

# Utah Biannual Qualitative HIV Needs Assessment Report



UTAH DEPARTMENT OF  
**HEALTH**

Utah Department of Health

Division of Disease Control & Prevention

Bureau of Epidemiology

Treatment and Care Services Program

Ryan White Part B Program

2014

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Vulnerable Populations and Best Practices Regarding HIV and AIDS Care in Utah

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HIV, human immunodeficiency virus, is the virus that can lead to acquired immunodeficiency syndrome (AIDS). Unlike other viruses, though, the body cannot get rid of HIV (CDC, 2015). Once an individual has HIV they will have it for life. The virus affects, in particular, CD4 T cells in the human immune system (CDC, 2015). Over time, HIV may destroy so many CD4 cells that the body cannot fight off other infections or diseases (CDC, 2015). It is at this stage that HIV leads to AIDS.

HIV, in the U.S., is mainly spread by sexual activity or sharing drug injection equipment with infected persons (CDC, 2015). HIV cannot be spread by casual contact. However, HIV is preventable and prevention tactics include safer sex, limiting the number of sexual partners, never sharing needles, testing and even pre-exposure prophylaxis for high-risk individuals (CDC, 2015).

The HIV and AIDS epidemic is growing most rapidly among underserved populations such as ethnic and racial minorities, marginalized populations and those typically outside the health care system (Hayes et al., 2005; Hopson, 2006). In today's modern world, health care is data-driven; thus, efforts to conceptualize, contact and benefit these underserved populations need to be supported by data especially in terms of estimating unmet need (Ikard et al., 2005). The following literature review will attempt to provide an overview of the situation, a brief summary of barriers encountered and suggestions for best practices regarding vulnerable populations living with HIV in Utah.

Connecting with and engaging, underserved and vulnerable populations, is essential for preventing and treating HIV. Currently, an estimated one million people are living with HIV in the U.S. (AIDS Action Foundation, 2006). Roughly half of those individuals are not receiving care (AIDS Action Foundation, 2006; Thompson et al., 2012). Of those half-million, further

estimates suggest nearly 300,000 are HIV-positive yet unaware of their status; a factor affecting why they are not receiving care (Hopson, 2006; AIDS Action Foundation, 2006). In the fight against HIV and AIDS, treatment is prevention. Thus, it is paramount that public health professionals reach out to, connect with and continuously engage individuals not receiving care. In order to do that it is important to understand who these people are, how to reach them, and how best to serve them. Furthermore, as HIV and AIDS care increasingly focuses on primary care it is necessary to tailor care to subpopulations and their unique needs (Hopson, 2006).

As of 2011, 2,364 HIV-positive individuals were living in Utah (HRSA, 2012a). However, the 2012 estimated number of clients served by Ryan White HIV and AIDS Programs in Utah (such as the AIDS Drug Assistance Program and the Early Intervention Services) was 1,414 (HRSA, 2012a). Nearly 1,000 individuals are not in need of Ryan White HIV and AIDS Programs; in need but do not qualify; or in need but not accessing care. In reality, it is a mixture of these situations but there is definitely an element of unmet need in Utah. HRSA defines “unmet need” as individuals who are living with HIV, aware of their HIV-positive status, but not engaged in regular medical care (AIDS Action Foundation, 2006).

### **Mentally Ill**

People living with HIV or AIDS (PLHIV) are significantly more distressed than the general population (Israelski et al., 2007). These individuals have higher rates of trauma-related mental illness, such as post-traumatic stress disorder, acute stress disorder and depression, which reflects the higher rates of traumatic life events for this population (Israelski et al., 2007).

### **Demographics**

While PLHIV may be at a higher risk for mental illness in general, subpopulations among PLHIV are at even higher risk. Among those subpopulations living with HIV, women have seen

higher rates of mental illness compared to men, so have African American and non-Hispanic whites compared to Hispanics (Israelski et al., 2007). Furthermore, the prevalence of co-occurring mental illness with substance abuse has been well-documented in all populations (Sacks et al., 2011). This holds true for PLHIV who suffer from a mental illness – they are more likely to be diagnosed with a substance abuse disorder, resulting in multiple comorbidities (Sacks et al., 2011). In Utah specifically, one study of HIV-positive women at a University of Utah clinic found, among study subjects, high rates of mental illness and substance abuse (Simonsen et al., 2014).

### **Barriers to Care**

In the study conducted by Israelski et al. (2007) they found, among their study subjects who qualified as having a mental illness, 43 percent were not receiving any psychiatric treatments. They attributed this to a lack of primary care providers screening their at-risk HIV and AIDS patients for mental illness (Israelski et al., 2007). It is apparent some barriers exist to integrating HIV and AIDS and mental health care. However, those barriers are not readily defined in the literature.

### **Best Practices**

Increased use of regular and routine mental illness diagnostic tools and screenings could improve primary health care for PLHIV (Israelski et al., 2007). Studies have shown PLHIV who suffered from a mental illness who were receiving treatment for that mental illness were more likely to adhere to their antiretroviral treatments (Israelski et al., 2007). Improved mental illness treatments, therefore, could also decrease the risk of HIV transmission and protect partners of PLHIV as successful antiretroviral treatments have been shown to reduce the risk of transmitting the virus (CDC, 2013).

Case management is common to support individuals in substance abuse treatments, HIV and AIDS treatments, and mental health treatments. Thus, many patients end up with multiple case managers each responsible for discrete aspects of the patient's overall care (Sacks et al., 2011). Integrating care services for PLHIV with co-occurring mental health and/or substance abuse disorders could improve treatment outcomes and retention in care (Thompson et al., 2012).

It is especially necessary to tailor and specialize treatments for PLHIV who also require treatment for mental illness. As Thompson et al. (2012) point out, several treatment strategies not recommended for all PLHIV are recommended for those with co-occurring mental illness or substance use disorders.

### **Physically Disabled**

Many of the risk factors for HIV are the same risk factors experienced by disabled persons in general: poverty, illiteracy, stigma, marginalization, ostracization and social exclusion (Grace, 2005; Wazakili, Mpofu & Devlieger, 2006). Therefore, physically disabled people are at equal or increased risk of exposure to all known HIV risk factors (Grace, 2005). As for high-risk sexual behavior, disabled persons engage in high-risk behavior at least as often as their nondisabled counterparts (Grace, 2005). Often, disabled people feel extra pressure to engage in sexual activity as a means for social acceptance and inclusion; or as a means of employment (i.e. prostitution) (Grace, 2005). Additionally, disabled individuals, especially women and girls, are at greater risk of physical and sexual abuse and are more routinely denied reproductive rights (Grace, 2005; Wazakili, Mpofu & Devlieger, 2006).

### **Demographics**

Utah has the lowest percentage of disabled residents in the nation with between 8.7 to 8.9 percent of residents reporting a disability (U.S. Census Bureau, 2011; Chambless, McCormick &

McIlvenna, 2013). In Utah, the most commonly reported disability is ambulatory difficulties followed by cognitive difficulties (Chambless, McCormick & McIlvenna, 2013). No definitive numbers of disabled PLHIVn Utah were found through this literature review.

### **Barriers to Care**

Often, disabled people are the poorest of the poor and socially isolated (Grace, 2005). A number of those with a disability depend on others for assistance with daily activities including accessing medical care (Grace, 2005). When assistance is available, physical and institutional barriers exist such as buildings not being accessible to those with mobility disabilities or clinics lacking the appropriate sign-language interpreters (Grace, 2005; Wazakili, Mpofu & Devlieger, 2006). Social and emotional barriers exist as well, such as a disabled person's reluctance to disclose personal medical information to those who are assisting them (Grace, 2005).

Moreover, a lack of comprehensive sex education along with HIV and AIDS education can disproportionately affect disabled people (Grace, 2005). With regard to education, disabled people often receive little or no information as many view the disabled as asexual or otherwise not needing information regarding safe sex practices and HIV and AIDS (Grace, 2005; Wazakili, Mpofu & Devlieger, 2006). As a result, many disabled people turn to the media for information about sexuality, sexual behavior and HIV and AIDS (Wazakili, Mpofu & Devlieger, 2006). However, this can have its own disadvantages such as blind people who are unable to benefit from billboard campaigns or deaf individuals who can't hear radio campaigns (Grace, 2005). For individuals with intellectual disabilities many of the euphemisms used regarding sex education are too vague to be useful for them even when an HIV and AIDS education is provided (Grace, 2005).

Lastly, many disabled people also self-identify with other vulnerable or marginalized populations such as ethnic minorities, those with mental health issues, or those who are less educated (Chambless, McCormick & McIlvenna, 2013). When combined, these identities create a complex web of barriers to HIV care and treatment.

### **Best Practices**

Currently, there is limited research and guidance regarding best practices for public health professionals working with disabled PLHIV. Wazakili, Mpofo and Devlieger (2006) mention the importance of training parents of disabled individuals as well as the disabled themselves in HIV and AIDS matters. Also, knowledge of a disabled person's real life situation is necessary to further identify barriers and to illicit behavior change (Wazakili, Mpofo & Devlieger, 2006). Grace said it succinctly, "Virtually nothing is known about how disabled populations can best be reached as part of general HIV and AIDS outreach efforts or through disability-specific programs" (Grace, 2005, p. 222).

### **Low Literacy**

Low literacy levels in general, as well as low levels of health literacy in particular, are negatively linked to HIV care and treatment (Wolf et al., 2007; Kalichman, Cherry & Cain, 2005; Cargill, 2013; Gakumo et al., 2015). Specifically, low literacy is a significant predictor of poorer HIV treatment knowledge, medication knowledge, correct medication identification, treatment adherence and lower levels of self-efficacy regarding taking medications (Wolf et al., 2007; Kalichman, Cherry & Cain, 2005; Cargill, 2013; Gakumo et al., 2015; Thompson et al., 2012). Kalichman, Cherry and Cain (2005) found patients with low literacy were more likely than those with higher literacy to have detectable viral loads, lower CD4 counts and more HIV-related symptoms. In the words of Wolf et al., "Limited literacy impacts the ability of individuals to

perform the constellation of skills needed to manage chronic disease” (Wolf et al., 2007, p. 258). Therefore, efforts to raise health literacy as well as programs designed for low literate groups are essential for HIV and AIDS care.

### **Demographics**

Individuals at increased risk of experiencing lower literacy levels include low-income individuals, minority groups and those in rural areas (Wolf et al., 2007; Gakumo et al., 2015). In a 2007 study, Wolf et al. found approximately one-third of study participants with HIV and AIDS had limited literacy skills. Specific to their study, participants were more likely to have lower literacy skills if they were African American, male, and had less education (Wolf et al., 2007). However, Gakumo et al. (2015) note racial disparities disappear when examining health literacy as a potential mediator; meaning, health literacy may be more of a factor than race.

Using 2010 U.S. Census Data, approximately 90.9 percent of Utah’s population aged 25 or older is at least a high school graduate (U.S. Census, 2015). However, this does not necessarily mean 90 percent of Utah’s population can read at a high school level.

### **Barriers to Care**

Many of the HIV and AIDS mass education programs cannot be applied to low literate groups or are not reaching them; namely pamphlets, posters and billboard campaigns are insufficient (Preidis et al., 2010). Thus, many low-literate persons are not adequately being reached by current campaigns. However, lack of knowledge alone does not fully explain the barriers experienced by low-literate individuals (Wolf et al., 2007). Further research is needed to investigate the interactions between low literacy levels and barriers to health care.

Low literacy has been linked to an individuals’ inability to perform the multitude of tasks necessary to treat chronic diseases (Wolf et al., 2007). Individuals with low literacy are more

likely to misinterpret medical instructions and have difficulty translating those instructions into actions (Kalichmann, Cherry & Cain, 2005).

It is apparent many of the barriers experienced by low-literate populations are tied to their status among other vulnerable and underserved populations (Kalichman, Cherry & Cain, 2005).

### **Best Practices**

Programs and interventions can and should be designed specifically for low-literate populations (Wolf et al., 2007; Kalichman, Cherry & Cain, 2005; Preidis et al., 2010; Gakumo et al., 2015). Low health literacy can be addressed through simplified patient education and behavioral interventions, as well as programs aimed at increasing patient understanding and self-efficacy, increased use of interactive and multi-media technologies, pictographic or color-coded materials, and also improvements in the communication skills of health care providers (Wolf et al., 2007; Kalichman, Cherry & Cain, 2005; Gakumo et al., 2015). Preidis et al. (2010) implemented and documented a successful HIV education intervention that used community drama as the presentation media.

Second, Wolf et al. (2007) argue the responsibility for successfully managing chronic diseases such as HIV should not reside solely with the patient. The entire health system should be reshaped taking patients' health literacy levels into account. Specifically, Wolf et al. (2007) call for decreased complexity in the demands the current health system places on patients.

Case management may help provide the extra support and individual attention necessary. One successful pilot study of interventions among low-literate individuals relied heavily on case management, personalized feedback and one-on-one interactions with a trained nurse (Kalichman, Cherry & Cain, 2005). After this counseling intervention, the number of nonadherence events reported had decreased (Kalichman, Cherry & Cain, 2005). Individualized

and personalized care, such as with case management that is tailored to a patient's specific knowledge level and holistic needs has been shown effective when working with all populations but especially low-literate populations (Gakumo et al., 2015; Kalichman, Cherry & Cain, 2005; Thompson et al., 2012)

### **Non-English Speaking**

Language issues continue to be a barrier for medical care for many Americans. For many non-English speakers who do seek medical care, they often act as their own interpreters or have help from more English-proficient family members. However, this can lead to medical catastrophes stemming from miscommunications (Flores, 2006). As noted earlier, a constellation of skills is necessary for proper and successful HIV treatment, which does not leave much room for such miscommunications.

### **Demographics**

Estimates suggest 18.7 percent of Americans speak a language other than English at home and that more than 8 percent have limited English proficiency (Flores, 2006). According to the U.S. Census Bureau (2015), 14.3 percent of Utah households speak a language other than English. In one review of a University of Utah HIV clinic, only 63 percent of female patients spoke English as their primary language (Simonsen et al., 2014). In Utah, the most common language other than English is Spanish followed by German. For Native American communities in Utah, the most common language is Navajo (Blatt, 2014).

### **Barriers to Care**

Many patients find themselves without access to medical interpreters (Flores, 2006). Providers and organizations have cited cost concerns as one reason to not provide interpreters, however to deny or delay medical care because of language barriers is discrimination (Flores,

2006). As noted above, patients often act as their own interpreters or enlist the help of family members but then miscommunications are common (Flores, 2006; Zuniga & Blanco, 2009). Thus, many patients find themselves without access to medical interpreters (Flores, 2006). Furthermore, medical interpreters are often not adequately trained, particularly in medical terminology. Additionally, the use of an interpreter can inhibit patients from having discussions with their providers regarding sensitive subjects; when sensitive subjects are broached patients with interpreters must sacrifice some level of medical privacy (Flores, 2006; Robinson et al., 2012). As many PLHIV already face stigma barriers, communicating through a stranger is an additional burden. Patients who face language barriers are less likely to have a primary source of medical care, less likely to receive preventive care, and are more likely to not adhere to medications (Flores, 2006). This is of particular importance regarding HIV care as adherence to medications and treatments benefit PLHIV and their partners as mentioned above.

In addition to office visits, medical information is often provided in English only. For example, PLHIV who do not understand English will not benefit from English prescription labels or English instructions (Zuniga & Blanco, 2009).

### **Best Practices**

The first step to effectively engaging non-English speaking PLHIV is to enlist and engage health care providers (Zuniga & Blanco, 2009; HRSA, 2012). As Zuniga & Blanco state, “Provider’s commitment to the delivery of linguistically- and culturally-appropriate care is important to minimize barriers to health care access for patients who are English-language learners” (Zuniga & Blanco, 2009, p 40). Furthermore, if providers make an effort to learn their patient’s native language, such as Spanish, patients were appreciative, which may enhance the patient-provider relationship (Zuniga & Blanco, 2009).

As noted above, the use of interpreters is necessary to avoid miscommunications. However, beyond that, offering non-English speaking patients the option to pick between in-person or phone interpreters has been shown to foster patient-provider trust and communication (Zuniga & Blanco, 2009). More technologically advanced interpretation services may have use as well, such as computer-mediated interpretation (Zuniga & Blanco, 2009). Finally, any materials used must be translated into languages understood by PLHIV (HRSA, 2012). The research also supports incorporating bilingual and bicultural staff as it helps retain Latino PLHIV in care, which leads to better treatment adherence (HRSA, 2012).

### **Refugees**

Refugees are a subpopulation particularly vulnerable to HIV infection and disease (CDC, 2012). The environments and situations refugees find themselves in, such as exposure to sexual violence, economic vulnerability, conflict, oppression and discrimination may enhance the transmission of HIV. (CDC, 2012; PEPFAR, 2006). However, few studies have actually documented increased high-risk behavior among refugee populations (CDC, 2012). Some studies show higher HIV rates among refugees while other studies show lower HIV rates (PEPFAR, 2006). Regardless of the rates of infection, HIV and AIDS services are important in this subpopulation to protect refugees and the people in host communities (PEPFAR, 2006).

Notably, HIV is no longer a condition denying admission into the U.S. for refugees and routine HIV testing prior to departure no longer takes place (CDC, 2012).

### **Demographics**

Estimates suggest at least 45,000 refugees have settled in Utah since 1988. Of those, at least 70 percent are women and children (Utah Refugee Center, 2014). Exact numbers of HIV and AIDS prevalence among Utah refugees is not readily available.

**Barriers to Care**

Immigrants and refugees face complex structural obstacles regarding integration and use of the health care system (Robinson et al., 2012; CDC, 2012). Refugees may be unaware of how to access care, where to access care, or simply excluded from care (CDC, 2012). Resettled refugees often face transportation barriers, which limit their access to HIV care (PEPFAR, 2006). Furthermore, many immigrant and refugee individuals may encounter language barriers, as they are often non-English speaking (Robinson et al., 2012; PEPFAR, 2006). Thus, many foreign-born individuals are more likely to enter into HIV care later with a number of additional problems related to their delayed care (Robinson et al., 2012). In addition, refugee populations are often omitted from HIV and AIDS plans entirely (PEPFAR, 2006).

Moreover, refugees often suffer from the stereotype that they are bringing HIV and AIDS to their host country (PEPFAR, 2006). However, studies have shown lower rates of HIV among refugee communities when compared to their surrounding populations (PEPFAR, 2006).

**Best Practices**

The most important best practice regarding HIV care in refugee populations is routine screenings. The CDC recommends screening all refugees for HIV unless they specifically decline testing or “opt out” (CDC, 2012). They also call for adhering to refugee cultural and social norms, including providing HIV and AIDS information in native languages (CDC, 2012).

The goal of The President’s Emergency Plan for AIDS Relief (2006) is to ensure refugee populations have access to the same HIV prevention, treatment and care as nationals of the host country. Prevention is the principal focus regarding refugees (PEPFAR, 2006).

Most refugee services use case management systems to aid refugee settlement; in Utah the two providers are the International Rescue Committee and Catholic Community Services

(Utah Refugee Center, 2014; International Rescue Committee, 2014c). Case management offers the opportunity to integrate HIV care with other factors of refugee resettlement, and integrated care is highly recommended for refugee HIV services (PEPFAR, 2006). The case management provided to Utah refugees includes interpreter services; health and wellness classes; and orientation to the U.S. health care system including information regarding health exams, doctor's visits, and the difference between family doctors, urgent care and emergency rooms (International Rescue Committee, 2014a and 2014b).

### **Communities of Color**

HIV and AIDS have disproportionately affected communities of color (Robinson et al., 2012). With regard to HIV and AIDS care, the percentage of clients receiving assistance via Ryan White CARE programs who are ethnic minorities is nearly two-thirds (Hopson, 2006). Not only do communities of color account for increasing cases of AIDS but also increasing AIDS-related deaths (Hopson, 2006). In addition, while the U.S. population as a whole has seen a decrease in AIDS cases, for a number of factors related to HIV treatment, this decrease has not held true for communities of color (Vernon & Jumper-Thurman, 2005). One factor is that Latinos and blacks are more likely than other ethnic groups to present late for HIV care and as a result are more likely to be diagnosed with AIDS. They also experience higher rates of associated morbidities and mortalities (Cargill, 2013).

When examining minority groups, it is necessary to remember many groups are not homogenous (Zaidi et al., 2005; Vernon & Jumper-Thurman, 2005; Robinson et al., 2012). For example, Asian and Pacific Islander peoples have distinct and differing languages and cultures stemming from more than 70 countries and territories (Zaidi et al., 2005). Similarly, Native American populations identify strongly with their unique and distinct tribes each with unique and

distinct cultures (Vernon & Jumper-Thurman, 2005). As Vernon and Jumper-Thurman (2005) note, the concept of “two-spirit”— a term describing any gender nonconforming individual – is acceptable in some Native American tribes and thus appropriate to include in HIV and AIDS care; however other tribes find the term offensive and would not be receptive to its use. While it may be convenient to discuss Native American populations as a whole, public health professionals working with Native Americans must remember each tribe is unique.

### **Demographics**

According to the U.S. Census Bureau (2015), white Utahns comprise the largest proportion of the population at 91.6 percent. The largest minority population is Hispanic or Latino at 13.4 percent; the second largest minority groups are tied at 2.3 percent: Asian and those self-identifying as two or more races (U.S. Census, 2015). The rest of the Utah population rounds out as follows: American Indian and Alaska Native (1.5 percent), Black or African American (1.3 percent), and Native Hawaiian or Other Pacific Islander (1.0 percent) (U.S. Census 2015).

The largest minority group in Utah that is currently living with HIV is Black/African American Utahns (CDC, 2011). In fact, just over 1,030 per 100,000 Black/African American Utahns are living with HIV while the rate for Hispanic/Latinos is only 177 for 100,000 (CDC, 2011). Thus, while Black/African Americans comprise only a small fraction of Utah’s population, they account for a disproportionate amount of Utah’s HIV population. Furthermore, HIV rates for most minority groups in Utah are higher than rates for white Utahns (CDC, 2011).

### **Barriers to Care**

The health care system, historically, has excluded or mistreated many communities of color (Vernon & Jumper-Thurman, 2005). Thus, many members of minority groups neither

overtly seek out medical care nor overtly welcome it into their lives (Vernon & Jumper-Thurman, 2005). Regarding Native American health in particular, lack of funding combined with distrust in the system has resulted in tribal health lagging decades behind the health status of the general population (Vernon & Jumper-Thurman, 2005).

A second large barrier to care involves a lack of knowledge (Zaidi et al., 2005). In fact, Zaidi et al. found Asian and Pacific Islanders living with HIV to be less aware of several care-related services when compared with white populations (Zaidi et al., 2005). Asian and Pacific Islanders were also less likely to undergo testing for HIV (Zaidi et al., 2005). Also affecting the likelihood of being tested is a minority culture's acceptance of both homosexuality and HIV-positive individuals. A number of minority groups report stigma and fear regarding positive HIV diagnoses so severe that they avoid getting tested altogether (Vernon & Jumper-Thurman, 2005). Logically, without proper testing, HIV-positive individuals will not receive the care they need, as they are unaware it is necessary.

Lastly, many minority groups experience poverty at higher rates than the general population (Vernon & Jumper-Thurman, 2005). Poverty can impact HIV and AIDS care in a number of ways by preventing full health education, inhibiting access to quality medical care, increasing health disparities and increasing the risk of poverty-related diseases which also have connections to HIV infection (Vernon & Jumper-Thurman, 2005).

### **Best Practices**

As with all public health programs and interventions, the target population needs careful examination and proper input prior to implementation. The same holds true for HIV and AIDS care among people of color (Robinson et al., 2012). Vernon & Jumper-Thurman (2005), call for an "indigenist" etiology paradigm regarding HIV and AIDS. They also highlight the usefulness

of case management and declare HIV testing “essential,” suggesting universal and routine HIV testing (Vernon & Jumper-Thurman, 2005).

Best practices will need to include basic health education and raising awareness regarding HIV and AIDS. In particular, Zaidi et al. (2005) found Asian and Pacific Islanders to be engaging more often in behaviors that are at high-risk of HIV infection yet not perceiving themselves to be at risk for HIV. When considered in combination with the general lower rates of HIV testing, this is another reason to implement universal and routine HIV testing.

The need to provide resources, programs and care in an individual’s native language may prove immensely beneficial. Currently a number of areas lack programs in tribal, Asian and Pacific Islander languages (Vernon & Jumper-Thurman, 2005; Zaidi et al., 2005).

Lastly, as the HIV and AIDS barriers and risk factors for communities of color are not merely related to racial behavior, HIV and AIDS programs that target attitude adjustment and behavior modifications will be incomplete and ineffective (Robinson et al., 2012). The long history and continued effects of structural inequalities make these individuals more likely to encounter HIV and less likely to seek or be offered treatment for HIV (Robinson et al., 2012). Interventions and programs need to address the root causes of structural inequalities and social determinants of health that are at play within these communities (Robinson et al., 2012).

### **Non-Urban/Rural Residents**

Rural individuals face situations and barriers regarding HIV care that are distinct from urban individuals. The lifestyle and general living conditions they experience can exacerbate feelings of social isolation and loneliness (Hubach et al., 2015). Recent studies indicate stigma, discrimination and loneliness may be higher among rural men who have sex with men (MSM) when compared to urban MSM populations (Hubach et al., 2015). Combined with previous

studies that have implicated sexual behavior as a coping mechanism for rural MSM, there may be extra pressures for rural MSM to engage in high-risk behaviors (Hubach et al., 2015).

### **Demographics**

Utah, geographically, is extremely rural with 98.9 percent of the land mass qualifying as rural (U.S. Census, 2010). However, population-wise, Utah has a very small percentage of rural residents. The U.S. Census estimates only 9.42 percent of Utah residents reside in rural areas. This is because the majority of Utahns reside in urban areas along the Wasatch Front.

### **Barriers to Care**

As mentioned above, negative stigma surrounding HIV and AIDS and particularly HIV status can negatively influence HIV care. In rural communities, this HIV-related stigma may be particularly intensified (Hubach et al., 2015).

Geographic barriers also exist. Nationally, for rural persons, the average roundtrip drive to an infectious disease physician may be 86 miles or more (AIDS Action Foundation, 2006). Also, the quality of care available in these areas is an issue as some physicians have treated fewer than ten people living with HIV (AIDS Action Foundation, 2006).

### **Best Practices**

Given that loneliness and stigma are heightened among rural populations, providers and practitioners working with rural HIV populations should incorporate evaluations of loneliness and HIV-related stigma in their care (Hubach et al., 2015).

Programs and interventions aimed at rural populations should work to reduce discrimination, bring HIV specialists to rural patients and create support systems that can combat the social isolation and stigma experiences by rural PLHIV (AIDS Action Foundation, 2006). The *Connecting to Care* workbook published by the AIDS Action Foundation (2006) suggests

rural interventions such as home-based treatments, support group socials, mail-based care, travelling HIV clinics, radio programs, case management, videoconferencing, and brown-bag lunch programs. Overall, specialized and novel treatments and interventions may prove useful for public health professionals working with rural PLHIV. For areas without access to medical doctors, research has shown nurse, peer, even volunteer models have similar outcomes as traditional doctor models (Thompson et al., 2012).

### **Discussion**

Engagement in HIV care begins at the testing site (Cargill, 2013). The barriers and best practices discussed above need to be addressed at all levels of HIV care but particularly at testing facilities. Timely entry into HIV care is essential for effective antiretroviral therapy and improved survival (Thompson et al., 2012; CDC, 2012). Thompson et al. (2012) recommend individual-level monitoring of treatment entry and retention because this factor is so important to HIV care and outcomes.

Many of the suggested best practices for working with the vulnerable and underserved populations discussed here are very similar or overlapping. The two most common topics were tailoring HIV treatments to specific subpopulations and using case management to integrate multiple levels of treatment. Tailoring treatments allows for specialization, individualization and personalization that is necessary for reaching and engaging underserved communities. This approach also relates to the increased use of native languages. Case management was called upon a number of times for its ability to integrate and facilitate multidisciplinary approaches to HIV care. In addition, a number of authors directly call for or allude to, holistic approaches to HIV care; that is seeing the patient as a complete individual and addressing all factors affecting their HIV care. Furthermore, the use of peers or peer navigators was suggested a number of

times; as was increased use of technology or multimedia systems. Lastly, the concept of stigma was discussed in relation to all vulnerable and underserved populations. This included stigma related to HIV and AIDS as well as stigma related to the other facets of their identities, such as their immigrant status, ethnicity, literacy level or disability status.

As for actually reaching these populations in need, a thorough examination of their daily lives, living experiences and lifestyles may prove useful for identifying areas open for engagement. For example, do rural households typically have internet access? If so, maybe a targeted internet campaign would be useful in reaching them. For Native Americans living on reservations, highly frequented public buildings should be identified. Perhaps a poster or flyer campaign at those locations would prove successful. In Utah, a number of programs help disabled persons find employment (Chambless, McCormick & McIlvenna, 2013). These programs could be enlisted to help identify disabled persons also in need of HIV care.

Furthermore, individuals can generally be trusted to act as experts on their own experiences. Therefore, it may prove useful to solicit assistance from individuals who are currently engaged in care to help reach other members of their communities. For example, it could be as simple as asking how they were initiated into care and what suggestions they would have in initiating their compatriots who currently have unmet needs. The best resources are often the individuals themselves. Additionally, soliciting this information from an individual in care empowers them, empowerment positively affects self-efficacy and research has shown self-efficacy predicts positive HIV treatment outcomes and combats the negative effects of low health literacy (Wolf et al., 2006; Cargill, 2013).

A number of “enabling factors” have been identified in the literature that positively affects patient engagement in general: health insurance, transportation, social support, self-

efficacy, resiliency, easing of structural barriers, low-effort interventions such as brochures and pill boxes, incentives, peer navigation, and multidisciplinary team approaches (Cargill, 2013; Thompson et al., 2012). Any of these factors can be applied to any subpopulation affected by HIV and AIDS regardless of their particular backgrounds. The key is to modify them to fit the population, tailoring the programs to address the specific barriers encountered as discussed above. Also, combinations of interventions have shown useful. Thompson et al. (2012) specifically call for combining adherence tools and reminder devices with education and counseling.

### **Limitations**

There exists one distinct and looming disadvantage to discussing vulnerable and underserved populations discretely and separately as done in this review. The research shows many individuals are members of multiple subpopulations (Aguilar-Gaxiola et al., 2008; Cargill, 2013; Robinson et al., 2012; Gakumo et al., 2015). Just because an individual identifies with one vulnerable population does not preclude their other identities from affecting their lives or their HIV care.

Many of the articles cited in this literature review are not Utah-specific. In fact, a number of articles are not U.S.-specific. Care was taken to not relate inapplicable information to Utah residents and situations, however as the research regarding Utah is limited some level of extrapolation was necessary.

This literature review should not be considered exhaustive. There are other populations affected by HIV and AIDS, beyond the vulnerable and underserved populations discussed here, that require their own unique approaches and considerations. For example, incarcerated or

formerly incarcerated populations, older adults and youth populations have distinct and unique factors affecting their HIV risk and their treatment as PLHIV but were not discussed here.

### **Conclusion**

Many similarities exist among the vulnerable population discussed above, in terms of HIV and AIDS treatment and care. Namely, each population requires further research specific to Utah. Secondly, the importance of tailoring programs, interventions and care to vulnerable populations cannot be overstated. A number of similar best practices were suggested for each population including tailoring and individualizing interventions, case management, involving community members themselves in program design, integrating health care, and viewing an individual as a whole person.

While extra attention should be provided to vulnerable HIV and AIDS populations, the rest of the HIV and AIDS population should not be forgotten. For example, in their study of a University of Utah HIV Clinic, Simonsen et al. found many routine, preventive services lacking among women with *fewer* socio-demographic risk factors (Simonsen et al., 2014). This implies providers were accurately identifying high-risk women but to the detriment of other women at slightly less risk.

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