both internal and external forces. It is also complicated by multiple layers of identity. Everyone has a culture. Even within cultures, there is diversity.

Since culture encompasses almost all that we do and how we view and understand the world around us, culture influences how illness, disease, and their causes are perceived; appropriate methods of treatment; help-seeking behaviors; and attitudes toward health care

providers. Culture can support negative or positive behaviors and values (Airhihenbuwa and Webster 2004). Airhihenbuwa and Webster (2004) argue that within an African cultural context, culture must be at the center. This necessity is based on the premise that African societies are collectivist and that family and community relationships bind individuals. For that reason, personal actions and decisions function within and affect broader social cultural contexts. Individual behavior can either be supported or rejected through family, religious, and communal structures.

### **HIV among African-born People in the United States**

African-born people represent one of the fastest-growing groups of foreign-born immigrants to the United States, bringing a diverse mixture of ethnicities, cultures, religions and spirituality, and native languages. Between 2000 and 2010, the population doubled from 881,300 to 1.6 million. According to the 2010 census, African-born populations comprised 4 percent of the foreign-born population and 3 percent of the total black population. African-born communities are particularly concentrated in urban areas. The largest number of African-born people reside in five states: California, New York, Texas, Maryland, and Virginia (Immigration Policy Center 2012).

In a study that analyzed the HIV surveillance data of eight jurisdictions—California; Georgia; King County, Washington; Massachusetts; New Jersey; New York City; and the northern Virginia-D.C. area—African-born people accounted for .6 percent of the general population and 3.8 percent of HIV diagnoses. HIV diagnoses for African-born blacks ranged from 2.5 percent of all blacks diagnosed in Georgia to 49.8 percent of all blacks diagnosed in Minnesota. Overall, within this group, African-born women account for 15.8 percent of HIV diagnoses within the population of black women, and African-born men account for 7.4 percent of HIV diagnoses within the population of black men. Heterosexual sex was the main mode of transmission, with 23.1 percent reporting heterosexual contact with a partner of known HIV risk and 68.8 percent with no risk reported (NRR). Under the surveillance definitions of the federal Centers for Disease Control and Prevention (CDC), NRR notes heterosexual exposure to partner of unknown risk of HIV (i.e., HIV positive, injection

drug users, or men who have sex with men) (Kerani et al. 2008).

The necessity to disaggregate data becomes more apparent as studies show a distinct difference in the transmission, incidence, and distribution of HIV among U.S.-born and foreign-born blacks. Data reported to the CDC on adults and adolescents infected with HIV (2001–2007) identified three important differences: (a) heterosexual contact is the major mode of HIV transmission among foreign-born blacks; (b) the HIV epidemic most affects foreign-born black women; and (c) foreign-born blacks are more likely to be diagnosed with AIDS within one year of their HIV diagnosis (Johnson, Hu, and Dean 2010). Compared to native-born blacks, foreign-born blacks are also more likely to have lower mortality rates and survive one year and three years after an AIDS diagnosis (Blanas et al. 2012).

Migration trends are showing African-born blacks moving to smaller cities or towns partly due to refugee resettlement programs and the increasing costs of living in metropolitan areas (Reed, Andrzejewski, and Strumbos 2010). In 2009, the Utah HIV/AIDS Surveillance Report profile included country of birth for the first time. As noted in the report, from 2008–2009, there was a 33 percent increase in HIV diagnoses in African-born persons. HIV prevalence is more than six times higher among African-born blacks than U.S.-born blacks. African-born blacks made up 0.25 percent of Utah's total population, but accounted for 7.9 percent of all HIV/AIDS cases (Ashton et al. 2012). The results concluded both that African-born blacks are an emerging population in Utah and that there is also a need to disaggregate racial data in areas with a low incidence of HIV.

Thus, the need to develop culturally responsive HIV screening and care strategies is critical, given the documented epidemiological differences among foreign-born blacks and U.S.-born blacks, increased influx of Africans, and increased reporting of African-born immigrants being diagnosed as HIV positive.

### **HIV and African-born Communities: Cultural Factors**

Complex cultural factors put members of African-born communities living in the United States at risk for HIV/AIDS and directly influence social interaction within partner relationships, families, and the greater community. Often, cultural and religious values dictate

that sexual behavior and expression, homosexuality, drug use, and HIV/AIDS are taboo topics. Therefore, parents seldom discuss sexual behavior with children, and intimate partners deny the need to discuss preventive measures, such as condom use.

Gender dynamics and the different standards for men and women put African-born women more at risk for contracting HIV (Worthington et al. 2013). There is a cultural acceptance allowing men to have multiple partners, whereas women are expected to be faithful. African-born women are more vulnerable due to “being dependent on their husbands for resources, handicapped by unequal access to education and information, and subject to more severe stigma around infection and imputed promiscuity relative to men” (Blanas et al. 2012). Practices such as widow inheritance, polygamy, female circumcision, and dry sex increase the risk of contracting HIV, primarily for African-born women. African-born women are still challenged with not having the knowledge and skills needed to make better decisions about their sexual health, still feel ashamed and scared to mention the various cultural names for their body parts, and are afraid to initiate the use of condoms for fear of rejection. These cultural norms in turn affect the capacity of African-born women to engage their daughters, nieces, and others in discussions and to educate them about preventive measures.

In addition, several studies found low or inconsistent condom use among African-born men and women. Barriers to condom use included the cost, negative response from a partner, and perception that condoms reduce sexual satisfaction (Asare et al. 2013). Using condoms is also seen as inappropriate when married because married individuals are presumed not to be at risk for HIV/AIDS (Worthington et al. 2013).

The social environment in their home countries compounds negative perceptions about seeking health and HIV services once in the United States. In some African countries, health services are limited and expensive, leading to a misconception of how, when, and where to access services in the United States. Many in this population are not, traditionally, accustomed to preventive health. Being from countries where the concept of “living with the virus” is not common and testing positive is seen as a “death sentence,” many African-born individuals do not get tested and usually wind up seeking medical services in an emer-

gency room after experiencing symptoms of an illness. Table 1 notes key risk factors and behavioral determinants of risk influenced by culture.

**Table 1: Risk Factors and Behavioral Determinants**

<b>Risk Factors</b>	<b>Behavioral Determinants</b>
Health beliefs and practices	Low perception of risk for HIV/STD
Help-seeking behaviors	Lack of intentions for consistent condom use
Access to services, including health insurance	Negative attitudes about condom use
Language	Lack of social norms of condom use
Immigration status, including fear of deportation	Inadequate knowledge of HIV/STD transmission
Gender inequities	Lack of skills for correct condom use
Stigma	Low perception of need for condom negotiation
Poverty	Lack of social norms for new behavior change
Health literacy levels	Lack of knowledge of community resources
Education levels	Attitude of dominant power by males in male-female relationships

The most detrimental cultural and social factor among African-born communities that impedes people’s ability and willingness to seek help is stigma (Koku 2010). HIV-related stigma refers to “all unfavorable attitudes, beliefs, and policies directed toward people perceived to have HIV/AIDS as well as toward their significant others and loved ones, close associates, social groups, and communities” (Brimlow, Cook, and Seaton 2003). There is a perception among African-born individuals that only people who have engaged in unacceptable sexual behavior or drug use become infected. Stigma has significant negative consequences on testing. Individuals are discouraged from knowing their status due to the fear of being ostracized within their families and social networks. Stigma also affects HIV-positive individuals. After a person tests positive, he or she faces many difficult decisions that include how to enter and adhere to care and whether to disclose HIV status to family members, health care providers, and coworkers.

## **Culture and the Impact of Migration**

Migration is “the process of going from one country, region or place of residence to settle in another” (Bhugra and Becker 2005). Individuals resettle in the United States for various reasons, including seeking better educational opportunities or leaving unstable living environments in their home country that are due to political conflict, genocide, or famine. When individuals resettle in this country, they bring their cultural traditions and values to their new environments.

Foreign-born immigrant communities bring an additional complexity to experiencing culture as an evolving factor in one’s life. The process of migration is an external factor that causes foreign-born populations to examine both their traditional cultures and the culture(s) of their new environment. The initial experiences of foreign-born communities that migrate to the United States often result in negative physical or emotional responses brought on by being in a culture that is unfamiliar and significantly different than their homeland. Foreign-born individuals often experience feelings of anxiety, loss, confusion, and isolation while trying to resettle in a new environment. How migration affects an individual’s willingness and ability to change his or her cultural beliefs, values, and practices can depend on a number of factors, including the reasons for the migration, the duration of the process, the age at which the individual migrates, whether or not an individual is alone or within a group at the time of migration or resettlement, and whether an individual stays connected to his or her homeland.

As foreign-born communities become more culturally and linguistically congruent with their new environment and gain a sense of belonging, they may adopt the beliefs, values, and practices of the new country. This process is called acculturation. It includes examining one’s beliefs, values, and practices, adjusting to new cultural surroundings, and navigating between the two. Not only are aspects of that individual’s cultural and ethnic identity changed, but the culture of the new environment may also be affected. Although acculturation is a dynamic, nonlinear, and reciprocal process, it often results in one cultural group dominating the other group (Bhugra and Becker 2005). In the United States, the dominating culture tends to be framed by “whiteness.”

Being uprooted, separated from family and traditional values, and placed in a new social and cultural environment—either voluntarily or by force—can be highly traumatizing. Experiences of acculturation, pre-migration trauma, and post-migration stressors put foreign-born individuals at risk for various mental and physical health issues. Acculturation indicators such as fluency in English; preservation of cultural identity, values and norms; adoption of host country customs and traditions; and social contact with people native to the country of immigration have been found to be significantly associated with depression, anxiety, or post-traumatic stress disorder (PTSD). In a study of 143 Somali immigrants, 33.8 percent had a mood disorder and 14 percent had symptoms consistent with PTSD; the risk of suicide was present for 9.1 percent of this cohort (Bhui et al. 2006). HIV positive foreign-born individuals are also at increased risk of developing depression due to stressors associated with immigration, language, and citizenship barriers (Noh et al. 2012). Limited studies have been conducted to examine the impact of experiences of acculturation, premigration trauma, and postmigration on HIV risk behavior and HIV-positive African-born blacks. In a sample of 122 sub-Saharan African immigrants residing in Sweden, a history of premigration trauma was found to be associated with HIV-risk behavior. According to the authors, symptoms associated with post-traumatic stress disorder, depression, adjustment disorder, and substance abuse resulted in psychiatric conditions, which may increase an individual's risk to be infected with HIV (Steel et al. 2003).

Mental health issues due to trauma are often exaggerated for African-born blacks if the trauma is associated with the person's HIV infection. In a retrospective chart review study of 34 refugee patients living with HIV, most from Africa, patients presented with a high prevalence of mental health issues, including PTSD (32 percent). Twelve patients (35 percent) declined to discuss all or part of their trauma history. Those who did disclose had endured several different forms of abuse, of which the most common were beatings, threats, use of handcuffs/shackles, forced observation of dead bodies, forced witnessing of killings, and rape. Thirty-five percent of the patients were exposed to HIV risk situations as a consequence of torture. Hence, being infected with HIV was used in a similar way as other torture techniques. Most of

the patients in the cohort were upset by three issues: (1) eliciting history of substance abuse, (2) receiving safe sex education, and (3) discussing appropriateness of antiretroviral medications (Moreno et al., 2003).

## **Case Study: HIV among African-born Populations Living in Massachusetts**

### ***HIV Profile of African-born Immigrants in Massachusetts***

HIV surveillance data on foreign-born blacks from the Massachusetts Department of Public Health (MDPH) reflects similar trends found nationally.

In Massachusetts, 23 percent of people living with HIV/AIDS were born outside of the country, and their representation compared to the U.S.-born population has increased over the past ten years. Females increased from 37 percent to 52 percent, and males increased from 22 percent to 28 percent (MDPH, 2012). Within the three-year period 2008 to 2010, 51 percent of black (non-Hispanic) individuals diagnosed with HIV infection were born outside the United States. (MDPH, 2012). Within this same period, the largest proportion of foreign-born individuals diagnosed with HIV infection in Massachusetts were from sub-Saharan Africa (32 percent) and the Caribbean Basin (32 percent). Four of the five countries representing 70 percent of foreign-born black individuals diagnosed with HIV infection are in Africa—Uganda, Cape Verde, Ghana, and Kenya (MDPH, 2012). Differences in HIV testing patterns, HIV knowledge, and stigma were also found in a self-administered cross-sectional survey completed by 1,060 black individuals in Massachusetts (57 percent foreign-born Caribbean or African). Foreign-born black individuals were less likely to report recent testing than U.S.-born blacks. Of those who recently tested, the majority did so for immigration purposes, not because of perceived risk. Stigma was significantly higher and knowledge lower among foreign-born blacks (Ojikutu et al. 2013).

Foreign-born black women of varying ethnicities remain highly affected. Among females recently diagnosed with HIV, 52 percent are black (non-Hispanic). Of all black women diagnosed with HIV, 70 percent were not born in the United States (MDPH, 2012). Forty-eight percent of the total diagnoses among foreign-born females were from sub-Saharan Africa (MDPH, 2012).



The MDPH HIV/AIDS Surveillance Program reported significant shifts. Within the past several years, the distribution of exposure modes for foreign-born individuals has become similar to that of U.S.-born individuals recently diagnosed. Forty-one percent of people diagnosed with HIV infection who were not born in the United States within the years 2007 to 2009 were classified as exposed through presumed heterosexual sex (female having sex with male of unknown HIV status and risk) or through known heterosexual sex (MDPH, 2012). Also, for the first time in recent years, the proportion of individuals diagnosed with both HIV infection and AIDS within two months has become similar for all regions of birth—within the United States, outside of the United States, and Puerto Rico/U.S. dependencies. In prior years, between 2007 through 2009, a total of 37 percent of people born outside the United States who were diagnosed with HIV infection were concurrently diagnosed with AIDS within three months, compared with 30 percent of people born in the United States (MDPH, 2012).

Notable shifts that reduce the disparity gap between foreign-born and U.S.-born individuals are partly due to the strategic focus by the state of Massachusetts to invest in the development and implementation of programs that directly affect foreign-born populations, specifically African-born populations.

### **Program History and Overview**

Between 1994 and 1996, Dr. Sergut Wolde-Yohanes, Dr. Nawal Noor,<sup>1</sup> Miriam Gas,<sup>2</sup> and Dr. Juliette Tuakli<sup>3</sup> were invited to a series of meetings organized at the State Laboratory of the Massachusetts Department of Public Health (MDPH). The intention of these meetings was to find ways to address reproductive health issues in a culturally sensitive manner, including the increasing rates of HIV/AIDS among African-born women. In 2000, the Office of HIV/AIDS at MDPH continued meeting with a group of African-born immigrants who were providers, consumers, and community advocates. MDPH decided to develop a task force to spearhead planning in addressing HIV in the African-born community.

The first step for the task force, along with MDPH, was to work with John Snow Inc. and JSI Research and Training Institute to conduct a community-needs assessment. The purpose of the assessment was to

collect preliminary data on the need for HIV/AIDS information and care within the African-born population of Massachusetts, including identifying and defining key issues for more comprehensive needs assessments in the future. Qualitative methods were used to gather information: focus groups and telephone interviews with health care providers. The researchers held three focus groups—one with the Board of the Somali Women and Children’s Association located in Boston and two with members of the Boston community representing HIV/AIDS organizations, health care and social service agencies, and other community groups. In total, 36 individuals participated, representing Uganda, Kenya, Ghana, Nigeria, Tanzania, Zambia, Burundi, Malawi, Somalia, and Democratic Republic of Congo. The researchers conducted telephone interviews with 22 HIV specialists (physicians and nurse practitioners) and 2 social workers who provide HIV/AIDS care in urban health care facilities.

The findings were similar to what is still being reported in current literature. The level of stigma found in the African-born population was very surprising to health care providers, given that individuals are migrating from high-prevalence countries. Because of the stigma associated with HIV/AIDS, individuals often tell no one of their status, frequently causing African-born people with HIV/AIDS to live in extreme isolation and fear that they will be ostracized if their status were to become known to family, friends, and the greater community. Immigration status was found to be a barrier to HIV testing. Immigrants fear being reported to immigration authorities and removed from the country if they are found to be HIV positive. HIV education requires breaking the silence around HIV, sexual behavior, and sexuality. HIV/AIDS is the “unspeakable” illness, and cultural norms make it challenging for conversations to happen, not only with family and friends, but also with health care providers. Many African-born individuals still see HIV as a death sentence. There is a great deal of misinformation about who is at risk for HIV, how the virus is transmitted, and steps to prevent transmission. Many immigrants also have difficulty understanding and navigating the health care system. Institutions do not provide adequate language-access programs and are not considerate of sensitive cultural nuances. For example, African-born women patients may not be comfortable receiving care from male providers. Using face-to-face interpreters might

also discourage patients from talking about their HIV status for fear of disclosure to the community. Providers who participated reported that most of their African-born patients entered into care late, presenting with low CD4 (T-cell) counts or symptomatic illness. Also, providers noted seeing a higher number of co-infections with tuberculosis or sexually transmitted disease among their African-born patients. Stigma arose again as a huge barrier in African-born people living with HIV/AIDS accessing mental health services or joining an HIV support group.

Participants recommended action strategies that covered the underpinning principles needed to develop effective HIV services and programming and infrastructure needed to sustain efforts, including concrete steps. A central guiding principle community focus group participants expressed is that efforts to address HIV/AIDS among African-born communities must be community-driven and take into account the social and cultural norms of those communities. New initiatives should be planned and implemented primarily by community members and not imposed by “outsiders.” In emphasizing that “all Africans are not the same,” participants strongly recommended that all educational efforts should be based on a thorough understanding of each country’s cultures and languages. Such efforts must also be directed to all family members (e.g., men, teenagers) and focus on the family as a whole, drawing upon the rich African tradition of extended family. Specific strategies included the following:

- » Utilizing African radio, TV, and other media
- » Providing HIV/AIDS and health care information concurrently with other health information
- » Using trained outreach workers who are members of the community
- » Publishing and distributing a directory of services and resources appropriate for African-born populations

While asserting the importance of understanding cultural differences, focus group participants also recognized a need to work across country groupings and develop a unified voice as African-born immigrants living in Massachusetts. Participants recommended forming an HIV/AIDS coalition of community members (individuals affected by and living with HIV/AIDS), providers, advocacy groups, and others as an effective way to generate strength in numbers and enable the commu-

nity to advocate for needed resources, policies, and programs.

In 2000, during the same period that JSI and others were conducting the community-needs assessment, the Multicultural AIDS Coalition (MAC) was funded through the federal CDC to implement one of eleven community coalition-development projects. MAC's mission is to mobilize communities of color to end the HIV/AIDS epidemic. The Black HIV/AIDS Coalition (BHAC), led by MAC, convened health providers in Massachusetts to address the urgent need for accessible and effective HIV/AIDS treatment and prevention services focused on black residents. More than 35 organizations and individuals met monthly to plan a successful linked network addressing HIV, sexually transmitted diseases, hepatitis, and tuberculosis. Early in its development, members of BHAC recognized that the "one size fits all" approach would not be effective in addressing HIV within socially, culturally, and linguistically diverse groups of people of African descent; hence, population-specific clusters were developed. The populations of focus for the cluster networks are the priority populations identified by Massachusetts HIV surveillance data, neighborhood task forces, and focus groups. Hence, three population-specific clusters were formed: men who have sex with men (MSM), members of faith-based (FB) organizations and communities, and members of the African-born community. These clusters were composed of BHAC coalition members as well as individuals and organizations not actively involved in the larger coalition (e.g., civic organizations). It was decided that subgroupings within the black community allowed for the development and delivery of more responsive programming and dedicated services, and that the working groups had the expertise to present concerns and opportunities within each of their respective communities.

In 2000, MAC worked with the MDPH task force, and the BHAC group focused on African-born communities to merge the two entities. Community mobilization and planning coordinated by Rosette Serwanga<sup>4</sup> and the combined task force, led to the development in 2000 of the Africans for Improved Access (AFIA) program at the Multicultural AIDS Coalition. AFIA was the first state-funded program in Massachusetts specifically focused on providing HIV prevention and education services to African-born immigrants and refugees living in Massachusetts.

The Africans for Improved Access program is grounded in four principles.

1. Nurture a community-led process in all activities.

AFIA started as a staffed community coalition, and with funding from MDPH, matured into a structured program led by community members. They have a central and active responsibility in the program. As a key way of operating, the process of involving community recognizes and values additional ways of knowing that are grounded in culture and experiences. It also creates spaces for the community to decide and act on what changes are important and relevant in their lives. African-born individuals migrated with and built culturally sound infrastructures as a mechanism to survive and integrate into their new environment. AFIA's approach also builds on the existing social capital—institutions, strengths, talents, and resources—within local communities to respond to the challenges associated with HIV/AIDS. The process of true and sincere community involvement is iterative and requires humility, trust, and patience. The end result not only achieves AFIA's goals of eliminating stigma, increasing utilization of HIV services, and reducing new infections, but also leads to more sustainable initiatives that are engrained in the social fabric of the community.

2. Build long-lasting bridges in the community.

AFIA focuses heavily on identifying the channels through which community members obtain news and information and identifying trusted groups and organizations within the different communities. Relationships with these entities are based on a common goal of building a healthier community, not only addressing HIV.

Local African radio and television programs that are accessible online and through other venues, have welcomed AFIA's messages focused on HIV prevention, screening, and care. The information shared provides basic education information and also addresses some of the myths and challenges that continue to fuel the epidemic. For example, an internationally known Ugandan gay activist was in Boston and, because of AFIA's relationship with a local Ugandan radio show, staff members were able to have the activist on the show to discuss Uganda's Anti-Homosexuality Bill, which features several provisions regarding homosexuality and HIV/AIDS. In the discussion, AFIA's staff was able to correct misinformation about

HIV transmission and provide resources that support African-born lesbian, gay, bisexual, and transgendered individuals living in Massachusetts.

Members of African-born communities often turn to faith organizations and grassroots associations that earlier immigrants and refugees founded to help members of their communities find support. These formal and informal associations are often created to serve individuals from specific countries of origin as loose membership organizations in which community members attempt to maintain cultural ties and provide assistance to each other in times of crisis. These truly grassroots associations are often the only agents that African-born people trust and utilize frequently. As a result, they are in a unique position to reach out to newcomers and others to promote access to health care, disseminate health information, and serve as a point of entry into the formal health care system.

AFIA's partnership with faith organizations, mainly churches, is called the African Faith Collaborative. Existing since 2006, the collaborative has more than 20 active churches. As a beginning step, AFIA encouraged faith leaders to attend the Micah training created by the Multicultural AIDS Coalition, which is a 12-hour, video-based training grounded in the scripture Micah 6:8—"He hath shewed thee, O man, what is good; and what doth the Lord require of thee, but to do justly, and to love mercy, and to walk humbly with thy God?" The primary focus of the training is to enhance and build the capacity of faith leaders to minister effectively to individuals struggling with the spiritual, emotional, and behavioral dynamics of HIV/AIDS. Over the years, churches have hosted worship services during the National Week of Prayer for the Healing of HIV and World AIDS Day, distributed HIV/AIDS faith brochures, and/or collaborated with AIDS service organizations to provide HIV testing at church-sponsored events.

3. Incorporate African-centered social and cultural principles.

The AFIA program has incorporated social and cultural norms, beliefs, and practices into HIV risk assessments, HIV testing initiatives, and mobilization efforts.

**Collectivism:** There is a communal nature of African societies that encourages making decisions as it relates to the common good of the family/community. The family and the community must accept the reality that we are collectively responsible for our failures as well

as our victories and achievements. Hence, the AFIA situates HIV in the context of “we” versus “you.” Also, because of HIV stigma, this approach facilitates individuals being more open in discussion because they do not have to personally identify with the disease.

**African Proverbs:** Proverbs are central to communication in many African societies. They are culturally rooted expressions of wisdom acquired through reflection, experience, observation, and general knowledge. Shown in Table 2 are some African proverbs that are in alignment with HIV/AIDS education and are used in AFIA’s culturally relevant programming.

**Table 2: African Proverbs Used by AFIA**

African Proverbs	HIV/AIDS Taglines
A problem shared is a problem solved.	Get Involved
Having a good discussion is like having riches.	Get Talking
Lack of knowledge is darker than night.	Get Educated
Not to know is bad, not to wish to know is worse.	Get Tested
No one knows caution as regret.	Get Care

**The Arts:** Traditionally and contemporarily, the arts (music, theater, and dance) are important modes of communication in many African societies. In dealing with sensitive issues, such as HIV/AIDS, international initiatives recognize this asset in African culture and employ the arts as an effective means of increasing awareness, decreasing stigma and taboo, and talking about sexuality and condom use.

One example of AFIA integrating arts into HIV prevention and education is the production of *In Our House: An African Story Video & Curriculum (IOH)*. A community group convened by AFIA decided to develop and produce the film because of the traditional African art of storytelling. As a central component to communication, storytelling draws on the collective wisdom and experiences of a community, reinforcing their history, values, and ways of life, thus having social and ethical importance. Creating an HIV film was also seen as an ideal way of reaching out to African-born individuals of limited literacy. The group was engaged to identify themes, write the script, set the scene, and direct the film. IOH includes a step-by-step instruction manual and 25-minute

video based on the journey of an African immigrant family dealing with HIV/AIDS in the United States. It takes into consideration the root causes of the epidemic for Africans and incorporates cultural ways of teaching and learning. IOH is designed to provide basic information, explore real and perceived barriers to care, increase skill levels, and shift attitudes. Achieved through a strength-based approach, IOH fosters responsibility, and requires individuals to build on the strengths of the community and normalize the issue of HIV by actively participating in an achievable solution. IOH also serves as a tool for educating service providers about cultural competency issues affecting their provision of services to this community.

#### 4. Maintain strong linkages with other needed services.

It is broadly acknowledged that stigma greatly dictates if people will seek out HIV/AIDS information or attend educational programs devoted to only HIV/AIDS. To address this, AFIA provides information about social services and other diseases during events and public gatherings. In addition to holding HIV/AIDS-specific events, AFIA attends and provides information at culturally significant celebrations, such as music concerts and independence day celebrations of various countries. Other services typically include health insurance and immigration assistance.

The infrastructure of the program was also essential in ensuring its success. Members of the African-born and first-generation community staff AFIA. First-generation individuals are children of one or more African-born parents. Even though not born in the home country of their parent(s), first-generation individuals are important in educating African-born communities about HIV/AIDS because first-generation individuals tend to have a strong connection to and an understanding of the cultural beliefs and practices of their parents' countries of origins. There is also a conscious effort to hire individuals from diverse African countries and to cover different regions (e.g., a West African from Liberia and an East African from Kenya). Different genders are also represented on the staff.

## **Discussion**

The United States is a country where people are first and foremost identified by race rather than ethnicity. Published in August 2013, a *New York Times* essay written by Kenneth Prewitt, director of the U.S.



Census Bureau from 1998 to 2000, states that the current racial categories are flawed, outdated, and based on the legacy of maintaining white supremacy. He argues that statistics must reflect the country's changing demographics and, instead of the current five racial categories, the census should ask questions that relate to ethnicity, national origin, and parental place of birth to account for second-generation individuals. Information gleaned from these questions is more useful in understanding health disparities and takes into consideration the vastly different experiences and culture of African Americans whose ancestors were enslaved and members of the newly arrived African and other foreign-born populations of African descent (Prewitt 2013).

The traumatic experience of being ripped from home and lineage forced enslaved Africans to rethink identity within an environment that flattened and labeled them according to race rather than ethnicity. The ongoing reverberations of that process ripple through U.S. society today and are not completely resolved, largely because of institutionalized racism. Within this extremely polarizing matrix, new African-born populations are forced to navigate multiple layers of their own identities, learn the patterns of racism, and acculturate to living not only as immigrants, but now also as "black" people. This process is complex. African-born immigrants learn conversance with at least three new identities, that of being a "foreign-born individual," an "African-born individual," and a "black person." This is a phenomenon that non-black people do not have to experience. In addition to balancing multiple identities, the process of migration can be traumatizing. Not only does it cause immigrants to adjust their cultural understandings and ways of life, but it also leads to additional barriers to maintaining healthy behaviors by putting foreign-born individuals at risk for various mental and physical health issues. Given this situation, there are numerous cultural factors to consider when determining how to provide widely effective health care, including HIV/AIDS, education, and services to different ethnicities within the black or African American racial categories. These include spirituality and religiosity; issues of gender equity or lack thereof; language barriers; physical and emotional trauma as a result of social, economic, or political instability or persecution; social taboos on topics that are sexual in nature; cultural consideration for age and eldership; poverty;

marginalization because of ethnicity; immigration status issues; and family and kinship structure.

HIV/AIDS programs slated broadly for “African Americans” or “blacks” fail to take into consideration cultural identity and the migration of black individuals from regions with elevated HIV prevalence. HIV among African-born populations has been called a “hidden epidemic” because of the high prevalence of HIV in this population, the failure of current U.S. surveillance reporting requirements to collect data on the country of origin (Kerani et al. 2008), the lack of research on the complex social and structural barriers African-born populations face in accessing care (Blanas et al. 2012), and finally, because of the lack of interventions that consider culture as a key component in individual behavior change (Airhihenbuwa and Webster 2004).

In order to effectively address the HIV epidemic in the African-born population, interventions need to be developed that take account of social and cultural factors, including the overwhelming effects of stigma on discussing, being tested for, and being treated for HIV/AIDS. There are no evidence-based HIV prevention and education interventions that directly address the complex and unique cultural barriers of African-born populations. In 1996, the Centers for Disease Control and Prevention initiated Replicating Effective Programs (REP) and the Diffusion of Effective Behavioral Interventions (DEBI), which are evidenced-based, community- and group-level HIV prevention interventions (<http://www.effectiveinterventions.org>). These interventions were developed for injection drug users, young teenagers, African American women, people living with HIV/AIDS, and men who have sex with men (MSMs), and they focus on behavior changes, such as condom use, disclosure, safer sex negotiation, and reframing from substance use. In situations in which social and cultural norms of the targeted population may differ, providers are encouraged to tailor and adapt the REP and DEBI interventions. Even in tailoring and adapting these interventions, however, the core components cannot be changed and still may create barriers toward implementation. Once core components of the REP and DEBI interventions are changed, they no longer have a basis in the scientific research that has proven them to be effective.

Massachusetts has seen an improvement in HIV prevalence and incidence. Yet, still there is a distinct bias that privileges creating programming for black or African Americans and ignores the disparity between U.S.-born blacks and foreign-born blacks. In an effort to address the complex barriers to HIV prevention, education, and care for African-born communities and the lack of culturally and linguistically appropriate interventions, the Multicultural AIDS Coalition established the Africans for Improved Access program in 2000 with community members. AFIA has been instrumental in engaging the African-born population in its own process of empowerment by encouraging dialogue, decreasing stigma, and increasing access to health services. AFIA has formed strong partnerships with the faith community, other community-based civic organizations, cultural groups, and service providers to ensure a collective approach built on African principles and cultural understandings.

The importance of sincere and deep community engagement in relation to developing culturally and linguistically appropriate services for African-born populations cannot be undervalued. This approach is often seen as integrating individuals who reflect the community (e.g., community health workers and cultural brokers) or partnering with a community group or coalition. Regardless of the method, nurturing community-led initiatives is effective because liaisons know what works, how their community functions, and what is important in those communities. Additionally, it cannot be assumed that only one community liaison will be sufficient to work with any and every African-born community. There is significant regional, national, ethnic, linguistic, and cultural variation across the continent of Africa and with each African country. It would not be fiscally and logistically feasible to have on staff a person from every possible ethnicity in a given locale. It is advisable, however, that there should be regional liaisons (representing North, South, East, West, and Central Africa) to help bridge the cultural gaps between service providers and communities.

There are a myriad of questions that liaisons can help answer when developing HIV/AIDS programs and services for African-born communities. These include, but are not limited to, the following:

- » Are there taboos or rules governing when, where, how, or with

- whom matters of a sexual nature can be discussed?
- » How do people transmit or share information in this community?
  - » What are their ideas about education?
  - » How are people educated? What styles of education do they value?
  - » Do men and women have equal access to outsiders?
  - » Do men and women have equal access to resources?
  - » How are families and households set up? Is there one person whose permission must be obtained before speaking with others in the family?
  - » What are the best places to access immigrants?
  - » Will men and women discuss matters of a sexual nature in the same space?
  - » Is the particular immigrant community religious? How does religion come into play, or not, with attitudes toward sex and sexual behavior?
  - » Is there a language barrier? Are there even words in the language of a given foreign-born community for sexual ideas and behaviors that need to be discussed in reference to HIV/AIDS?

In addition to answering these questions, time and money should be allocated to comprehensively assess community needs and assets. An assessment process will also help to uncover what questions beyond those listed above need to be answered and how best to serve the community in a way that its members feel engaged, supported, and above all respected.

## **Conclusion**

This paper has tried to illustrate several points that conclude black is decidedly not just black. First, the homogenizing process of people of African descent en route to and in the Americas is one that has a longstanding historical precedent. Second, the process was not only homogenizing, but it stripped Africans of their varied cultural backgrounds and flattened them individually and politically into a racial category that was and is essentially determined not by themselves but by society at large. Third, this flattening into a category called “black” or “African American” causes African-born populations to disappear and ignores distinct factors that could hinder or promote health among individuals, affecting aspects of the community as a whole, such as

culture and the process of migration. In the context of providing health services, including HIV/AIDS prevention, education, and screening programs, the failure to recognize a population causes inaccurate data on disease prevalence and incidence. Whereas the allocation of resources is dictated by new HIV diagnoses, inaccurately tracking the epidemic by only using the black/African American racial category puts black populations migrating from high-HIV prevalence areas (e.g., African-born populations) at a disadvantage. Lastly, collecting HIV surveillance and social behavior data on black subgroups, such as African-born populations, is imperative to developing culturally and linguistically appropriate HIV services. Programming should be developed and implemented with these communities so that HIV/AIDS education and preventative activities are formed, executed, and evaluated recognizing culture as a major determinant affecting individual, group, and community health.

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## Notes

<sup>1</sup> In 1999, Dr. Nawal Noor established the African Women's Health Center (AWHC) at the Brigham and Women's Hospital, which is a Harvard-affiliated hospital. The overall mission of the AWHC is to holistically improve the health of refugee and immigrant women who have undergone female genital cutting.

<sup>2</sup> Miriam Gas is the executive director of the Refugee & Immigrant Assistance Center, formerly known as the Somali Women and Children's Association. It was founded in 1993 to provide comprehensive services to refugees and immigrants, including resettlement, counseling, health care, cultural assimilation, job counseling, and social services.

<sup>3</sup> In 1990, Dr. Juliette Tuakli founded Maternal & Child Healthcare Associates, a private practice serving underprivileged children and adolescents in Boston, and cofounded the African Community Health Initiative in 1998 in response to the increasing burden of HIV/AIDS among immigrant African families in Massachusetts.

<sup>4</sup> Rosette Serwanga founded the Namugongo Fund for Special Children (NFSC) in 1986. It is a community-based nongovernmental organization in Uganda helping orphaned and other vulnerable children reach their full potential through education and other opportunities. NFSC cares for handicapped children in Namugongo and surrounding communities.