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# Stigma

HIV AND HCV  
Discussion Paper



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ISBN: 978-1-927110-33-1

## Introduction

Stigma associated with HIV and HCV represents a global crisis, causing needless harm to millions of adults, youth and children. Stigma refers to negative attitudes toward a specific person/group, behaviours, social class, health conditions, etc. Closely related to stigma is discrimination, which is often the outcome of stigma whereby a person or group of people are intentionally disadvantaged or mistreated because they are identified as having a stigmatized characteristic. People living with HIV are one of the most stigmatized populations in the world. This viral infection is most often transmitted through sexual activity or injection drug use, the former often stigmatized outside of heterosexual or partnered contexts and the latter almost universally stigmatized. Likewise, Hepatitis C (HCV) is associated with injection drug use and therefore highly stigmatized.

The colonial roots of Canadian society involve a racist ideology that continues to stigmatize and perpetuate discriminate against Indigenous peoples. This is multiplied for those living with HIV and/or HCV as well as for women, those living in conditions of low income and those using injection drugs. Stigma and discrimination of Indigenous people living with HIV and/or HCV becomes potentially life threatening when it occurs within health care environments, resulting in diminished care, treatment and support. Indigenous people living with HIV and/or HCV may also face stigma and discrimination in their communities of origin, requiring them to leave home, thereby distancing them from critical family and social supports.

The burden of stigma is detrimental to overall health and wellness. In particular, mental health is negatively affected by stigma, often leading to anxiety and depression. Unfortunately, stigma can sometimes become internalized, causing feelings of shame and fear of disclosure, which acts as an additional barrier to accessing care, treatment and support.

Response to stigma occurs at individual, community, systems and structural levels. Indigenous people living with HIV and/or HCV often seek both individual and family centered support to deal with the emotional, mental and relational impacts of stigma and discrimination. Organizations and communities have developed interventions aimed at reducing HIV and HCV stigma by providing accurate information and encouraging empathy for people who are infected or affected. This has included development of the GIPA and MEPA principles that encourage greater and meaningful engagement with those living with HIV in the development and implementation of programs and services intended to serve them. Within health care environments, stigma is being addressed through awareness campaigns, while cultural safety programs attempt to reduce race-based discrimination. Finally, but by no means least importantly, is a growing global discourse that identifies racism as an important determinant of Indigenous peoples' health. Anti-discrimination legislation and reconciliation commissions are attempting to mend the relationship between Indigenous peoples and settler societies, thus addressing an crucial layer of stigma experienced by Indigenous people living with HIV and/or HCV in Canada.



## **Epidemiology of HIV and HCV among Aboriginal Peoples in Canada**

**HIV:** In 2011, approximately 390 Aboriginal people<sup>1</sup> acquired a new HIV infection, representing 12.2% of all new HIV infections that year. The categories of HIV exposure for the Aboriginal population in 2011 include: intravenous drug use (IDU) (58.1%), heterosexual contact (30.2%), men who have sex with men (MSM) (8.5%) and MSM-IDU (3.1%), compared with IDU (63.4%), heterosexual contact (28.3%), MSM (6.0%) and MSM-IDU (2.4%) in 2008. Aboriginal people also represented 8.9% of those living with HIV during 2011, which was an increase of 17.3% from the 2008 estimate (Public Health Agency of Canada (PHAC), 2014a). HIV has had a considerable impact on Aboriginal females and youth. “Between 1998 and 2012, nearly half (47.3%) of all positive HIV test reports among Aboriginal people were females, compared with 20.1% of reports for people of other ethnicity.” Likewise, “almost one-third (31.6%) of the positive HIV test reports from 1998 to 2012 among Aboriginal people were youth aged 15 to 29 years old, compared with 22.2% among those of other ethnicities” (PHAC, 2014a, p. 1).

**HCV:** In 2011, the Public Health Agency of Canada (PHAC) estimated that between 0.64% and 0.71% of Canadians were living with chronic Hepatitis C Virus (HCV) infection, 44% of them undiagnosed. Between 2002 and 2008, the rate of HCV diagnosis was 4.7 times higher among Aboriginal people than those of other ethnicities (Minuk, O'Brien, Hawkins, Emokpare, McHattie, Harris, . . . Uhanova, 2013; PHAC, 2014b). Women represent 48.7% of Aboriginal HCV cases, compared to 33.9% among females among other ethnicities (PHAC, 2014b). A slightly lower prevalence (4.2 times higher) was reported for Aboriginal youth who are street-involved (PHAC, 2014b). However, they are at elevated risk, as approximately 27% of Aboriginal street-involved youth have reported ever injecting drugs, which was the single strongest predictor of HCV infection (Callacombe, 2016; PHAC, 2014b).

**HIV and HCV:** Co-infection of HCV and HIV has become increasingly common, occurring among approximately 30% of people globally and 20% of those living in Canada (Rourke, et al., 2011). Sadly, 10% of street involved youth with HCV also test positive for HIV and over 97% have been previously diagnosed with a sexually transmitted infection (PHAC, 2014b). Among Aboriginal people who have previous or current HCV infection, and who also use injection drugs, 24% were positive for HIV (PHAC, 2014b). Compared with those who are HIV mono-infected, co-infected individuals are more likely to utilize healthcare services, yet less likely to be on anti-retroviral treatment. They also report higher levels of depression, homelessness, poor quality of life and poor health outcomes (Rourke, et al., 2011).

### **Stigma /Discrimination**

#### **Stigma**

The Greeks used the word ‘sigma’ to refer to a mark on a person’s body that indicated something unusual and bad about them (Duffy, 2005). In 1967, sociologist Erving Goffman defined social stigma as emerging from “an attribute that links a person to an undesirable stereotype, leading other people to reduce the bearer from a whole and usual person to a tainted, discounted one”

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<sup>1</sup> **Aboriginal people...4.3% of the Canadian population – will complete one I know above term**

<sup>2</sup> “The first and second epidemics of AIDS are considered to be the spread of HIV infection and subsequent development of AIDS cases” (Connor, 1989, p. 95)



(cited in Stuber, Meyer, & Link, 2008, p. 11). People are stigmatized because they possess a moral, physical, mental, or behavioural feature or features considered unacceptable, unusual, feared or unattractive within a given family, community, culture or society (Duffy, 2005). Religious beliefs are often at the root of stigma, particularly as it related to certain sexual behaviours and drug use (Room, 2005).

Social identity is defined as a person's sense of who they are based on group membership(s); stigmatizing labels are intended to identify those whose social value is considered diminished within those groups (Duffy, 2005). Stigmatized people are viewed as substantially 'different from the rest of us', making it easier to discriminate against them (Duffy, 2005). Those attempting to justify stigma and discrimination often make claims about the value of maintaining social stability by excluding 'undesirables'. Ironically, this form of societal control inevitably breeds deep social divisions rather than cohesion (Parker & Aggleton, 2003; World Health Organization, 2016).

Stigma is closely linked to the production and reproduction of social difference (Mill, Edwards, Jackson, MacLean, & Chaw-Kant, 2010; Parker & Aggleton, 2003), so that individuals are less likely to stigmatize someone in their own social network. For instance, those who live in poverty rarely stigmatize poverty; likewise few injection drug users stigmatize others engaged in the same behaviour (Room, 2005).

In many cases, stigma is intended to deter people from engaging in certain behaviours (e.g. sex work, drug use). However, in order to fully understand this social process, we must view it as primarily a mechanism of inequity and exclusion (Stuber, Meyer, & Link, 2008). Stigma has more to do with the expectation that everyone will reflect a socially constructed ideal, which for many is difficult (e.g. wealth) or impossible (e.g. race) to obtain (Room, 2005). Many people believe that stigma is fueled by dominance and oppression, involving the struggle for power and privilege between stigmatized and non-stigmatized people (Earnshaw et al., 2013). Thus, stigmatizing rhetoric tends to focus on the most extreme or "problematic" cases in an attempt to justify discrimination (Room, 2005).

Stigma can occur within many contexts including: individual relationships, community and employment networks, as well as organizations such as health and social services, policies, and laws (Logie, James, Tharao, & Loutfy, 2011). Although the social processes of stigma are remarkably similar across diverse contexts, the roots of stigma are subject to the beliefs, attitudes and social norms of a given group or time in history (Stuber, Meyer, & Link, 2008). For instance, some cultures fully accept diverse sexual orientations, while others stigmatize same sex relationships. Education also appears to influence stigma, as highly educated persons tend to have less stigmatizing beliefs (Wolitski, Pals, Kidder, Courtenay-Quirk, & Holtgrave, 2009).

It is important to understand the concepts related to stigma, as some represent its roots and others its consequence. Stereotyping refers to a broad representation of an entire group of people based a shared characteristic (e.g. being Indigenous or having HIV) (Kanahara, 2006) as well as the inaccurate and unfair belief that all people with a particular characteristic are the same in every other way (Merriam-Webster, 2016). Prejudice has been described as "an aversive or hostile attitude toward a person who belongs to a group, simply because [they] belong to that group, and are therefore presumed to have the objectionable qualities ascribed to the group" (Allport, 1958,



p. 7, cited in Stuber, Meyer, & Link, 2008, p. 352). Marginalization occurs when a group of people is excluded from participation in society and may also be subjected to deprivation (Speight, 2007). Stereotyping can bring about stigma and prejudice, which can lead to discrimination and marginalization.

## **Discrimination**

Stigma and discrimination are defined differently, yet we tend to conflate the two terms and use them interchangeably (Mill et al., 2010). Discrimination refers to the behavioural expression of stigma (Earnshaw et al., 2013). It is sometimes referred to as enacted stigma, and is performed through a number of social processes that begin with labeling an individual based on a devalued (e.g. being Indigenous) or non-conforming (e.g. being Two Spirit or gay) attribute, often accompanied by stereotyping and inevitably treating them poorly in multiple ways (Earnshaw, et al., 2013).

The mechanisms of discrimination include “exposure to negative attitudes, structural and interpersonal experiences of discrimination or unfair treatment, and violence perpetrated against persons who belong to disadvantaged social groups” (Stuber, Meyer, & Link, 2008, p. 352), as well as negative media images and judgmental discourse (Butt, Paterson, & McGinness, 2008), all of which leads to marginalization in which the stigmatized person not only experiences discrimination but often lives in anticipation or fear of it (Hutton, Misajon, & Collins, 2013). Social exclusion is a common form of discrimination that is sometimes used to enforce social norms or ‘acceptable’ behaviours or simply to enact stigma (Golden, Golden, Conroy, O’Dwyer, & Hardouin, 2006; Palamar, Halkitis, & Kiang, 2013).

## **HIV and HCV Stigma**

During the beginning of the AIDS epidemic, Dr. Jonathon Mann, founder of the World Health Organization’s Global Program on AIDS, claimed that a third AIDS epidemic<sup>2</sup>, one that would involve social, cultural, economic and political denial, blame, stigma and discrimination would evolve from the epidemic of AIDS as a medical condition (Fee & Parry, 2008). In 1990, the Panos Institute made a similar statement that HIV would challenge “our compassion, our judgment, and our humanity” (Panos Institute, 1990, p. ii). Unfortunately, although HIV stigma has diminished over the intervening decades (Wolitski, Pals, Kidder, Courtenay-Quirk, & Holtgrave, 2009), HIV-positive people continue to experience stigma and discrimination and we all continue to struggle against the overlapping forces of racism, classism, and homophobia that have shaped the HIV crisis (Chambers, Rueda, Baker, Wilson, Deutsch, Raeifar, E., . . . Stigma Review Team, 2015; Gilbert, et al., 2015; Logie, James, Tharao, & Loutfy, 2011; Visser, 2012).

Human disease holds powerful cultural meanings that can stigmatize a person as clearly as a “the yellow Star of David sewn to the sleeve of a Nazi concentration camp victim” (Kleinman, 1988, p. 159, cited in Duffy, 2005). The Euro-western biomedical model of health emphasizes control over individual bodies, with little consideration given to social determinants of health like poverty. Subsequently, those who become sick are often blamed for losing control of their

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<sup>2</sup> “The first and second epidemics of AIDS are considered to be the spread of HIV infection and subsequent development of AIDS cases” (Connor, 1989, p. 95)



bodies, particularly when a stigmatized behaviour like sex or drug use is linked to their illness (Duffy, 2005; Earnshaw et al., 2015).

HIV is a highly stigmatized illness. In fact, several studies have discovered higher levels of stigma associated with HIV than with cancer or diabetes (Herek, 1999; Mill, Edwards, Jackson, Austin, MacLean, & Reintjes, 2009; Mak, Cheung, Law, Woo, Li, & Chung, 2007). Some of this stigma is based on misconceptions about HIV transmission and overestimates of contagiousness. However, there are several other characteristics attributed to HIV that increase the likelihood that PHAs<sup>3</sup> will be stigmatized, including: association with violating moral norms, sexual transmission, and association with marginalized identities (e.g. gay men, prisoners, sex workers and Aboriginal people) (Mill et al., 2010). The association of HIV and HCV with stigmatized behaviours, further compounds stigma (Baker, Wilson, & Winebarger, 2004). In particular, both HIV and HCV are associated with injection drug use, which is a distinctly stigmatized behaviour (Golden et al., 2006; Hutton, Misajon, & Collins, 2013; Jiménez, et al., 2011).

HIV and HCV stigma discourse has been shaped by social norms around acceptable forms of sexuality and substance use (Hutton, Misajon, & Collins, 2013) and heavily laced with themes of ‘protecting public morality and health’ by socially isolating those who are infected (Golden et al., 2006). Whether consciously or unconsciously, many people believe that transmission can be voluntarily controlled through behaviour modification and see stigma as an appropriate deterrent to behaviours that might lead to infection (Hutton, Misajon, & Collins, 2013). According to this logic, those who contract HIV or HCV are justifiably held responsible for their infection and for putting others at risk.

HIV and HCV stigma arises from deep social roots that produce and spread fear, dismissal and sometimes hatred of those who are stigmatized (Parker and Aggleton, 2003; Tanny, Naar-King, & MacDonnel, 2011). In fact, the epidemic is sustained “largely because of the social organization that supports its propagation, not simply because of the biological characteristics of the causative agent” (Basset & Mhloyi, 1991, p. 144). Researchers have also discovered that socially produced inequities such as poverty, unstable housing, and racism not only increase exposure to and harms of HIV and HCV, but also influence the degree, type, and impact of associated stigma (McCall, Browne, & Reimer-Kirkham, 2009; The Cedar Partnership, 2008; Jongbloed, Thomas, Pearce, Christian, Zhang, Joeques, Schechter, & Spittal, P.,...the Cedar Project Partnership, 2015).

### **Contextualizing HIV and HCV Stigma**

HIV and HCV stigma is a global phenomenon. However, its nature, pervasiveness, and expression differ across cultural contexts (Parker & Aggleton, 2003). For instance, behaviours known to increase exposure to HIV (i.e. MSM) are more stigmatized in certain cultures than others. The experience of stigma and discrimination can also vary depending on the size of the epidemic and therefore, the perceived threat of exposure (Earnshaw et al., 2013). Although HIV stigma does exist within the gay community, MSM may experience less stigma within this community as a result of the extended and collective experience of HIV and AIDS (Wolitski et

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<sup>3</sup> The term PHAs is used in this paper when referring to research and literature about People Living with HIV/AIDS that is not specific to Aboriginal people living with HIV/AIDS but is also relevant to them.



al., 2009). Similarly, HCV stigma within injection drug using communities is rare (Golden et al., 2006).

At the root of APHA-directed stigma is a toxic blend of racism, colonialism, classism, and disease stigma (Reading, 2014; McCall, Browne, & Reimer-Kirkham, 2009; Treloar, Rance, & Backmund, 2013). Grounded in colonialism and racism, it begins with deeply held beliefs that position Aboriginal people as the ‘demonized’ other (Bourassa, McKay-McNabb, & Hampton, 2004; de Leeuw, Kobayashi, & Cameron, 2011). These beliefs fuel stereotypes about widespread poverty and violence among Aboriginal people (de Leeuw, Kobayashi, & Cameron, 2011) as well as the perception that Aboriginal identity is associated with addictive behaviour (Reading, Brennan, & Masching, 2013).

Stigma is enacted in a variety of interpersonal and systemic environments. On an interpersonal level, APHAs experience judgmental treatment (Cain, Jackson, Prentice, Collins, Mill, & Barlow, 2013; McCall, Browne, & Reimer-Kirkham, 2009) in the sense that they are asked disrespectful questions (e.g. if they are on disability or social assistance) yet seldom asked about their job or career (Green, Ion, Beaver, Nicholson, Derr, & Loutfy, 2015). In one study, a service provider recounted how practitioners can be invasive in their approach with Aboriginal women, asking personal questions about sexual activity, number of children, or state of housing, that are not asked of non-Aboriginal women (Reading, Brennan, & Masching, 2013). APHAs also describe being excluded, either directly or indirectly, from decisions about their treatment and care (Mill et al., 2010).

### **Historical and Socio-Political Context**

Most scholars agree that any discussion of HIV and HCV among Aboriginal peoples must be informed by the unique historical context within which these epidemics have evolved. In particular, it is critical to consider the legacy of colonization, forced resettlement, loss of traditional lands, assimilation policies, racism, economic and cultural discrimination, as well as genocidal child ‘welfare’ systems (Adelson, 2005; The Cedar Project Partnership; Mehrabadi, Paterson, Pearce, Patel, Craib, Moniruzzaman, Schechter, & Spittal, 2008; Mill et al., 2010; Reading, Brennan, & Masching, 2013). Residential school attendance has been closely linked to the transmission of collective trauma over several generations, which continues to negatively impact the health and well-being of Aboriginal peoples (Barlow, 2009; Chandler & McGregor, 2014; The Cedar Project, 2008; TRC, 2015). Adelson (2001) refers to this collective, “institutionalized and ultimately invisible suffering...as the ‘soft-knife’ of long-term oppression” (p. 77, cited in McCall, Browne, & Reimer-Kirkham, 2009).

### **Economic Context**

In 2005, rates of poverty among Aboriginal people (on and off reserve) in Canada were estimated at 18.7% for families and 42.8% for individuals (Parliament of Canada, 2009). Researchers and community activists agree that Aboriginal poverty is often a precursor to HIV and HCV. The mechanisms are thought to be colonialism, racism, residential school legacy, intergenerational trauma and abuse, followed by coping through drug use and/or high-risk sexual activity, which can result in exposure to HIV and HCV (Hoffman-Goetz, Friedman, & Clarke, 2005).





Homelessness and unstable housing are also a reality for some Aboriginal people living with HIV and/or HCV, who face unjustifiable blame - not just for their unstable housing but also for their HIV or HCV status (Wolitski et al., 2009). Mill et al., (2010) claim that, possessing the 'social capital' of whiteness, higher education, and middle class can provide a great deal of protection from the affects of HIV [and HCV] stigma. Thus, it is no surprise that the challenge of poverty, added to the individual, systemic and structural oppression already faced by Aboriginal peoples, greatly magnifies the experience, impact and capacity to cope with HIV and/or HCV stigma (ibid).

### **Gendered Context**

Researchers seeking to understand why Aboriginal women utilize anti-retroviral therapy (ART) less often and die of AIDS sooner than the general population, must consider the uniquely intersecting inequities experienced by this segment of the Aboriginal population (Benoit, Zadoroznyj, Hallgrimsdottir, Treloar, & Taylor, 2010; McCall, Browne & Reimer-Kirkham, 2009). Aboriginal women not only face sexism and gender discrimination, but also intersecting and racialized social, economic, and political injustices (Adelson, 2005; Logie, James, Tharao, & Loutfy, 2011; McCall, Browne, & Reimer-Kirkham, 2009). The poverty and social exclusion experienced by many Aboriginal women often generates trauma and, combined with a lack of supportive networks, can increase exposure to HIV and HCV (Logie, James, Tharao, & Loutfy, 2011; McCall, Browne, & Reimer-Kirkham, 2009).

Sexual violence is a strong predictor of exposure to HIV. Yet, policies and programs aimed at reducing HIV exposure among Aboriginal women often fail to consider the significance of sexual trauma (Hawkins & Reading, 2009; The Cedar Project, 2008) Sadly, multiple forms of violence against Aboriginal women are widespread in colonized countries like Canada, the US and Australia (Benoit et al., 2009; Etter & Palmer, n.d.; Hawkins & Reading, 2009; Prentice, 2015). The consequence of this violence is disproportionately high rates of posttraumatic stress and depression, as well as attempts at coping through substance abuse and unsafe sexual activities, sometimes resulting in HIV and/HCV infection (Currie, Wild, Schopflocher, Laing, Veugelers, & Parlee, 2013; Varni, Miller, & Solomon, 2012).

### **Health Services**

People living with HIV and/or HCV repeatedly report that health care settings are one of the most common sites of stigma (Treloar, Rance, & Backmund, 2013). Within and outside the HIV context, many Aboriginal people experienced discrimination in the health care system (Cain et al., 2013, Reading, 2014). Unfortunately, rather than promoting the health of Aboriginal people, particularly those living with HCV or HIV, health care environments that involve stigmatizing treatment actively disengage them from future care, thus undermining potentially positive health outcomes (Treloar, Rance, & Backmund, 2013).

On a more systemic level, APHAs report feeling as though they do not receive the same quality of health care service as non-Aboriginal PHAs (Cain et al., 2013), while others describe how services seem to be deliberately slow (Mill et al, 2009). Indeed, several studies have confirmed that as few as half as many Aboriginal people are referred to a specialist or specialized treatment as non-Aboriginal patients (Kressin & Petersen, 2001; Shah, Gunraj, & Hux, 2003). Bresee et al.



(2014) found that First Nations patients were less likely to receive angiography within one day after acute Myocardial Infarction than non-First Nations patients. This discrimination within health care settings can also be intensified by multiple stigmas related to sexuality, sex work and gender. For instance, HIV positive Aboriginal women report that HIV services are rarely tailored to meet their specific gendered needs (Logie, James, Tharao, & Loutfy, 2011) and that they often carry the additional burden of protecting their children from stigma, as well as being labelled ‘a bad mother’ (Greene, Ion, Beaver, Nicholson, Derr, & Loutfy, 2015).

### **Aboriginal Community HIV and HCV Stigma**

It is important to note that the burden of stigma experienced by Aboriginal people living with HIV and/or HCV varies as a result of attitudes and norms within their own communities as well as the strength of their social networks (Mill et al., 2010). Far too many APHAs describe how community-level stigma has forced them to leave or otherwise disconnect from their home (McCall, Browne, & Reimer-Kirkham, 2009; Monette, Rourke, Gibson, Bekele, Tucker, Greene, . . . Positive Spaces, Healthy Places Team, 2011; Zoccole, et al., 2005). Community-level discrimination can include violence but typically involves shunning, the withdrawal of family members, friends and co-workers as well as exclusion from community events, often prompted by misconceptions about how HIV and HCV are transmitted (Hawkings & Reading, 2009; Jackson, Reimer, & Canadian Aboriginal AIDS Network, (CAAN), 2008). For many, widespread knowledge of their diagnosis can create barriers to accessing community health and social services, resulting in a lack of support and unstable housing, ultimately affecting their ability to manage their illness (Jackson et al., 2008; Mill et al., 2010). Regrettably, widespread HIV and HCV stigma within Aboriginal communities also creates barriers for youth in feeling safe to access resources around sexual health and testing for HIV and sexually transmitted infections (Larkin, Flicker, Koleszar-Green, Mintz, Dagnino, & Mitchel, 2007; Saewyc, Clark, Barney, Brunanski, & Homma, 2013).

Community-level discrimination is particularly relevant for gay or Two-Spirit people who face sexualized stigma from community members who have adopted Euro-western prejudices about diverse sexual and gender expressions (Jackson et al., 2008; Saewyc, Clark, Barney, Brunanski, & Homma, 2013). Homophobia- and transphobia-based discrimination, harassment, bullying, and violence in home communities can motivate Two-Spirit and gay youth to migrate to cities, where they often encounter racism, violence, and homelessness, all of which heighten their exposure to HIV and HCV (Saewyc, Clark, Barney, Brunanski, & Homma, 2013). In a study involving 86 Aboriginal men who self-identify as gay or Two-Spirit, most reported having experienced discrimination based on their sexual orientation, with approximately 25% being the victim of physical violence, including sexual assault (Zoccole et al., 2005).

The degree of tolerance toward gay/lesbian/bisexual or Two-Spirit Aboriginal persons varies among and within Aboriginal communities, but has a decidedly negative impact on how those who test positive are accepted and treated by community members, family and medical staff. It may also determine whether they seek help because HIV/AIDS is associated with same-sex behaviour in communities where there is intense homophobia, so some may never be diagnosed (Klassen-Westerder, n.d.). As well, in communities where hostility exists towards Two-Spirited people, Elders and other leaders may be reluctant to speak about the issue or provide support to those who are infected or affected (Zoccole, et al., 2005).



In 2005, researchers explored how HIV was represented in Aboriginal newspapers across Canada, exposing the stigma that many APHAs have reported in other studies. In particular, about one-third of these articles used stigmatizing terms such as “self-destructive, playing with fire, getting burned, dangerous life, wrecking havoc, [and] tragic” in describing sexual behaviours (Hoffman-Goetz, Friedman, & Clarke, 2005, p. ). In an analysis of 14 Aboriginal newspapers over a four-year time frame, between 50 and 60% of the articles emphasized unprotected sex as the primary risk behaviour in Aboriginal communities. Yet, heterosexual populations were not portrayed as being at high risk of exposure to HIV, while many of the articles emphasized male same-sex as the primary risk behaviour in contracting the virus (Hoffman-Goetz, Friedman, & Clarke, 2005), thus promoting misperceptions about HIV transmission within Aboriginal communities.

### **Racism and Social Determinants**

Race is a socially constructed concept that has taken root across the world to become one of the most destructive foundations of stigma and oppression. In 1735, a Swedish botanist named Carolus Linnaeus published a classification of four human races described as Europaeus (Europeans), Asiaticus (Asians), Americanus (American Indian) and Africanus (Africans), with Europeans positioned at the top of a racial hierarchy (Brace, 2005). It is important to note that no biological basis for these claims has ever been found. Yet, during the 17<sup>th</sup> and 18<sup>th</sup> centuries, European and American authors enthusiastically promoted a racial hierarchy, suggesting that Caucasians (i.e. white people) were superior to other ‘races’ in every way, particularly to those classified as African or American Indian (Graves, 2001). Thus, race became a widespread and erroneously accepted truth and racism a social reality.

Racism is defined as:

1. “a belief that cultural or individual differences between racialized groups are inherent;
2. a policy, system of government, etc., based upon or fostering such a doctrine; discrimination;
3. hatred or intolerance of another race or other races” (Dictionary.com, n.d.).

Since the time of first contact, Aboriginal peoples have been subjected to racism on interpersonal, systemic and structural levels (Alfred & Alfred, 2009; Reading, 2014; Royal Commission on Aboriginal Peoples, 1996). The additional layer of racial stigma for APHAs creates ‘multiple jeopardy’ in the sense that they endure discrimination not only based on HIV status, but on the basis of racialization as well as other stigmatized identities (Barlow, 2009; Cain et al., 2011; Stuber, Meyer, & Link, 2008).

Racial stereotyping of Aboriginal people occurs in a number of settings including health care, social services and justice (Bourassa et al., 2004; Reading, 2014). Within health care and social service settings, racial stereotyping severely undermines the quality of care treatment and support APHAs receive (CAAN, 2013; Greene et al., 2015). For instance, the *Trends and Issues Report* states that 33% of APHAs in Canada do not seek health services because they fear racial discrimination (2000). These findings have been replicated in recent studies (Currie et al., 2013; Hawkings & Reading, 2009; Reading, Brennan, & Masching, 2013).



Although there is substantial evidence linking inequitable social determinants to the disproportionate burden of HIV and HCV experienced by Aboriginal peoples, there is a marked absence of policy or media attention toward the structural determinants that create these inequities (Chandler & McGregor, 2014; McCall, Browne, & Reimer-Kirkham, 2009; UNAIDS, 2007). Likewise, research, programs and policies directed towards Aboriginal peoples living with HIV and/or HCV, often focus narrowly on “risk factors” such as sexual activity and addiction, while neglecting historical, structural and socio-economic determinants (Jackson et al., 2008; Reading & Wien, 2009; Zoccole, et al., 2005). There is a conspicuous absence of discussion about how Aboriginal people represents a young population, often living in geographically isolated communities or socially segregated neighbourhoods, typically facing relentless poverty, inadequate opportunities for education and employment, as well as limited community supports (Reading & Wien, 2009). There is also a dearth of attention paid to evidence that suggests a history of involvement with child welfare and residential transience may be associated with increased drug use and HIV (Longbloed et al., 2015). These intergenerational traumas often generate community and family conflict, which can lead to repeated migration, homelessness, street involvement, sex work, injection drug use, and incarceration - all familiar routes of HIV and/or HCV infection (Cain et al., 2011; Hawkings & Reading, 2009).

### **Stigma and Drug Use**

According to the Public Health Agency of Canada (PHAC) (2014b), approximately 113,000 people living in Canada inject drugs, representing 0.4% of the population 15 years and older. Drug use is more prevalent among street youth, those currently or formerly incarcerated, and people who are homeless (PHAC, 2014b). PHAC (2014a) estimates that approximately 13% of all new HIV infections in Canada are acquired through injection drug use; that estimate is much higher among Aboriginal people (58%). Injection drug use is the primary mode of transmitting HCV in Canada, with 66% of people who inject drugs and 28.5% of people who formerly injected drugs testing antibody positive for hepatitis C in 2011 (Challacombe, 2016). In 2012, PHAC reported that a greater proportion of Aboriginal people living with HCV report injecting drugs (67% vs. 53%). Within the general population, males are more likely to use injection drugs than females (Palamar, Halkitis, & Kiang, 2013). Yet, both *The Cedar Project* (Jongbloed et al., 2015) and *I Track* (PHAC, 2012) found that Aboriginal women living in urban areas are more likely to inject drugs than Aboriginal men. Current estimates reveal that, among those who inject drugs, co-infection of HIV and HCV affects 10% of non-Aboriginal people (PHAC, 2012) and 24% of Aboriginal people (PHAC, 2012).

### **Determinants of Drug Use**

Although injection drug use has been associated with higher levels of anti-social behaviour and psychiatric disorders (Shaw, Deering, Jolly, & Wylie, 2010), there is growing evidence that drug use is closely linked to social determinants that negatively impact psychological and emotional health, including: poverty, lack of education, substandard or unstable housing, unemployment, early childhood trauma, and unsafe physical environments (Chansonneuve & Aboriginal Healing Foundation, 2007; Reading & Wien, 2009). Depression has also been identified as a determinant of drug and alcohol use (Cain et al., 2011; CAAN, 2013). People suffering from depression report higher rates of drug and alcohol use as a source of self-medication (Ahern, Stuber, & Galea, 2007; CAAN, 2013). In addition to these determinants, substance use among Aboriginal





peoples has been linked to centuries of colonization, colonialism, racism, cultural genocide, social exclusion and ultimately intergenerational trauma (CAAN, 2013; Reading & Wien, 2009).

A single traumatic experience can have a profoundly damaging effect on psychological wellness. However, when multiple traumas are experienced, the damage is compounded and drug use can be viewed as a rational form of coping. Several studies have also demonstrated that a lifetime of trauma is strongly associated with drug and alcohol abuse (Palamar, Halkitis, & Kiang, 2013; Room, 2005; The Cedar Project, 2008). Among Aboriginal women, drug use can stem from the trauma of childhood abuse and survival sex work (Greene et al., 2015; Hawkings & Reading, 2009; The Cedar Project, 2008).

### **Injection Drug Use (IDU) Stigma**

The stigma and discrimination associated with HCV (and HIV within Aboriginal populations) is inextricably linked with injection drug use (Minuk et al., 2013; Treloar, Rance, & Backmund, 2013). In six studies in the US, Australia and Britain, participants claimed that, “illegal drug users should all receive less priority in health care”, because “the users’ behaviour contributed to their own illness” (Room, 2005, p. 147). IDU stigma is so powerful that it can persist even against former drug users (Teloar, Rance, & Backmund, 2013). In fact, HCV’s “association with illicit drug use is so pervasive that those who contract the virus through non-stigmatized means (e.g., contaminated blood products) often experience stigmatization regardless of the source of their infection” (Butt, Paterson, & McGinness 2008, p. 205). In a study involving 14 countries, ‘drug addiction’ ranked among the top 18 most stigmatized behaviours, being equally or more stigmatized than burglary (Room, 2005). “This societal symbolism of deviation as a sign of character weakness is one of the most vivid and isolating distinctions which can be made in a culture which attributes morality, success, and respectability to the power of disciplined will” (Room, 2005, p. 150).

Although stigma associated with injection drug use is almost universal, social judgment about substance use in general varies over time and across cultures (Room, 2005), (Palamar, Halkitis, & Kiang, 2013). Likewise, within cultures, substance use stigma may vary depending on who is using what drugs (Room, 2005). For instance, wealthy people using powdered cocaine is virtually ignored, while poor, racialized or marginalized people injecting heroin or crack cocaine is highly stigmatized (Ahern, Stuber, & Galea, 2007).

Loss of control continues to be the key theme in discourse about addiction, so that those who use injection drugs are seen as dangerous and irresponsible about their own health and the well being of others (, Paterson, & McGinness 2008; Room, 2005). Consequently, western society generally views people who are intoxicated as being unpredictable, disinhibited and potentially unsafe (Room, 2005). “At a minimum, to be stoned or drunk in specific circumstances—e.g. when about to drive a car, or as a parent looking after small children—is unacceptable to nearly everyone” (Room, 2005, p. 149).

Moralistic language (e.g. sinful) is often used to describe IDUs, and a diagnosis of HIV or HCV is seen as the predicable result of poor lifestyle choices (Hoffman-Goetz, Friedman, & Clarke, 2005). Indeed, injecting illicit drugs is largely viewed as a criminal issue rather than a health issue (Ahern, Stuber, & Galea, 2007; Nowgesic, Meili, Stack & Myers, 2015; Palamar, Halkitis,



& Kiang, 2013). For example, in the US, a family can be evicted from public housing if a member of that family is convicted of selling drugs (Room, 2005). However, activists and scholars argue that criminalizing injection drug use simply promotes stigma and discrimination, thus forcing people further to the margins of society and away from treatment, care and support. Labeling people who use injection drugs as irresponsible criminals also fosters less public concern for their well-being (Chandler & McGregor, 2014). Indeed, several researchers have discovered that even when people who inject drugs overcome the substantial barriers to accessing health care (e.g. fear of stigma, lack of transportation and support), they often face judgmental attitudes, disrespectful treatment, and overt discrimination by health professionals (Ahern, Stuber, & Galea, 2007; Nowgesic, Meili, Stack & Myers, 2015; Pauly, McCall, Browne, Parker, & Mollison, 2015).

### **Intersecting Stigma**

Although we typically focus on a single form of stigma (e.g. HIV), the experience of intersecting multiple stigmas is more often the case (Stuber, Meyer, & Link, 2008; Logie, James, Tharao, & Loutfy, 2011). Several researchers and scholars claim that stigmatizing behaviour is often linked to existing prejudices related to race, gender and social class that shape discrimination within diverse settings and relationships (Link & Phelan, 2006). Intersectional stigma is understood as “interlocking forms of oppression”, which can be identified as separate, but their power to impact peoples’ lives becomes much more apparent when viewed “as interactive and interdependent on each other” (Berger, 2004, p. 30; Earnshaw et al., 2015). Researchers have suggested that when stigmas interact, they produce synergistic experiences of oppression as well as exacerbate the harms of existing structural inequities (Herring, Spangaro, Lauw, & McNamara, 2013; Logie, James, Tharao, & Loutfy, 2011).

Intersectional stigma, sometimes referred to as layered or synergistic stigma, is common for APHAs as HIV stigma often intersects with other stigmas related to racism, sexism, homophobia, and trans-phobia (Earnshaw et al., 2015; Logie, James, Tharao, & Loutfy, 2011; Mill et al., 2010). Intersectional stigma is best understood as having a compounding rather than additive affect. In other words, in order to grasp the experience of total stigma, the effect of each additional stigma is multiplied, rather than merely added to the total burden (Earnshaw, et al, 2013).

### **Internalized Stigma**

Cumulative and unrelenting experiences of oppression and humiliation can gradually erode feelings of self-confidence and self-worth (Speight, 2007). Internalized or self-stigma has been described as the perception of diminished self-worth resulting from being seen as socially undesirable by others (Vogel, Bitman, Hammer, & Wade, 2013). It occurs when a member of a stigmatized group subscribes to negative attitudes and stereotypes about that group, and therefore themselves. The most damaging form of internalized stigma is associated with an unchangeable characteristic (e.g. being Aboriginal), as these beliefs can be accompanied by feelings of shame and unworthiness about one’s own character (Mak et al., 2007; Sheikh & McNamara, 2014). If the stigma is association with a behaviour (e.g. injection drug use), individuals might feel a sense of guilt and self-blame (Sheikh & McNamara, 2014), as if they deserve any negative outcomes



that might occur as a result of the behaviour. Ironically, this can even occur when the person does not feel as though they had control over the circumstances of infection (e.g. infection through blood transfusion) (Sheikh & McNamara, 2014).

Researchers have suggested that stigma doesn't have to be blatant or even traumatic for it to be internalized. "Small daily doses of personal devaluation usually suffice" (Speight, 2007, p. 130). Internalized stigma is not always recognizable or measurable and it typically involves more than a single person, often hiding in the minds and heart of families, communities and nations (Berger, 2009; Speight, 2007). Ironically, internalized stigma frequently moves beyond beliefs and feelings to become manifest in behaviour that demonstrates a devalued sense of self – e.g. drug use (Speight, 2007).

### **Internalized HIV and HCV Stigma**

It is important to acknowledge that stigma is not always internalized and many people who experience external stigma (including HIV stigma) have a positive self-image (Buseh & Stevens 2006; Hofer, Mizuno, Frajo-Apor, Kemmler, Rauch & Uchida, 2015). However, those living with HIV and/or HCV can internalize negative beliefs and feelings, leading them to feel personally and socially diminished by their illness (Earnshaw et al., 2015). In research about HIV, internalized stigma appears to be more common among people who have been recently diagnosed, by those who don't have access to formal or informal supports, and/or by those who don't know many other people living with HIV (Earnshaw, et al, 2013).

HIV stigma is primarily based on the belief that infection can be prevented, thus there is increased likelihood that responsibility for infection will to be attributed to PHAs' judgement and/or behaviour. These same beliefs can also be held by PHAs themselves, who assign self-blame for their HIV and/or HCV status (Mak et al., 2007; Wolitski et al., 2009). In addition to self-stigma of HIV and/or HCV, internalization of intersecting stigmas related to race, sexuality, incarceration and/or drug use could also have a devastating impact on APHAs' quality of life (Stewart, Mikocka-Walus, Harley, & Andrews, 2012; Earnshaw et al., 2015).

The internalization of racial stigma and stereotypes is all-to-common among ethno-racially marginalized groups in North America (Hipolito-Delgado, 2010; Dancy & Jean-Marie, 2014; Speight, 2007). In the case of Aboriginal peoples, centuries of structural racism, cultural genocide and Indian Residential Schools have created feelings of racialized shame, sometimes resulting in rejection of Aboriginal identity and culture (Berger, 2009). If we look "to the larger society to construct a sense of self, [Aboriginal people will] find negative images that serve to colonize and recolonize them" (Speight, 2007, p. 130). Thus, the added internalization of HIV stigma leaves many Aboriginal people feeling ashamed and inadequate (Cain et al., 2011; Cain et al., 2013; Currie et al., 2013).

A particularly pernicious form of stigma is the assignment of blame, which is often based on perceptions of character, which inform opinions about deservedness of negative outcomes, thus creating an intersection of blame and condemnation. Following a similar pattern, self-blame by APHAs can combine judgement about behaviour in the context of racial self-degradation (Sheikh & McNamara, 2014). Even among non-stigmatized groups such as victims of violence, self-blame has been directly linked to social messages about what they might have done to provoke or



escalate the attack (Sheikh & McNamara, 2014); this is particularly true of victims of sexual assault (Hawkings & Reading, 2009; Greeson, Campbell, & Fehler-Cabral, 2016).

The internalization of stigma may have the most destructive impact because it represents a wound to the very essence of who we are (Campbell & Deacon, 2006), influencing mental, physical and spiritual wellness. High levels of internalized stigma has been linked to: low self-esteem, anxiety, depression, reduced social support and feelings of control, as well as diminished self-care, including increased illicit drug use and high risk sexual behaviours (Dancy & Jean-Marie, 2014;; Dawson, et al., 2014; Simbayi et al. 2007; Stuber, Meyer, & Link, 2008) and decreased feelings of personal control (Earnshaw, et al, 2013).

The term self-schema refers to a person's beliefs, experiences and generalizations about themselves. This schema can be positive or negative and is formed during children and later in life. If someone is severely criticized during their early life, they might develop a 'defensive schema' as a result of their feelings of inferiority or unacceptability. Likewise, early experiences of abuse, neglect or rejection can severely impair the development of positive self-schemas (Jiménez, et al., 2011; Simbayi et al., 2007; Vogel et al., 2013). Those who suffer with diminished self-schema are more deeply affected by stigma, which represents yet another layer of rejection, thus multiplying the toxic effect on their self-schema (Jiménez, et al., 2011).

Stigma can also produce feelings of loneliness and isolation, which further damages one's self-schema and increases high-risk behaviours such as drug use and unsafe sexual activity (Jiménez, et al., 2011; Wolitski, Pals, Kidder, 2009). Researchers have also discovered a strong association between internalized stigma and depression among PHAs, particularly those who have a history of drug use (Earnshaw et al., 2015). It can deeply penetrate and erode the self-esteem of PHAs, interfering with their mental health (Jiménez, et al., 2011) and negatively affecting attitudes toward counselling (Vogel, Bitman, Hammer, & Wade, 2013). This is sometimes linked to fears of disclosure, which ultimately reduce social integration, increase social conflict and alter the perception of support (Earnshaw, et al, 2015; Mak et al., 2007).

Self-care or self-compassion – treating oneself with care and concern - plays a critical and powerful role in the management of HIV (Dawson et al., 2014). Researchers have found that internalized stigma can create a barrier to seeking or continuing mental health services, in an effort to avoid being further stigmatized as mentally ill (Vogel, Bitman, Hammer, & Wade, 2013). Alternatively, the presence of self-compassion seems to be linked to improved response to illness, including adherence to ARVs and other treatments (Dawson, et al., 2014).

Clearly, the root of internal stigma is external stigma. In fact, the internalization of stigma is widely recognized as a direct result of oppression. Once internalized, it is a formidable foe, requiring "battle on two fronts: the oppressor within and the oppressor without" (Bulhan, 1985, p. 123, cited in Speight, 2007, p. 129). In the absence of stereotyping, devaluing, rejection, censure and discrimination, internalized stigma simply does not exist (Sheikh & McNamara, 2014; Vogel, Bitman, Hammer, & Wade, 2013).





## **Impact/Burden of Stigma**

A critical mass of research confirms that HIV and HCV stigma is associated with a number of negative health outcomes and stressors that can also influence access to prevention, testing, treatment, care and support (Earnshaw, et al, 2013; Hutton, Misajon, & Collins, 2013; Sengupta, Banks, Jonas, Shandor Miles, & Corbie Smith, 2011; Stuber, Meyer, & Link, 2008). Those living with HIV and/or HCV also describe how the fear and effects of stigma leads them to conceal their HIV and/or HCV status, to blame themselves or others, and/or to alter their social relationships (Butt, Paterson, & McGinness, 2008; Drazic & Caltabiano, 2013).

In the case of employment, if PHAs' status becomes known, they often face restrictions to employment or must endure unfair treatment by co-workers and employers; they may be fired, be asked to quit or have their hours severely reduced (Earnshaw, et al, 2013). Unfortunately, many policies foster stigma against those who become infected, thereby hindering prevention, treatment, care and support. The most overtly stigmatizing policies are those, which segregate people who become infected (e.g. restricting HIV positive children from school or HIV positive people from immigration). Policies aimed at those seen to be "at risk" of HIV are also widespread. For example, drug policies that prohibit access to clean injection material or limit access to drug treatment actually foster conditions in which exposure to HIV and HCV is increased (Earnshaw, et al, 2013). Similarly, lack of policy attention, as was the case in North American during the 1980s, represents a subtle but powerful form of stigma – essentially ignoring those most likely to be exposed (Chandler & McGregor, 2014; UNAIDS, 2007).

### **Health**

There is a wealth of well-documented studies that link stigma and discrimination to the production of health disparities (Stuber, Meyer, & Link, 2008; Logie, James, Tharao, & Loutfy, 2011; Wolitski et al.,2009). For example, a review of 138 studies revealed that racism is closely associated with poor physical and psychological health, including HIV (Logie, James, Tharao, & Loutfy, 2011). More generally, HIV and HCV stigma has been linked to adverse impacts on quality of life, family life and employment/career (Drazic & Caltabiano, 2013; Treloar, Rance, & Backmund, 2013). Another review of 24 studies involving PHAs in North America discovered that HIV stigma is strongly associated with mental and physical health issues (Earnshaw, et al, 2013). Hutton, Misajon, & Collins (2013) discovered that poor social interactions had the strongest effect on PHAs' quality of life. This association includes the self-assessed mental and physical health of people living with HIV (Wolitski et al.,2009), as well as adjustment of those living with HCV, including: the perceived extent and effect of symptoms, diminished concentration, and problems related to work and social networks (Golden et al., 2006; Stewart et al., 2012).

Whether resulting from awareness/fear of stigma or from actual discrimination, people generally experience an emotional response to this form of oppression (Jiménez, et al., 2011). Responses tend to be personal and emotional, including feeling wounded, sad, ashamed, embarrassed, overwhelmed, guilty, defeated, and angry (Butt, Paterson, & McGinness, 2008; Jiménez, et al., 2011). Stigma, particularly in the context of HIV and HCV, can activate a stress response. A constant state of vigilance resulting from anticipated or felt stigma and discrimination can generate chronic stress, which can lead to other illnesses (Currie, et al., 2013; Stuber, Meyer, &



Link, 2008). In fact, when an illness is associated with psychological stress, people tend to report more symptoms and less overall wellbeing (Hutton, Misajon, & Collins, 2013), including HIV symptoms (Earnshaw, et al, 2013). Researchers have discovered that the stress of stigma and discrimination, especially when it is persistent and long-term, can negatively influence both the hormonal and nervous systems (Ahern, Stuber, & Galea, 2007; Stuber, Meyer, & Link, 2008). In the case of HIV and HCV, the unrelenting stress associated with stigma can interfere with neurological processes that generate feelings of balance and positivity even more so than illnesses themselves, sometimes causing severe pain and/or critical health risk (Hutton, Misajon, & Collins, 2013).

**Mental health:** In terms of health outcomes, many believe that mental health issues such as depression and anxiety are as important to consider as those that threaten physical health (Cain et al., 2013; Hutton, Misajon, & Collins, 2013). A number of studies have reported high rates of depression among people living with HIV (Cain et al., 2011; Cain et al, 2013; Sherr, Clucas, Harding, Sibley, E., & Catalan, 2011), and stigma has been identified as an important mental health determinant (Tanney, Naar-King, & MacDonnel, 2011). Similarly, research focused on HCV points to stigma as the strongest predictor of depression and anxiety, which rise with levels of stigma (Golden et al., 2006). Among those using injection drugs, discrimination and the distress it produces have also been associated with depression (Hutton, Misajon, & Collins, 2013). Unfortunately, depression is also linked to potentially health-harming behaviours such as substance use, non-adherence to treatment, and unsafe sexual activity (Hutton, Misajon, & Collins, 2013; Tanney, Naar-King, & MacDonnel, 2011).

### Help Seeking

**Health Care:** The cumulative impact of stigma and discrimination leaves many people living with HIV and/or HCV with a tainted view of the kind of treatment they can expect from others. In the case of health care, past experiences of disregard and disrespect justifiably contribute to the choices people make about whether or not to engage in the health care system (Earnshaw, et al, 2013; McCall, Browne, & Reimer-Kirkham, 2009; Reading, Brennan, & Masching, 2013). In reality, fears of HIV and HCV stigma within health care settings are not unfounded, as subtle and overt discrimination against those seeking treatment and care for HIV and/or HCV has been well documented (CAAN, 2013; Chandler & McGregor, 2014; Treloar, Rance & Backmund, 2013). For instance, HIV stigma has been linked to unnecessarily long waits in emergency departments, as well as outright refusal to provide care (Jackson et al., 2008; Reading, Brennan, & Masching, 2013). This is also true for people using illicit drugs, who often avoid seeking health care for fear of poor treatment or being reported to authorities (Ahern, Stuber, & Galea, 2007).

Several researchers have found that the fear of HIV and HCV stigma can lead people to avoid testing altogether. For those who are diagnosed, reluctance to disclose their status to others and delays in seeking treatment are also linked to stigma. Even when they do begin a regimen of medication, fear and negative mental health outcomes associated with stigma can interfere with adherence to treatment (Wolitski et al., 2009), particularly when medication cannot be obtained or taken openly (Reading, Brennan, & Masching, 2013). All of these stigma-related outcomes can ultimately contribute to the spread of HIV and HCV within social networks and communities (Hutton, Misajon, & Collins, 2013; Wolitski et al., 2009).



## Social Networks

It is clear that stigma and social rejection adversely affect PHAs' quality of life (Mak et al., 2007). Stigma can weaken social support structures by reducing social networks and increasing social conflict (Earnshaw, et al, 2013; McCall, Browne, & Reimer-Kirkham, 2009). This is particularly true when PHAs are rejected by friends, family and community; those who one typically turns to for love and support. High levels of stigma within social networks can be particularly damaging to feelings of connectedness, sense of one's role in the family and/or community, and hopes for the future (Hutton, Misajon, & Collins, 2013; Stewart et al., 2012).

Deliberate or unwitting messages of disappointment or discomfort can be conveyed through the expression on someone's face, the tone of their voice, or their body language, for example. These interactions can undermine relationships by negatively impacting PHA's sense of relational security (Hutton, Misajon, & Collins, 2013; Stewart et al., 2012). In fact, researchers have discovered that unsupportive social interactions with loved ones have a greater impact on mental health than supportive interactions with those same people. For this reason, PHAs often choose not to disclose within unsupportive social environments (Wolitski et al., 2009).

In the process of protecting themselves from negative social experiences, PHAs may unknowingly hinder support (Golden et al., 2006; Hutton, Misajon, & Collins, 2013). Fear as well as actual discrimination prompts some people living with HIV and/or HCV to withdraw from their social networks and isolate themselves, which actually further harms their mental health (Ahern, Stuber, & Galea, 2007; Stewart et al., 2012). Not only does withdrawal and isolation fail to promote health, but it can also exacerbate the effects of stigma (i.e. depression, anxiety) and have negative implications for treatment and care (Ahern, Stuber, & Galea, 2007; Duffy, 2005).

## Response to Stigma

If we fail to acknowledge the structural, systemic and interpersonal origins of social judgment, stereotyping, and discrimination, we will also fail to address these powerful and complex determinants that shape the health and wellness of Aboriginal people living with HIV and/or HCV. Likewise, if we ignore the myriad manifestations of stigma and discrimination, we will likely 'miss the mark' when attempting to intervene. Lastly, but by no means least, we must develop, facilitate, and implement interventions aimed at supporting APHAs in a daily struggle to protect their mental, physical, emotional and spiritual health from the devastation wrought by unrelenting and intersectional stigma and discrimination.

Despite the tremendous impact HIV and HCV stigma has on individuals, families, communities and nations, it is surprising that there have been so few studies that explore the effect of anti-stigma campaigns and interventions. The findings of one such review of 48 interventions, from 28 countries, between 2002 and 2013 are not surprising, in that the most effective interventions involve multiple strategies that target both the source and manifestation of intersecting stigmas, as well as those that target structural, organizational, social, interpersonal and individual levels of stigma (Prinsloo & Greeff, 2016).



## APHAs

In the same way that anti-stigma strategies must be diverse, so too must interventions intended to address the impacts of stigma on APHAs who might experience internalized stigma, trauma, health issues and/or diminished self-care. It is important to reiterate that not all people living with HIV and/or HCV internalize stigma (Butt, Paterson, & McGinness 2008). For those who do, cognitive-behavioural interventions have been used effectively in acquiring coping skills to manage the effects of stigma as well as addressing depression, anxiety, stress and anger in people living with HIV and/or HCV (Sanjuan, Molero, Fuster, & Nouvilas, 2013; Stewart et al., 2012; Parker & Aggleton, 2003). Likewise, interventions such as counseling and group therapy, which are intended to assist in overcoming feelings of guilt and shame, can enhance self-compassion, both of which have been linked to decreases in drug use and unsafe sexual activity as well as increased disclosure to sex partners (Dawson, et al., 2014; Wolitski et al., 2009). There is also some evidence that reduced internal stigma might lead to improved treatment adherence (Sumari-de Boer, Sprangers, Prins, & Nieuwkerk, 2012; Vogel, Bitman, Hammer, & Wade, 2013). Engaging in Indigenous cultural practices and ceremonies with other APHAs, Elders and traditional knowledge holders has also led to enhanced feelings of self-worth, connection and self-determination for people living with HIV and/or HCV (Prentice, 2015).

### Anti-Stigma Activism and Campaigns

HIV literature has identifies stigma and discrimination as key targets for intervention (Sengupta et al., 2011; Vogel, Bitman, Hammer, & Wade, 2013). To date, more than 90% of countries around the world have programs aimed at reducing HIV stigma and discrimination (Hutton, Misajon, & Collins, 2013). The vast majority of those interventions are aimed at increasing acceptance of people living with HIV by the general public, including empathy strategies to enhance compassion, educational strategies to reduce contagion fears, and psychological strategies (e.g. skill building) to manage emotional responses to difference (Parker & Aggleton, 2003; Sengupta et al., 2011). The HIV stigma reduction framework developed by the *International Centre for Research on Women* (2013) underscores concepts such as knowledge, moral judgment, and fears as most amenable to intervention. Experts suggest that using more than one strategy has a greater impact (Sengupta et al., 2011) as does increasing contact with and testimonials from PHAs (Parker & Aggleton, 2003). Aboriginal organizations have undertaken several strategies to prevent the spread of HIV and HCV (Jackson et al., 2008; Pauktuutit, 2013 a&b) and the stigma associated with them. The Canadian Aboriginal AIDS Network has been recognized for taking a leadership role in addressing HIV related stigma and discrimination (CAAN, 2013; Jackson et al., 2008).

As early as the late 1980s, anti-stigma poster campaigns in Canada have attempted to inform and sensitize the public to the realities of HIV (Taylor, 2014) and beginning in the early 1970s, PRIDE parades and events around the world have tackled ant-LGBT stigma by promoting dignity and social justice and celebrating sexual and gender diversity. Aboriginal people who identify as gay, lesbian, bi-sexual, queer, Two-Spirit, etc. often join these celebrations or organize events of their own (PRIDE Toronto, 2016; Zoccole et al., 2005).



## GIPA/MEPA Principles

In 2001, 189 United Nations member countries endorsed the GIPA (Greater Involvement of People Living with HIV/AIDS) Principle as part of the *Declaration of Commitment on HIV/AIDS*. The GIPA Principle was developed to clarify the rights of people living with HIV to be actively involved in decisions that affect their health, particularly related to global, national, regional and local interventions (UNAIDS, 2007).

The rationale for GIPA is obvious – the involvement of people who have lived experience with HIV will improve the relevance, acceptability and effectiveness of programs and services intended to prevent or treat HIV as well as to care for and support those living with HIV. The benefits of GIPA are far-reaching, beginning with individual well being and reduced isolation of PHAs who are involved in the development and implementation of interventions. At the organizational and community level, authentic engagement with HIV positive people can reduce stigma and discrimination as people work toward a common goal (UNAIDS, 2007).

Since 2007, the GIPA Principle has been expanded to MIPA (M – meaningful) or MEPA (ME – meaningful engagement). This refinement of the principle emerged from a growing awareness that, while ‘involvement’ connotes participation, ‘engagement’ involves meaningful dialogue and respectful partnership, neither of which can occur in an environment of stigma.

**Health Care:** During the past 20 years, the health care system in Canada has slowly begun to address stigma and discrimination by implementing myriad initiatives aimed at enhancing the cultural safety of health care environments as well as promoting better relationships between providers and PHA clients. Health care professions are either encouraged or required to participate in interventions aimed at reducing their biases, stereotypes, and discrimination of diversely ethno-cultural, gendered and/or sexually oriented people living with HIV and/or HCV (Li, Guan, Liang, Lin, & Wu, 2013; Nyblade, Stang, Weiss, & Ashburn, 2009). At the individual level, several interventions have attempted to increase awareness of stigma among health professionals and promote reflection on potentially stigmatizing practices and the adverse consequences for clients (Provincial Health Services Authority of BC, 2016). Health care providers are being encouraged to provide thoughtful and respectful services that will not only improve the quality of care for PHAs but might also increase clients’ willingness to disclose HIV and/or HCV status and improve adherence to treatment regimens. Similarly, specific anti-discriminatory policies and clear behavioural guidelines not only protect clients from discrimination but can also improve relationships between PHAs and health providers (Nyblade, Stang, Weiss, & Ashburn, 2009). Studies have shown that stigma reduction strategies within health care settings have produced positive changes in knowledge, attitudes and behaviours, with resulting improvements to the quality of care for PHAs (Li, Guan, Liang, Lin, & Wu, 2013; Nyblade, Stang, Weiss, & Ashburn, 2009).

Trust appears to be a defining feature of good relationships between health care providers and clients and an essential feature of effective therapeutic encounters (Treloar, Rance, & Backmund, 2013). Trust in one’s health provider can influence willingness to seek health care, the uptake and adherence to treatment, as well as health behaviours (ibid). Mutual trust and respect within the Aboriginal client/care provider relationship means that APHAs are treated as more than just a



stereotype but as a valued person capable of making informed decisions about their wellness (Jackson et al., 2008; Reading, Brennan & Masching, 2013; Hawkings & Reading, 2009).

### **Structural**

In responding to intersecting stigmas experienced by APHAs, structural drivers must be carefully considered (Logie, James, Tharao, & Loutfy, 2011; McCall, Browne, & Reimer-Kirkham, 2009; Parker & Aggleton, 2003). Racism plays a powerful role in contributing to APHA-targeted stigma; so the re-socialization of non-Aboriginal peoples must be prioritized. Guerin (2003) suggests that racial socialization begins with learning about and acknowledging the existence and extent of racism, followed by engaging empathetically in the pain of rejection and exclusion that racism produces. Finally, racism can only truly be defeated when non-Aboriginal people respond appropriately to racist remarks and incidences, whether they originate with their families or peer group, or in private, work or public settings.

Colonialism has produced intergenerational traumas, widespread poverty and health inequities, all of which justifiably hinder trust in colonial systems, even those meant to support Aboriginal people in general and APHAs in particular. A restructuring of this relationship must begin before we can combat HIV and HCV stigma against APHAs. Trust is being slowly rebuilt, but far too many interventions continue to unwittingly or intentionally ignore the historical, political, economic and cultural contexts within which Aboriginal interventions must be developed and implemented (Reading, 2014; Treloar, Rance, & Backmund, 2013).

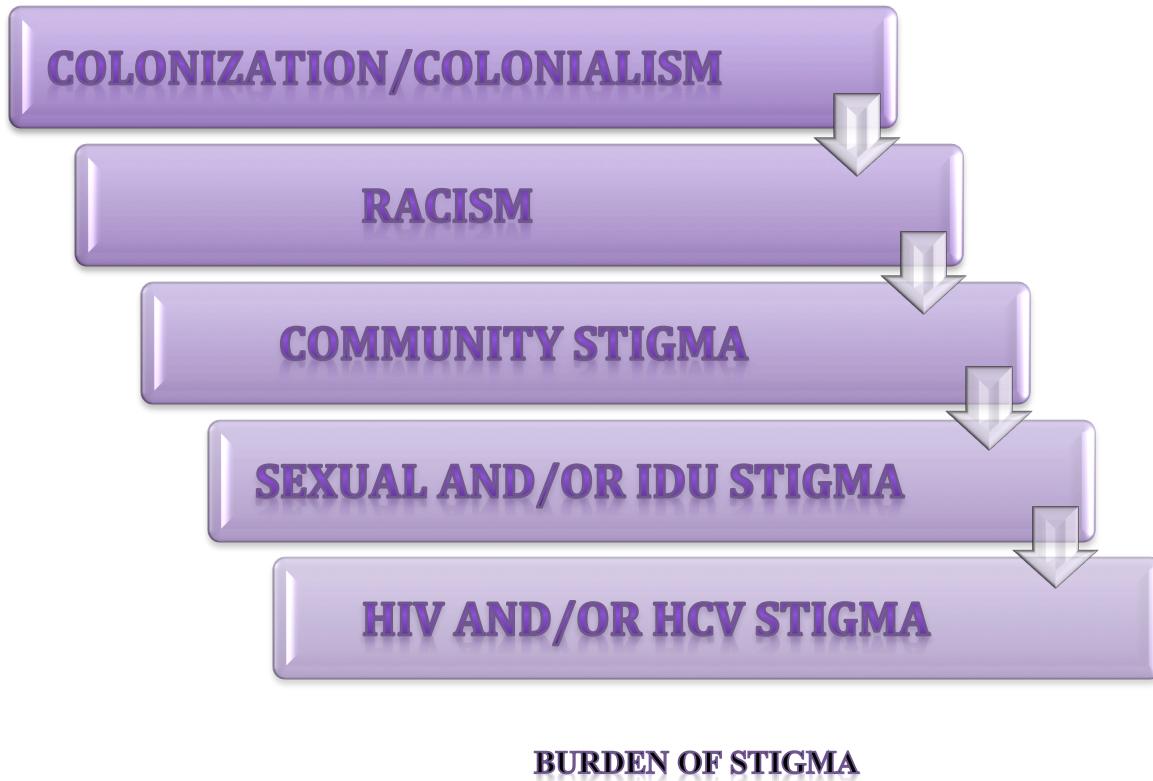
Many developed nations have created laws to prevent discrimination by employers and service providers (Hutton, Misajon, & Collins, 2013). For example, the *Canada Human Rights Act* prohibits discrimination on the basis of race, sex, age, religion, in employment, accommodation, and publicly available services (Government of Canada, 1985). Similarly, the Royal Commission on Aboriginal Peoples (1996) and the Truth and Reconciliation Commission of Canada (2015) represent an attempt on the part of the Canadian government to acknowledge their role in the oppression of Indigenous peoples and to begin to repair that relationship.

### **Conclusion**

HIV and HCV stigma experienced by Indigenous people cannot be understood or addressed in isolation of the historical, political, and social contexts, which continue to shape environments that increase Indigenous peoples' exposure to HIV and HCV. Likewise, the synergistic harm caused by multiple and intersecting forms of stigma must be considered when attempting to develop supports for APHAs. Figure 1 illustrates the compounding burden of multiple stigmas on the health and well being of Indigenous peoples living with HIV and/or HCV.



**Figure 1: Compounding Burden of Multiple Stigmas**



Most people living with HIV and/or HCV experience some form of stigma within diverse relational, occupational, and/or service environments. The harm caused by isolation and discrimination within these domains can be devastating. When HIV and/or HCV status is associated with stigmatized behaviours such as unsafe and/or same-sex activity or injection drug use, the stigma and related harms are multiplied. When someone also experiences family and/or home community rejection on the basis of their HIV and/or HCV status, the roots of social connection are eroded, often leaving them without a home to turn to for support and strength. When someone is also identified with a racial group that has been relegated to the bottom of a socially constructed hierarchy, their value as a human being is questioned. And when that person's culture, language, and lands have been colonized by others who believe them to be inferior, and who establish laws and policies that harm and marginalize them, that person's very existence is threatened.

Each additional layer of stigma doesn't simply add to the physical, mental, emotional and spiritual burden for those living with HIV and HCV, but rather it compounds that burden with insidious and intersecting effects – not easily recognized without careful examination. With each consecutive layer of stigma, overall wellness is diminished and an additional barrier is created to resources that might mitigate stigma and/or provide physical treatment, social support and emotional care. The combined force of colonization, racism, and community stigma has further



distanced APHAs from important cultural teachings, practices and ceremonies that represent critical supports for many Indigenous peoples.

The structures of Canadian society isolate and discriminate against Indigenous peoples – this is no longer debatable. The intersecting web of colonial elitism, racism, sexual and behavioural bigotry essentially incapacitates Indigenous people who are seeking resources and supports taken for granted by other people living in Canada. For Indigenous people living with HIV, particularly as an outcome of stigmatized behaviours, the challenges to obtaining humane and respectful care can be almost insurmountable.

However, assertions such as the United Nations Declaration on the Rights of Indigenous Peoples (United Nations, 2004) and authorities like the Truth and Reconciliation Commission of Canada (TRC) recognize the structural inequities that have shaped epidemics such as the one we currently face with HIV and HCV. They have also contributed valuable recommendations for repairing the relationship between Indigenous and non-Indigenous peoples, including having those in positions of legislative, administrative, and professional power learn about our shared colonial history, racism and other social determinants and to work in solidarity with Indigenous people to create respectful, mutually beneficially and culturally safe relationships and environments (TRC, 2015). Through these and other collective actions, perhaps we can begin to ease the unrelenting burden of stigma on Indigenous people living with HIV and HCV.





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